POLICY AND MODELS OF SERVICE DELIVERY IN PEDIATRIC REHABILITATION

REIMAGINING POLICY AND MODELS OF SERVICE DELIVERY TO ENHANCE ACCESS AND ENGAGEMENT IN PUBLICLY FUNDED PEDIATRIC REHABILTATION SERVICES

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Lay Abstract

Family-centered care in children's rehabilitation helps children take part in everyday life. But some families have a hard time getting to and using these services. Families have said that rules and the way services are set up can make things harder. Right now, we do not know much about how things like discharge rules or online therapy (telerehabilitation) can help families get connected and stay connected with children's rehabilitation services. This thesis looks at research and ideas to show why we should change how services are offered, so they are easier for families to use. It also gives examples of how these systems can be improved by including the voices of families in how they are designed. People in positions to make rules, lead organizations, or do research can use these ideas to create better, family-friendly services.

Abstract

Family-centred pediatric rehabilitation services have widely accepted benefits related to a child's functioning and participation. However, some families experience barriers to accessing and engaging with these services. Families have identified that organizational policies and models of service delivery can impact their experiences with pediatric rehabilitation services. There is a paucity of research focusing on how policies and service delivery models impact access and engagement in Ontario's publicly-funded pediatric rehabilitation services. Furthermore, there is a gap in the evidence related to recommendations for potential modifications to these structures to enhance access and engagement in these services.

The first objective of this thesis is to critically examine policy in publicly-funded pediatric rehabilitation services to understand its impact on access to services. The second objective is to use co-design methodology to improve models of service delivery, with a focus on telerehabilitation, to improve access and engagement in pediatric rehabilitation services. These objectives are achieved through the research outputs of this thesis including recommendations supporting the development of inclusive discharge policies (Chapter 2) and co-created solutions aimed at enhancing experiences with pediatric telerehabilitation (Chapters 3 and 4).

Findings from the critical discourse analysis of discharge policies in Chapter 2 emphasized the importance of taking an ethical and family-centred approach to policy development that authentically includes and amplifies family voices. Chapters 3 and 4 used co-design methodology engaging caregivers, clinicians and pediatric rehabilitation service managers to develop solutions focused on improving the 3C's of communication, consistency and connection to enhance access and engagement with pediatric telerehabilitation services.

The findings of this thesis call policy-makers and pediatric rehabilitation service organizations to extend the provision of family-centred service beyond the point of care to include authentic engagement of families in the development of policies and service delivery models.

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My sincere thanks to the families, clinicians and leadership at KidsAbility for their enthusiastic support of this research. Your interest in this work moved it from ideas into action, so the findings can make an impact in the field of children's rehabilitation. I would also like to extend my gratitude to the parent partner, Dr. Jennifer Lasenby-Lessard and KidsAbility clinician/management partner, Cynthia Lennon for generously sharing their time and expertise as members of the research team. Your perspectives were invaluable to shaping the direction and outcomes of this research.

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List of Figures and Tables

List of Abbreviations and Symbols

CTC – Children’s Treatment Centre

UNCRC - United Nations Conventions on the Rights of the Child

UNCRPD - United Nations Conventions on the Rights of Persons with Disabilities

ICF - International Classification of Functioning, Disability and Health

Phoenix theory - The Phoenix Theory of Attendance, Participation and Engagement

SES - Socio-Economics Status

CDA - Critical Discourse Analysis

FCS – Family-Centred Service

CEO - Chief Executive Officer

OACRS - Ontario Association of Children’s Rehabilitation Services

EKO – Empowered Kids Ontario

OT – Occupational Therapy

PT – Physiotherapy

SLP – Speech-language Pathology

SW – Social Work

EBCD – Experience Based Co-Design

BCBA – Board Certified Behaviour Analyst

IT – Instructor Therapist

CDA – Communicative Disorder Assistant

PAC – Parent Advisory Committee

MS – Microsoft

REDCap - Research Electronic Data Capture

ASD – Autism Spectrum Disorder

3C’s – Communication, Consistency and Connection

Declaration of Academic Achievement and Contributions

This thesis is presented in a sandwich format and is comprised of an introduction (Chapter 1), three independent manuscripts (Chapters 2-4), and a discussion (Chapter 5). Published chapters are printed with permission from co-authors and under licence of open access publication.

I was the sole author of Chapter 1 and Chapter 5. These chapters were developed with review and feedback from my supervisor Dr. Michelle Phoenix and supervisory committee members, Dr. Briano Di Rezze and Dr. Lori Letts.

At the time of preparing this thesis, the three manuscripts comprising Chapters 2-4 were published in open access peer-reviewed journals. I am the first author of these three manuscripts and led all aspects of the research projects connected to these papers.

My contributions to each manuscript and the contributions of co-authors are described below:

Chapter 2

Reitzel, M., Di Rezze, B., Letts, L., & Phoenix, M. (2022). Does Policy Impact Equitable Access to Services? A Critical Discourse Analysis of Discharge Policies in Paediatric Rehabilitation. *International Journal of Disability and Social Justice*, *2(2)*, 65–90. https://doi.org/10.13169/intljofdissocjus.2.2.0065

Developed research question: MR, BDR, LL, MP

Designed the study: MR, MP

Data analysis and interpretation: MR, BDR, LL, MP

Drafted manuscript: MR

Reviewed manuscript and provided feedback: MR, BDR, LL, MP

Chapter 3

Reitzel, M., Letts, L., Lennon, C., Lasenby-Lessard, J., Novak-Pavlic, M., Di Rezze, B., & Phoenix, M. (2025). Describing Caregiver and Clinician Experiences with Pediatric Telerehabilitation Across Clinical Disciplines. *International Journal of Telerehabilitation*, *16*(2). https://doi.org/https://doi.org/10.5195/ijt.2024.6684

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Chapter 4

Reitzel, M., Letts, L., Lennon, C., Lasenby-Lessard, J., Novak-Pavlic, M., Di Rezze, B., & Phoenix, M. (2023). Co-designing solutions to enhance access and engagement in pediatric telerehabilitation. *Frontiers in Rehabilitation Sciences*, *4(1293833)*. https://doi.org/10.3389/fresc.2023.1293833

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Chapter 1. Introduction: Laying the foundation, why reimagine policy and models of service delivery in pediatric rehabilitation

Overarching purpose and novel contributions of this thesis

Given the widely accepted benefits associated with participation in rehabilitation, there is an international interest in understanding the facilitators and barriers that people experience when trying to access and engage in rehabilitation services (Hodyl et al., 2024; Htwe et al., 2024). In low- and middle-income countries, a lack of resources including financial, facilities and equipment have been identified as some of the most significant barriers to accessing rehabilitation services (Htwe et al., 2024). In Australia, clinicians identified service access barriers related to a lack of awareness about the services available, an unclear understanding about when referrals should be made to rehabilitation services, and limited preparedness to manage client diversity (Hodyl et al., 2024). In the Canadian context to date, literature examining issues of access and engagement in Ontario's publicly-funded pediatric rehabilitation services has focused on identifying facilitators and barriers from the perspectives of families (Lindsay et al., 2023; Phoenix et al., 2020a, 2020b). Families acknowledge the potential influence of organizational policies and service delivery models on access and engagement in services. For example, service delivery parameters related to the hours in which appointments are scheduled have been identified by families as having the potential to limit access to services as they often fall in working hours (Phoenix et al., 2020a). However, there is a paucity of research focusing on how organizational structures (i.e., policy and service delivery models) impact access and engagement in Ontario's publicly-funded pediatric rehabilitation services. Furthermore, there is a gap in the evidence related to recommendations for potential modifications to these structures (e.g., incorporating family and child voices into policy and service model design) to enhance access and engagement in these services.

The first objective of this thesis is to critically examine policy in publicly-funded pediatric rehabilitation services to understand its impact on access to services. The second objective is to use co-design methodology to improve models of service delivery, with a focus on telerehabilitation, to improve access and engagement in pediatric rehabilitation services. Chapter 1 frames the pediatric rehabilitation research context in which this work was conducted, paradigmatic worldviews, and the theoretical grounding in which this thesis is situated. This chapter reviews literature related to rights-based rehabilitation, life participation for disabled children[1], organizational structures and access and engagement in rehabilitation services, laying a foundation for why it is necessary to reimage policy and service delivery design in pediatric rehabilitation

Describing the research context

The studies in Chapters 2-4 were completed in the context of publicly-funded pediatric rehabilitation in Ontario, Canada. Although pediatric rehabilitation systems differ between Canadian provinces/territories and across countries, internal policies and organizationally adopted service delivery models are commonly used to inform how services are delivered. In Ontario, publicly-funded Children's Treatment Centres (CTCs) provide any combination of occupational therapy, physiotherapy, speech-language pathology services, amongst other clinical disciplines to disabled children, youth and their families (Government of Ontario,

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[1] Choice of language used in this thesis will be discussed in Chapter 1, Language and Positionality section.

2024b). Despite providing services to over 180, 000 children and youth annually, CTCs experience wait lists for their services (Government of Ontario, 2024a, 2024b). Equity and streamlined access to early assessment and intervention have been highlighted as priorities for the pediatric rehabilitation sector in the newly released Government of Ontario Preschool Speech and Language and Children's Rehabilitation Services Guidelines (Government of Ontario, 2024a).

The research described in this thesis began during the height of the COVID-19 pandemic, which had implications for how the research presented in Chapters 3 and 4 were framed. Prior to the COVID-19 pandemic appointments at CTCs primarily took place in person; however, the uptake of the telerehabilitation service model in the pediatric rehabilitation context increased dramatically in response to pandemic-related restrictions (Camden & Silva, 2021). This prompted interest from a CTC partner organization to learn more about the experiences of families and clinicians with the telerehabilitation service model to inform service design changes that optimized access and engagement.

Language and positionality

Person-first versus identity-first language in rehabilitation

There is ongoing discussion in the rehabilitation literature over the use of person-first versus identity-first language in relation to disability. Disability scholars acknowledge the tensions that exist between choice of language, expectations from the academy with respect to the use of language and the varying language preferences within the disabled community (Andrews et al., 2022; Andrews & Forber-Pratt, 2022; Sharif et al., 2022). At this time, it is evident that there is no 'one size fits all' approach to language in disability scholarship.

Recommendations have been made for academic publishing institutions to move away from mandating a single approach to writing about disability and calls researchers to be critical in their choice of language considering their own preferences, the community they are writing about, and for whom they are writing (Andrews et al., 2022).

Language positionality and rationale for language choices

I am clinically trained as an occupational therapist with nine years of experience working in publicly-funded children's rehabilitation in Ontario. During my training and throughout my clinical practice, I was taught to consistently use person-first language when working with clients. In recognition of the recent shift in language preferences and a personal belief that disability should be a celebrated facet of a person's identity, I have made the choice to pivot towards using identity-first language when appropriate to the context. This statement is made with the caveat that I will always aim to align my language with the preferences of those with whom I am communicating and an openness to move between person-first and identity-first language as desired by my communication partner(s).

As the reader progresses through the chapters of this thesis, they will note the use of both person-first and identity-first language. The choice of language for each published chapter (Chapters 2-4) was determined in collaboration with the research team taking into consideration factors such as the requirements of the journal in which the paper was published, the paradigm in which the research was positioned (i.e., critical theory vs. co-design methodology), as well as the language preferences of research partners (e.g., parents and children's rehabilitation organization). Chapters 1 and 5 were written solely by myself and therefore employ the use of identity-first language in alignment with my positionality.

Describing my positionality – The person, clinician and researcher

I acknowledge the potential obstacles to celebrating disability as part of one's identity. Disabled individuals experience oppression associated with ableism and other forms of systemic discrimination (e.g., sexism, racism) that might be connected to facets of their identity (Nixon, 2019). Conversely, as a cis-gendered, white, able-bodied, heterosexual, English speaking woman with settler ancestry and post-secondary education, I benefit from unearned advantages related to power and position linked to the privileged facets that make up my identity. The privilege afforded by the intersections of my identity, places me in a position to engage in critical allyship alongside disabled individuals to dismantle inequities (Carlson et al., 2020; Nixon, 2019). Critical allyship calls for those in positions of privilege to reframe their role away from being the people who need to fix the inequities to instead amplifying the voices of those experiencing the inequities so they can identify what needs to change (Carlson et al., 2020; Nixon, 2019). Childhood disability clinicians and researchers are well positioned to engage in critical allyship through learning about the experiences of children and families and elevating their voices to advocate for system-level change (e.g., resource allocation, policy reform) that enhances equity and life participation (Reitzel et al., 2021).

In clinical practice, I worked with families who did not consistently attend their scheduled appointments. As clinicians, we are at risk of making assumptions that there is a direct link between missed appointments and the value that a family holds for rehabilitation services. Our service structures, such as policy and service delivery models, were set up to discharge families who missed multiple appointments, without formalized procedures to prompt clinicians to speak to families about barriers they might be facing to attend appointments. As a clinician, it was often my responsibility to enact policies that resulted in families being discharged. From a professional standpoint, I often felt these families would have benefitted from the opportunity to remain connected to therapy services. This created an ethical tension within my clinical practice, which has also been examined in the pediatric rehabilitation literature (Phoenix, 2016). On one hand, I understood how missed appointments were problematic given the pressures put on our services resulting from finite resources and waitlists. On the other hand, I was responsible for discharging families with important therapy goals, due to patterns of missed appointments. My perception was that our organizational structures were failing both the families active in service as well as those waiting for service. This clinically-oriented problem is what motivated me to complete a doctoral degree. I wanted the opportunity to challenge the status quo by reimagining organizational structures in publicly-funded pediatric rehabilitation to alleviate tension from clinicians and better serve families.

As an occupational therapist, I am passionate about providing authentic family-centred service to the families with whom I work. In family-centred service, families are viewed as the expert about their child and the relationship between family and professional should be grounded in authentic partnership (McCarthy & Guerin, 2022; Rosenbaum et al., 1998). To practice in a family-centred way, families should be empowered to identify priorities for therapy and plans for intervention should be developed in a collaboration between family and clinician (McCarthy & Guerin, 2022; Rosenbaum et al., 1998). As a researcher, I continue to carry the values of family-centred service into the projects in which I engage. I am passionate about co-creating knowledge through research that prioritizes authentic engagement of community partners such as families, focusing on meaningful questions identified by the community and challenging dominant structures (e.g., policy, service models) to consider how things might otherwise be.

Paradigms and worldviews

As a paradigm, qualitative research is characterized by methodology that is inductive, interested in context, prioritizes participant experiences, and allows for iterative and flexible design (Creswell & Creswell, 2023). Qualitative methods are used across the research studies presented in Chapters 2 through 4 of this thesis. In alignment with Creswell & Creswell (2023), I will use the term worldview when discussing the philosophical assumptions of this research, because it provides a holistic term for discussing constructs related to ontology, epistemology and values in research.

Chapters 2-4 are aligned with a constructivist worldview, which aims to understand the experience of others, embracing the subjective and complex nature of individual experiences with no aim of simplifying them (Creswell & Creswell, 2023). From a constructivist worldview, research starts with a broad question, is inductive and relies heavily on participants sharing their views and ideas (Creswell & Creswell, 2023). Chapter 2 presents the findings from a critical discourse analysis of policy. With aims of examining inequities in accessing rehabilitation services for disabled children, an inductive approach to analysis was used to examine language of discharge policies, understand how they impact families' experiences with accessing services, and develop recommendations supporting inclusive policy design (Creswell & Creswell, 2023). Chapters 3 and 4 present research completed using co-design methodology, a group of methods that requires high levels of community engagement in all aspects of the research process (Moll et al., 2020). In co-design, lived experience is prioritized as expert knowledge crucial to informing meaningful research outcomes, emphasizing the important influence of context on the research (Donetto et al., 2015; Moll et al., 2020).

A constructivist worldview accepts the assumption that multiple realities exist, the subjective nature of knowledge and values the experience of the individual or community as crucial to guiding the direction of research (Creswell & Creswell, 2023). It is my belief that research involving groups experiencing marginalization[2] (e.g., disabled children and their families) should challenge the assumptions, ideas and structures that have become commonplace and accepted in society but perpetuate oppression through exclusion. My positionality compels me to co-construct knowledge alongside those with lived experience, using their expert knowledge to guide the completion of meaningful research that prioritizes their experiences of navigating the world. Given this positionality, I find myself adopting a constructivist worldview. A constructivist worldview aligns with the disability systems-focused research about which I am passionate. A constructivist worldview is represented in the content of this thesis and will continue to be embedded in the values, assumptions and positioning that I bring to research with which I have the privilege of being involved in the future.

Moving towards participation-focused rights-based pediatric rehabilitation – Guiding policies, theories and models

The United Nations Conventions on the Rights of the Child (UNCRC) (Article 23) states that disabled children should enjoy a life with access to the services and support (e.g., rehabilitation services) needed to facilitate life participation (United Nations, 1989). The United

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[2] Marginalization is the experience of exclusion based on the components of one's identity (e.g., race, gender, ability) and the inequitable distribution of resources (e.g., social, economic, physical) (NCCDH, 2025).

Nations Conventions on the Rights of Persons with Disabilities (UNCRPD) (Article 7) adds that the life enjoyment of disabled children should be equal to that which is experienced by all children (United Nations, n.d.). Furthermore, the UNCRPD (Article 26) states full inclusion and participation should be supported through the early access to rehabilitation services (United Nations, n.d.).

In the pediatric rehabilitation literature, focus has been placed on learning about factors that influence participation as well as participation-focused goals, interventions and outcomes (Anaby et al., 2015, 2018, 2022; Arakelyan et al., 2019; King et al., 2013; Williams et al., 2019). The focus on participation does not negate the importance of considering function as part of therapy, instead as illustrated by the International Classification of Functioning, Disability and Health (ICF), functioning becomes positioned as a factor with the potential to influence an individual's life participation (World Health Organization, 2001).

The focus on participation in pediatric rehabilitation not only demonstrates alignment with the UNCRC and UNCRPD, but it also aligns with a rights-based rehabilitation discourse. Rights-based rehabilitation calls for a holistic approach to rehabilitation that prioritizes the voices, values, desires and choices of disabled individuals (Shakespeare et al., 2018). Relational and participatory approaches are highlighted as critical components of participation-focused pediatric rehabilitation (Granlund & Imms, 2024). Children and families should be empowered to identify meaningful participation goals, prioritizing their lived experiences as expert knowledge when collaboratively developing participation-focused interventions (Granlund & Imms, 2024). From the perspective of parents of disabled children, using participatory methods to involve children in rehabilitation services has generated a sense of empowerment, independence and self-awareness in their children (Kronsell et al., 2021).

The Family of Participation-Related Constructs model describes activity competence, sense of self, and preferences as characteristics intrinsic to an individual that interact with the surrounding environmental context to impact experiences of participation (Imms et al., 2017). In rights-based rehabilitation, the unique preferences of each person need to be holistically considered alongside contextual factors that might limit desired access to rehabilitation services (Shakespeare et al., 2018). Acknowledging the influence of a disabled child's environmental context on their life participation or access to rehabilitation services situates the barriers they experience beyond the individual person. This consideration of context aligns with the social model of disability, whereby disability and barriers to life participation are imposed by social and systemic structures and not reduced to individual-level impairment (Curran & Runswick-Cole, 2014; Guenther-Mahipaul, 2015). The critical examination of predominant social and systemic structures embedded in pediatric rehabilitation (e.g., policy and service models) is required to further understand implications for life participation, access and engagement in services as well as to challenge current norms.

The ICF provides a framework for considering the influence of person and environment factors on participation and can be used to raise awareness regarding the need for social change (World Health Organization, 2001). A commentary by Reitzel et al., (2021), proposed using intersectionality theory alongside the ICF to the critically examine how the intersecting facets of a disabled child's identity interacts with their surrounding environment to influence their participation in rehabilitation services. Intersectionality theory explains that how a person experiences the world is connected to the socially constructed privilege or oppression associated with the interaction between multiple facets of their identity (Crenshaw, 1991; Hankivsky, 2012). Disabled children and their families have unique identities that interact with their surrounding environment. There are implications for a child's participation when they experience systemic inequities (e.g., ablism, racism, sexism) resulting from interactions between their intersectional identity and the broader environment (Reitzel et al., 2021).

As a critical theory, intersectionality seeks not only to understand the lived experience of marginalization, such as that experienced by disabled children, but also aims to rectify inequities through challenging power imbalance and generating new knowledge that disrupts established norms (Cho et al., 2013; Crenshaw, 1991; Nash, 2008). Further, intersectionality theory, has been described as an approach that can be embedded in qualitative health research to interrogate structures that sustain health inequities and develop equity-enhancing solutions (Abrams et al., 2020). Given the alignment between intersectionality and the equity-focused transformative aims of reimagining organizational service structures, intersectionality theory serves as one of the theoretical foundations for this thesis.

Implications of organizational structures on access and engagement in pediatric rehabilitation

Access and engagement in paediatric rehabilitation – Theoretical considerations

For a disabled child to engage in rights-based, participation-focused rehabilitation services, there is a need for both the child and family to be able to access these services. Accessing healthcare services has been conceptualized to include being able to identify a need for service, seeking out and reaching the service as well as obtaining the service to have the identified need addressed (Levesque et al., 2013). The Phoenix Theory of Attendance, Participation and Engagement (Phoenix theory) describes factors influencing access and engagement in pediatric rehabilitation services (Phoenix et al., 2020a). In the pediatric rehabilitation literature, attendance, participation and engagement are described as three constructs that contribute to how a disabled child and their family gets connected to (access) and actively takes part in (engagement) therapy (Carman et al., 2013; Imms et al., 2017; Phoenix et al., 2020a). Attendance is described as the actions required to physically show up for the appointment, participation is taking part in the session tasks or activities and engagement goes beyond participation requiring investment in the purpose, goals and outcomes of therapy (Phoenix et al., 2020a).

The Phoenix Theory discusses facilitators and barriers to attending, participating and engaging in rehabilitation appointments at the level of the child, family, clinician and organization (Phoenix et al., 2020a). Organizational factors described by the Phoenix Theory include logistics related to when and where appointments can take place, communication between the organization and families about appointments (e.g., reminder calls) and sharing of information with families about the organization's services (e.g., about models of service and policy related to missed appointments) (Phoenix et al., 2020a). Long wait times, constrained resources and a lack of continuity between services providers are some additional organizational barriers impacting attendance (Ballantyne & Rosenbaum, 2017; Boag-Munroe & Evangelou, 2012; Phoenix & Rosenbaum, 2015). These factors are substantiated by the Phoenix theory which discusses the influence of parent expectations on things like wait times and the parent-professional relationship on engagement in therapy (Phoenix et al., 2020a). Developed in the context of in-person publicly-funded pediatric rehabilitation in Ontario, the Phoenix theory acts as another theoretical foundation for this thesis.

Access and engagement in pediatric rehabilitation – Organizational considerations

When families are labelled as 'no shows', 'hard to reach', or 'unmotivated' after missing a therapy appointment, this places the blame and responsibility on them (Ballantyne & Rosenbaum, 2017). This perspective does not account for the influence of organizational factors known to impact access and engagement in pediatric rehabilitation services, nor the influence of how factors related to intersectional identities (i.e., disability, culture) influence attendance (Boag-Munroe & Evangelou, 2012). There needs to be a shift in thinking from families being labelled as 'hard to reach' to instead considering what makes services 'hard to access' (Boag-Munroe & Evangelou, 2012; Cortis, 2012). Constrained resources and rigid service models favour servicing those who do not encounter barriers to accessing services and risk limiting the engagement of families who have more complex support needs (Cortis, 2012). It can be assumed that due to finite resources, wait times for service and accountability to funders, that the policies and service models at CTCs are designed to enhance efficiency of seeing families. However, it is possible that these dominant practices disproportionately exclude some families from engaging with services, which has implications for equitable access. Reimagining policy and service models with an equitable lens and informed by the voices of families is critical to informing redesign recommendations that enhance access and engagement in pediatric rehabilitation services for all families.

Families have identified organizational structures as factors impacting access and experiences with participation in pediatric rehabilitation services, expressing as desire for these structures to be tailored to their needs (Pozniak et al., 2024; Teleman et al., 2021). Reimagining policy and service delivery design offers an entry point for intervening upon organizational factors impacting access and engagement and have been used as mechanisms of change in childhood disability research. For example, policy analysis and recommendations for policy reform have been used in the field of Canadian childhood disability research to understand families' experiences with accessing disability support programs and to advocate for the intentional inclusion of disabled children in health policy development (Finlay et al., 2023; Shikako et al., 2023). Further, service redesign has been identified as a potential mechanism to enhance access to pediatric rehabilitation services (Kuo et al., 2022; Phoenix et al., 2016). A 2022 systematic review examined the impact of service redesign on wait times for pediatric rehabilitation services (Harding et al., 2022). Findings from the review indicate that process efficiency measures, such as modifications to models of services can have a positive impact on wait times (Harding et al., 2022). Finally, there are examples of publicly-funded pediatric rehabilitation service organizations piloting and evaluating innovative approaches to service delivery as means of addressing outcomes related to service access and experiences (Camden et al., 2013; Reitzel et al., 2024).

Overview of thesis components

In its entirety this thesis aimed to generate novel knowledge and recommendations for reimagining policy and service delivery models (i.e., telerehabilitation) in publicly-funded pediatric rehabilitation to enhance equitable access and engagement. Chapter 2 takes a critical approach to examining discharge policies related to missed appointments in publicly-funded pediatric rehabilitation highlighting how current policy may contribute to inequitable access to services. Recommendations for equitable and inclusive policy design are discussed. Chapters 3 and 4 are manuscripts derived from a single study utilizing co-design methodology aiming to enhance experiences with the telerehabilitation service model at an Ontario CTC. Chapter 3 describes the experiences of both caregivers and clinicians with telerehabilitation. Chapter 4 reports on the findings from the co-design process where caregivers, clinicians and managers collaborated to co-create solutions aiming to enhance experiences with the telerehabilitation service model. Chapter 5 synthesizes and contextualizes findings to inform recommendations for the development of equitable policy and models of service delivery in pediatric rehabilitation.

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Chapter 2. Does Policy Impact Equitable Access to Services? A Critical Discourse Analysis of Discharge Policies in Paediatric Rehabilitation

Chapter 2 presents a published manuscript of a discourse analysis that took a critical approach to examining discharge policies related to missed appointments in publicly-funded pediatric rehabilitation. Findings highlight how current policy may contribute to inequitable access to services and recommendations for equitable and inclusive policy design are discussed.

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Does Policy Impact Equitable Access to Services? A Critical Discourse Analysis of Discharge Policies in Paediatric Rehabilitation

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ABSTRACT

Having the choice to access rehabilitation services is a right of disabled children. In Ontario, Canada, paediatric rehabilitation services are provided by Children's Treatment Centres (CTCs), and many manage missed appointments using discharge policies. The impact of discharge policies on access to rehabilitation services is unknown. This study critically examined the language of policies around missed appointments and impacts on service access. Using qualitative critical discourse analysis, text from discharge policies was analysed, considering how marginalised groups (e.g., low-income families, culturally diverse families) may be affected by CTC discharge policies. Discourses of family-centred service, health equity and the perpetuation of established power relations within paediatric rehabilitation were represented in the language of policies. Current policies place the organisation in a position of power, de-value family choice and risk infringing on the right of disabled children to access paediatric rehabilitation services when desired.

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KEYWORDS
Paediatric rehabilitation; rights-based rehabilitation; childhood disability; disability rights; service access; service equity; critical policy analysis; intersectionality

1. Introduction

In Ontario, Canada, every year over 74,000 disabled children access services from publicly-funded rehabilitation centres, referred to as Children's Treatment Centers (CTCs) (Government of Ontario Ministry of Children Community and Social Services, 2020). According to Article 26 of the Convention on the Rights of Persons with Disabilities, disabled people have a right to access early rehabilitation and to decide whether to participate in these services (United Nations, no date). Participation in rehabilitation is associated with positive functional outcomes for disabled children (Chen et al., 2004). Participation in the home, school and community can enhance developmental outcomes for children and provide them with skills needed to transition into adulthood (Larson, 2000; Gorter, Stewart and Woodbury-Smith, 2011; Anaby et al., 2014). Given that disabled children experience restrictions to their participation when compared to peers without disabilities, goals related to supporting participation are frequently targeted in paediatric rehabilitation (King et al., 2010; Bedell et al., 2013; King, Rigby and Batorowicz, 2013; Anaby et al., 2014), to optimise health and participation across the lifespan.

Missed appointments have been identified as a challenge in children's rehabilitation and outpatient services (Phoenix and Rosenbaum, 2015; Ballantyne and Rosenbaum, 2017). Missed appointments occur when a family does not attend a scheduled appointment, either with or without notification of an absence. It is estimated that 15% of ambulatory appointments are missed with the majority (74%) being missed without notification to the rehabilitation centre (Liscumb et al., 2016). Given the frequency of occurrence and the implications for clinical sites (e.g., unable to fill appointment time, resources lost planning for a session, waiting for a client, and following up with a client), this study focuses on appointments missed without prior notification or resulting from patterns of frequent cancellations and late arrival to appointments. Missed appointments are viewed as an inefficient use of clinician time, organisational resources and have potential to negatively impact child well-being (Phoenix, 2016; Ballantyne and Rosenbaum, 2017). As a result, many CTCs in Ontario use discharge policies as a dominant practice for managing missed appointments, which result in discharge from services after a specified number of missed appointments (Ballantyne and Rosenbaum, 2017). While these policies may serve the resource management interests of CTCs, the cause for missed appointments and implications of policies for families also need to be understood.

In a scoping review examining missed appointments in education, health and social services for children 0–18 years old, diverse logistical, cultural and demographic factors were identified as correlates for non-attendance (Arai, Stapley and Roberts, 2014). Barriers at the level of the child, family and organisation have been examined from the perspective of the family as well as healthcare providers (Ballantyne et al., 2015, 2019; Phoenix and Rosenbaum, 2015; Phoenix et al., 2020b, 2020a). At the level of the child, the complexity of health needs has been identified as a barrier to attending appointments (Phoenix and Rosenbaum, 2015; Phoenix et al., 2020b). Mothers of children with cerebral palsy identified that competing priorities related to managing their children's needs was a barrier to keeping health care appointments (Ballantyne et al., 2019).

At the level of the family, the parent–professional relationship has been identified as a family level factor impacting attendance (Phoenix and Rosenbaum, 2015; Phoenix et al., 2020a). For example, parents' perceptions of feeling judged for having missed an appointment was identified as a barrier to attending subsequent appointments (Ballantyne et al., 2015, 2019). Supports and resources available to parents (i.e. financial, emotional or informational supports) have been identified as family-level factors promoting attendance (Ballantyne et al., 2015; Phoenix and Rosenbaum, 2015; Phoenix et al., 2020b, 2020a). In a study examining barriers and facilitators to attendance in Canadian neonatal programs, mothers identified that financial concerns were a barrier to attending appointments while provision of information about the service facilitated attendance (Ballantyne et al., 2015).

Issues of low service engagement, such as missed appointments, have been problematised by organisations and policy-makers in relation to aspects of a family's identity that place them at a perceived higher risk of being 'hard to reach' (Winkworth et al., 2010). A systematic review examining literature on 'hard to reach' families identified factors such as homelessness, poverty, disability, culture, and parent mental health as having potential to impact engagement in health, education or social services (Boag-Munroe and Evangelou, 2012). Language barriers, navigating systems in a new country, and cultural differences were identified as challenges to accessing services by immigrant mothers of disabled children (Khanlou et al., 2015). The systemic discrimination associated with aspects of identity such as gender, sexuality, or ethnicity may place some families at higher risk for missing appointments. Organisations may compound these barriers and increase exclusion through structures and policies that discharge families after missed appointment.

At the level of the organisation, wait times for service, a lack of continuity between service providers and limited flexibility in appointment times have been identified as organisational factors impacting attendance (Phoenix and Rosenbaum, 2015; Ballantyne et al., 2019). Missed appointments result in families being labelled as 'no-shows', 'hard to reach' or 'unmotivated', terms which place blame on families (Ballantyne and Rosenbaum, 2017). An alternative perspective offered by Boag-Munroe and Evangelou (2012), shifts blame for missed appointments away from families and instead discusses that services might be hard to reach due to service-related factors (e.g., lengthy waitlists, high staff turnover) that make it challenging for families to engage in services. This literature, drawn from public health, medicine, and rehabilitation is reflective of the underlying presumption that children and families benefit from services and therefore access to services should be promoted. When a medical lens is applied, disability is described as impairment that requires intervention to be fixed and subscribes to a singular conceptualisation of normal functioning (Cooper, 2013; Hammell, 2015). Traditional rehabilitation discourse positions disability as an individual-level problem and overlooks the impact of social and systemic structures in creating and sustaining barriers to life participation (Curran and Runswick-Cole, 2014).

In opposition to the dominant impairment focus in the field of rehabilitation, the language of this article aligns with the social model of disability, whereby disability is imposed by societal structures and not by the body of the disabled person (Guenther-Mahipaul, 2015). Identity-first language is purposefully used to align with the position that those living with an impairment are disabled by the barriers encountered in the social environment and not by the impairment itself. The assumed benefits of rehabilitation services for child development highlight problematic notions of an 'otherness' associated with children who 'need' rehabilitation services when compared to peers who are described as following the expected trajectories of a Westernised discourse of typical development (Cooper, 2013; Curran, 2013; Curran and Runswick-Cole, 2014). This privileges the social construction of normal development as something to be strived for, which is embedded in the culture of providing paediatric rehabilitation services (Gibson, Teachman and Hamdani, 2015). The standard for normal development is perpetuated in the values ingrained in those working in the field of paediatric rehabilitation who are in positions of power to influence practices and structures in this system (Gibson, Teachman and Hamdani, 2015), such as policies associated with managing missed appointments.

The lived experience of disability and voices of disabled children and their families are not privileged in the prevailing developmental and rehabilitation discourses. The exclusion of children and families may perpetuate sustained assumptions by healthcare professionals that families value access to rehabilitation services and subscribe to ideals of a normal development in a way that aligns with how Western society privileges these constructs. Problematically, these assumptions, which pervade the development of dominant service models, practices and policies in the field of paediatric rehabilitation, discount the impact of systemic societal structures on the lived experiences of disabled children and their families (e.g., their experience accessing paediatric rehabilitation services). Instead, they perpetuate a siloed view of disability as a remediable ailment located at the level of the individual. The authors acknowledge the oppressive impact of the medically oriented discourse of rehabilitation and therefore situate their analysis in a rights-based rehabilitation discourse whereby rehabilitation is conceptualised holistically and driven by the choices, values and priorities of disabled people (Shakespeare et al., 2018). Rights-based rehabilitation acknowledges that the value and desire to access rehabilitation varies between disabled people and that not accessing rehabilitation services is a valid choice and the right of a disabled person (Shakespeare et al., 2018).

Grounded in intersectionality theory, this study critically examines access to paediatric rehabilitation services as influenced by CTC policies related to missed appointments. Intersectionality theory examines the intersection between aspects of identities such as race, gender or socio-economics status (SES) with dominant societal power structures that shape a person's socially created privileged or oppressed position in society (Crenshaw, 1991; Hankivsky, 2012). As an example, in the field of education, the intersection between race and disability has been examined and recognises how the experiences of racialised disabled students differ from white disabled students resulting from the systemic influences of racism and ableism, limiting equity in students' educational experiences (Annamma, Connor and Ferri, 2012). Intersectionality refutes notions of locating disability at the level of the individual emphasising the impact of systemic societal power structure on participation and lived experience. In qualitative research, intersectionality can be used as theoretical grounding to highlight oppression, generate new knowledge and address power imbalances that perpetuate inequities in health services (Abrams et al., 2020). Through seeking to understand the experiences of diverse groups and critically examining power relationships, intersectionality aims to create change that results in shifts toward a more just society (Crenshaw, 1991; Nash, 2008; Cho, Crenshaw and McCall, 2013). Equity concerns arise when the intersection between identities and power structures (i.e. social practices related to discharge policies) create systemically sustained disparities among who has access to paediatric rehabilitation services.

Applying an intersectional lens, it can be inferred that attendance at therapy appointments is influenced by the socially constructed privilege or marginalisation experienced by a family. This creates potential for ethical tension regarding fair distribution of CTC's resources between families who have the right to access these services should they choose to (justice) while also providing the best care possible for each family (beneficence) (Blackmer, 2000; Phoenix, 2016). Publicly-funded paediatric rehabilitation organisations experience pressure related to demonstrating service outcomes and efficient use of finite resources. Service pressures may increase risk of systemic bias in organisational practices, such as policies that focus provision of service on groups that are easier to engage and more likely to demonstrate positive outcomes, while limiting service access for those perceived as 'hard to reach' (Cortis, 2012). Additional time and resources are needed to attract 'hard to reach' families to services (Cortis, 2012). This poses challenges to organisations like CTCs which have more demand for services than their limited resources have capacity to address (Boag-Munroe and Evangelou, 2012; Cortis, 2012; Phoenix, 2016). When resources and efforts are directed towards improving access to care or service use among families that face barriers they typically focus on families who are referred to as 'hard to reach, vulnerable, marginalized' (Boag-Munroe and Evangelou, 2012; Nixon, 2019). These efforts problematise the child and family and seek individual-level resilience or capacity building, as opposed to interrogating the structures and systemic inequities that prevent access and engagement in care. This paternalistic approach to 'helping' may disempower children and families by presuming they want or need services and require support to access them.

Given that participation in rehabilitation is a right of disabled children (United Nations, 2006), it is imperative that families have access to the available services should they choose to engage with them. Systemic barriers, such as dominant policy practices, preventing families' access to paediatric rehabilitation services risk infringing on a disabled child's right to rehabilitation and becomes a social injustice (United Nations, 2006). Currently, little is known about the impact of policy as an organisational factor affecting families' access to paediatric rehabilitation services. The **aims** of this qualitative critical discourse analysis (CDA) are to (1) investigate trends in discharge policy for how missed appointments are managed in Ontario's CTCs (2) critically examine the policy discourse(s) about missed appointments and how they may impact families' access to services and (3) facilitate organisational change through developing recommendations for equitable policies to optimise attendance and service delivery continuation for all families. These aims are realised by answering the following **research question**: In Ontario's publicly-funded paediatric rehabilitation sector, what is the discourse about missed appointments and the potential impact on families' access to services for their children?

2. Methods

In a critical theory research paradigm, dominant cultural thoughts and social practices are examined and reconceptualised (Eakin et al., 1996; Kincheloe et al., 2011). Critical research acknowledges the influence of power relations on the acceptance of dominant social practices and privileging certain groups over others in our society (Kincheloe et al., 2011). Critical theory aligns with the transformative aims of this research to develop equitable policy recommendations that support families' efforts to access services they desire.

CDA is a qualitative approach that applies a critical lens to the analysis of text-based language (Janks, 1997), such as the language of discharge policies. Discourse can be conceptualised as a system of statements grounded in a social context that create and sustain patterned ways thinking (Lupton, 1992). CDA highlights the role of text-based language in shaping and sustaining social practices (Jorgensen and Phillips, 2011), such as CTCs using discharge policies to manage missed appointments. In CDA, new knowledge prompting changes in inequitable social practices is generated through examining power imbalances between privileged and oppressed groups (Jorgensen and Phillips, 2011; Fairclough, 2013).

Norman Fairclough's well-developed CDA theory and methods have been used in rehabilitation and policy analysis (Taylor, 2004; Jorgensen and Phillips, 2011; White and Cameron, 2015; Pedersen and Kristensen, 2016). Use of Fairclough's methodology promotes trustworthiness when used with interdisciplinary theories to inform study procedures (Shenton, 2004; Taylor, 2004; Fairclough, 2013).

This study is guided by Fairclough's four-stage dialectical–relational approach to CDA (Fairclough, 2013). This framework was selected because the stages support the researcher in both critically interpreting data as well as creating new knowledge, which satisfies the study aims of developing equitable policy recommendations

(Fairclough, 2013). The four stages of Fairclough's methodology are as follows: (1) focus upon a social wrong (i.e. aspects of social systems that, if not addressed, have potential to negatively impact peoples' well-being); (2) identify obstacles to addressing the social wrong; (3) consider whether the social order 'needs' the social wrong; (4) identify possible ways past the obstacles (Fairclough, 2013). Although the stages are presented in numerical order they do not have to be followed in sequence (Fairclough, 2013). The iterative process for completion of this study as guided by Fairclough's CDA methodology is described below.

2.1 Stage 1 – Focus Upon a Social Wrong

This stage of Fairclough's CDA methodology encourages the researcher to select a topic of research that, when examined critically, is linked to a social wrong (Fairclough, 2013). Integrating transdisciplinary theory and literature with the topic of research supports the development of what Fairclough terms an object of research, which allows the researcher to deepen their understanding of social processes associated with the identified social wrong and potential implications for peoples' well-being (Fairclough, 2013).

In this study, the identified social wrong centres on the potential for discharge practices, as outlined by policy documents, to impact families' rights to access paediatric rehabilitation services. This study was completed in the context of publicly-funded paediatric rehabilitation in Ontario, Canada. In Ontario, paediatric rehabilitation services funded through the provincial government are available to children and youth under the age of 19 through CTCs (Government of Ontario Ministry of Children Community and Social Services, 2020). There are wait times associated with accessing services and despite CTCs providing a cumulative total of over 750,000 visits in a year, thousands of children remain on the waitlist unserved (Empowered Kids Ontario, 2016).

The social wrong addressed by this study was identified through the first author's (MR) experiences implementing these policies while working as an occupational therapist in Ontario's publicly-funded paediatric rehabilitation system. In an effort to promote trustworthiness in this work, MR employed critical reflexivity and transparency about her position in relation to the context and data (Finlay, 2002). In author MR's clinical experience and perception, some families disproportionately experienced barriers to attending appointments, often leading to discharge from services in accordance with organisational policy. Author MR experienced ethical tension when discharging families who missed appointments. Although aware of the significant pressures on CTC resources, author MR was concerned that marginalised families who desired services were being discharged due to systemic barriers inherent to the CTC context. Furthermore, families that did not desire service might feel pressured to participate in rehabilitation given the service providers' recommendations and the punitive discharge practices encoded in policies. These experiences informed the lens brought to analysis and interpretation of the data.

Fairclough's approach to CDA emphasises the subjective nature of data analysis and that interpretation is influenced by the lens applied by the analyst as well as the integration of interdisciplinary theory (Fairclough, 2003). Exploring theoretical perspectives and literature in the areas of intersectionality, health equity and family-centred service (FCS) led to constructing an object of research for this CDA focused on examining the impact of policy related to missed visits, on equity in access to paediatric rehabilitation services. Trustworthiness of the process undertaken to develop the object of research was enhanced by using an audit trail to document critical decisions and reflective memoing, both of which were frequently reviewed by senior researchers on the team (Lincoln and Guba, 1986; Shenton, 2004). For example, the first author (MR) who was responsible for leading analysis engaged in reflective memoing about her assumptions and values related to constructs, such as rehabilitation, to be transparent and conscious about her positioning and biases.

2.2 Stage 2 – Identify Obstacles to Addressing the Social Wrong

This stage involves selection and analysis of texts to understand how they create and sustain discourse in relation to dominant social practices (Fairclough, 2013). As part of a larger project examining attendance and engagement in paediatric rehabilitation (Phoenix et al., 2020a, 2020b), 21 CTC organisations were contacted through an email sent from the Chief Executive Officer (CEO) of the Ontario Association of Children's Rehabilitation Services (OACRS, now Empowered Kids Ontario – EKO) that requested each centre's policy documents related to missed appointments (January, 2016), with two follow-up reminders sent by the study team and the CEO of OACRS (February, April 2016). Centres were requested to email the study team if they updated their policy and procedure documents, this occurred once, and the revised document was included in the analysis. 74 documents were submitted from 18 of the 21 CTCs during the period of January to April 2016, with one additional email received in November 2016 to state that the CTC did not have formal policy in this area. Ethics approval was received from the Hamilton Integrated Research Ethics Board (project #1006). All documents were de-identified of information linking the data to a specific CTC by an impartial individual not involved in data analysis. Inclusion and exclusion criteria (Table 1) for the data were developed in consultation with the full research team. Included documents were categorised as either 'Policy', which included policy documents only or 'Family Document', which included documents reviewed with or sent to families regarding the policy. The most common reason (n=18) for exclusion was because the document was a policy unrelated to missed visits. After applying these criteria, 38 documents were included for analysis.

Fairclough's approach to CDA requires two levels of textual analysis: linguistic analysis and interdiscursive analysis (Fairclough, 2013). Linguistic analysis involves analysing language in text-based documents, which in the case of this study were policy and policy-related documents (Fairclough, 2003). Interdiscursive analysis, whereby patterns from linguistic analysis are examined to identify emerging discourse from the data occurred iteratively and simultaneously with linguistic analysis

Table 1 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
• Policy with specific information and/or instructions for managing missed visits • Policy document supporting clinicians with carrying it out in practice (i.e., a service agreement document reviewed with families) • Policy document to communicate information with families (i.e., a letter sent via mail to notify family of missed visit)	• Document format was not widely accessible to employees of the organisation (i.e., written in an email) • Document did not contain instructions about discharge, reflected a policy that did not discuss discharge resulting from missed visits or were not policy-related documents • Multiple documents submitted by the same CTC containing identical information regarding management of missed visits across a variety services

(Fairclough, 2013). Integrating methods that support interpretation of texts is encouraged in Fairclough's approach to CDA (Fairclough, 2003). Iterative coding was used to describe and interpret the data (Baezeley, 2013). Microsoft Excel spreadsheets (Microsoft Corporation, 2016) were used to manage coded data.

The following descriptive information was extracted from included documents: document title, person or department that created the policy, year created or revised, document length, document type (i.e. policy or supporting document), definitions provided, specifications related discharge procedures, methods identified to share information with family about the policy, methods used to support families' attendance, methods used to contact a family after missing an appointment, and any exceptions to proceeding with discharge due to missed visits. As part of textual analysis, initial coding occurred through line by line reading of the data by the first author to label emergent patterns in policy document language (Baezeley, 2013). Further analysis prompted recontextualising initial patterns, to describe distinct FCS, health equity and power relations discourse embedded in policy language and positioned in the dominant discharge practices of the CTC context. Coding memos were maintained to explore the process of data coding and discourse identification, enhancing rigor (Lincoln and Guba, 1986; Birks, Chapman and Francis, 2008).

Interdiscursive analysis was guided by critical theoretical groundings in intersectionality, FCS and health equity. These theoretical concepts guided initial data coding as well as the questions posed of the data to recontextualise codes, identify patterns and extract meaning from the data to describe discourse (Birks, Chapman and Francis, 2008). Analytic memos were used to examine relationships emerging from linguistic analysis and enhance trustworthiness of results (Lincoln and Guba, 1986; Shenton, 2004; Birks, Chapman and Francis, 2008).

2.3 Stage 3 – Consider Whether the Social Order "Needs" the Social Wrong and Stage 4 – Identify Possible Ways Past the Obstacles

There is no prescribed flow for moving through the stages of Fairclough's CDA methodology; as such Stages 3 and 4 were addressed iteratively and cyclically, moving freely back and forth between them throughout data analysis (Fairclough, 2013). Reflective memos were used to transparently explore the relationship between the first author (MR)'s position in the research on data interpretation (Birks, Chapman and Francis, 2008). Narrative and diagrammatic analytic memos were used to examine data patterns, leading to its interpretation in the context of CTC discharge practices, as described in policy, and the potential impact on families' access to CTC service (Birks, Chapman and Francis, 2008). Results from linguistic and interdiscursive analyses were examined through memoing to identify possible solutions to address service access barriers (Fairclough, 2013). This level of analysis resulted in developing recommendations aiming to enhance equitable access and service delivery continuation for all families. Trustworthiness of data analysis processes was enhanced through the use of an audit trail, reflexivity and memos as well as frequent consultation with senior researchers on the team about emerging codes, patterns and discourse in the data (Lincoln and Guba, 1986; Shenton, 2004; Birks, Chapman and Francis, 2008; Baezeley, 2013).

3. Results

The results begin with describing trends in the policy documents across CTCs to contextualise the dominant practices used to manage missed appointments. Next, critical analyses of FCS, health equity and perpetuating power relationships are presented. Quotes and examples from the data are used to illustrate the discourses and situate them in the CTC context and the broader systems (e.g., health), policies (e.g., UN Convention on the Rights of the Child), and theories (e.g., intersectionality theory). These systems, policies and theories shape discourses about missed appointments and rehabilitation services for disabled children and their families.

3.1 Descriptive Trends in Discharge Policy for Managing Missed Appointments

15 of the 18 CTCs from which data were collected had formalised policies created between 2008 and 2016 to manage missed appointments. 13 CTCs with included documents had revised at least one discharge policy or policy related document from their initial published form. Of the 38 data documents that met inclusions criteria, 19 were formal policy documents, 3 were documents to support clinicians in sharing information with families about the discharge policy (e.g., service agreement between family and organisation) and 16 were documents sent directly to the family (e.g., letter to family notifying them of missing an appointment).

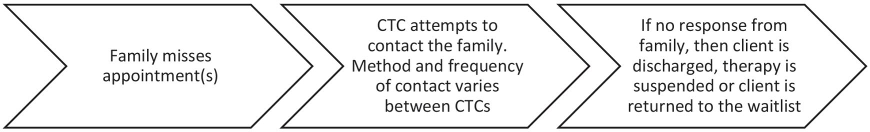
A variety of procedures were identified to minimise missed appointments including the use of appointment cards, reminder phone calls, reminders by mail, offering families an alternate service delivery method (e.g., change time or frequency of appointments), providing families with organisational contact to proactively cancel appointments and offering interpreter services. 6 CTCs utilised more than one method to minimise missed visits. Some exceptions to following discharge policies were identified including if appointments were missed due to inclement weather, illness, emergency situations, families having to manage multiple appointments, transportation issues, language barriers and unspecified extenuating circumstances.

Overall, CTCs vary in the policies used to manage missed visits. Some clear policies exist, however, grey areas leave room for interpretation and flexible application. Despite variability in the details of policies, a common flow for managing missed visits depicted in Figure 1 emerged from the data.

3.2 Family-Centredness Discourse in Policy Documents

Evidence indicates that FCS improves access, health outcomes and family satisfaction with care in children with special health care needs (Kuhlthau et al., 2011). In 2015–2016, as an indicator of FCS, parents' perception of the care they received was routinely measured using the Measure of Processes of Care at 11 of 19 CTCs (Empowered Kids Ontario, no date; King, Rosenbaum and King, 1996). FCS emphasises parents as experts on their children as well as partnerships between professionals and families (Rosenbaum et al., 1998; King et al., 1999; Law et al., 2003). Problematically, client-centred service (equated to FCS in the paediatric rehabilitation context) has been accepted as a discourse guiding rehabilitation practices with little critical reflection on the evidence for this approach. Who defines what this approach looks like in practice and whether it is successful at achieving the aim of shared power between client and professional has not been examined thoroughly (Hammell, 2013). In paediatric rehabilitation, FCS is intended to empower families to be active agents in directing care and choosing meaningful service options that suit their specific context (Rosenbaum et al., 1998). However, some families may prefer an expert model of care, feel overburdened by

Figure 1 Common flow from missed appointment to discharge at CTCs



the demands in leading their child's care, or prefer not to access care at all (Phoenix and Vanderkaay, 2015; Pluut, 2016). These choices may not be available to families when FCS is enacted in rigid ways that presume to know and act in families' best interests. This lens was brought to bear on the analysis of FCS discourse in the policy documents.

A discourse of family-centredness emerged from the language of policy documents analysed. However, despite CTCs mandating the provision of FCS, the language of policy documents analysed did not consistently align with family-centered principles. In the data, FCS is discussed as a singular desirable entity however, this discourse is challenged by language, practices and policies that do not align with traditional FCS values in children's rehabilitation (Rosenbaum et al., 1998; King et al., 1999; Law et al., 2003).

3.2.1 Explicit and Implicit Representation of Family-Centredness in the Language of Policy

In the data, FCS was at times identified explicitly, such as 'J provides family-centred practice' (J-Policy), however more often an implicit meaning of family-centredness was derived from the choice of language used in policy documents describing interactions occurring between the CTC and family related to missed appointments. The intention of providing 'meaningful service' (P-Policy) creates an understanding that families need to have an active role in determining what services best fit their specific context. A willingness to collaborate with families and tailor services to optimise access was evident in language such as, 'Clinical staff work as a team with clients and families in order to provide the type of service required, at a time and location that is appropriate, available and accessible for the client and family' (L-Policy). Acknowledgement that service needs vary between families is illustrated in this excerpt, 'H aims to provide services to as many clients as possible, working along with families to support their involvement as their needs dictate' (H-Policy). FCS is portrayed as a practice that aligns with a rights-based approach to ideally support all families, including those marginalised by systemic barriers, to access services through attempting to empower choice and direction in care. However, given that this FCS discourse is embedded in a culture driven by discourse of rehabilitation and development, the choice for families not to access services is not represented as a 'meaningful service' option, inadvertently restricting their right to choose.

Some policies acknowledged the cultural diversity of families and aligning with family-centred principles made policy objectives to 'ensure communication is understandable to ESL [English as a Second Language] clients/families' (G-Policy). Exceptions to proceeding with discharge were made if it was felt the family did not understand the policy, for example 'the termination process is not applicable when communication has not been understood by clients and families' (G-Policy). Supportive services such as arranging for 'use of an interpreter' (J-Policy) or linking family with social work services (I-Policy) were explicitly noted in some policy documents. Exceptions to discharge after missed appointments such as 'illness' (F-Policy), 'hospitalization' (K-Policy), 'challenging personal circumstances' (K-Policy), 'transportation issues' (G-Policy), or having 'multiple appointments scheduled' (M-Policy) also demonstrated consideration for family context. While concrete supports, such as interpreters, may help families to access care, they are predicated on the assumption that families want to access rehabilitation and may overlook potential cultural differences in views on rehabilitation, child development, inclusion that may underlie choices about care and participation in services.

Use of language like 'partnership' (P-Policy), 'team' (L-Policy), and 'relationship' (J-Policy) further illustrated a desire for collaboration between the organisation and family. In the data, the need for a family's involvement in service was formalised through procedures mandating discussions between clinicians and family about the shared commitment required from both the CTC and family. Often 'Families are asked to sign a partnership in therapy letter outlining attendance requirements' (J-Policy). Partnership or commitment to service agreements were commonly used to share information about discharge policies with families, ensuring 'both parties [CTC and family] understand their commitment to service' (M-Policy). It appeared that partnership agreements were presented as family-centred approaches to promote engagement in care. However, upon closer inspection, some agreements mandated parent attendance and outlined consequences of missed appointment such as:

> *Clients and families are expected to attend all scheduled therapy sessions and to arrive on time. Appointments that are cancelled or missed by the family will not be rescheduled. (B-Family Document).*

Other partnership agreements attempted to empower families to initiate conversations with their care team if experiencing challenges with attendance, illustrated in this excerpt from a service guideline document reviewed with families:

> *Therapists welcome parents to discuss any challenges with attending appointments as other options may be available to better meet my needs. (M-Family Document).*

By framing discussions or agreements as a partnership with responsibilities from all parties, an attempt is made to distribute power among all involved in the service relationship. Collaborative generation of solutions as well as inclusive policy statements such as, 'It is the policy of L to work with families to facilitate client and family attendance …' (L-Policy), tries to create a dynamic of shared responsibility and power between CTC and family, aligning with embedded principles of FCS in this context.

3.2.2 Policy Language in Conflict with Family-Centredness

A shift toward the CTC holding power over the family becomes evident in the use of punitive language situated in a legal discourse such as 'A reserves the right after careful consideration to discharge a client from treatment' (A-Policy) or having families 'sign a contract' (D-Policy) related to service expectations. Given the power differential between professional and family created through the choice of punitive language, families may feel coerced into signing these documents even if they anticipate not being able to fulfill the terms, infringing on their right to choose to participate in rehabilitation. Language of the policy documents becomes less congruent with FCS when the choice of language creates an understanding that the family has a less active role in identifying meaningful service options, as illustrated in this quote from a document reviewed with families, 'We cannot offer other treatment types until the recommended therapy has been completed' (M-Family Document). Similarly, family-centredness is compromised when families are not involved in generating solutions to missed appointments. In the following excerpt, families are not identified as being involved in meeting to generate solutions:

> *In the event that missed appointments persist after the plan has been jointly implemented, all involved services shall meet to discuss the appropriate course of action. (H-Policy).*

The family is placed in a position of limited power to identify when they feel attendance is becoming a concern as 'discussion regarding a family's barriers to attending appointments shall be initiated by the clinician when a clinician believes attendance is becoming a concern' (H-Policy). These examples illustrate that FCS was adopted by all CTCs without indication of critical consideration about whether it should be adopted or how it may affect client experiences of care. How FCS was enacted in policies may disempower families (e.g., via service agreements that outline actions and consequences). This may decrease families' right to choose the type of service and service delivery model that fits their cultural values and beliefs, which may include the choice to decline care.

3.3 Health Equity Discourse in Policy Documents

3.3.1 Portraying and Operationalising Equitable Service

Equitable treatment means giving people what they need to best suit an individual family preference or circumstance. Like family-centredness, a discourse of equity emerged from the data explicitly in examples such as, 'F strives to provide equitable access to client services within available resources' (F-Policy). When not mentioned explicitly, equity was often present in the implied meaning of the language of policy, as illustrated by excerpts like 'If the family is faced with challenges to attend, the therapist will determine a different service delivery method to assist the family' (C-Policy). 'Expected processes for new clients for O intervention will be clearly documented to provide timely and equitable service.' (O-Policy) is an example of a policy objective that explicitly mentions equity. However, the procedures written to operationalise this objective depicted a rigid process that each family was intended to move through. This rigid language depicted equality in which every client receives the same treatment, however, an equitable approach would allow for individual tailoring that accounts for the families' situation, needs and choice.

3.3.2 Making Room for Equity in the Language of Policy

Despite some incongruence between the objective and operationalisation of equitable service in CTCs' policies related to missed visits, the language used in these documents creates opportunity for health equity through procedural flexibility and examples of going above and beyond to provide families with specific supports needed to access services should that be their choice. Use of flexible language such as 'careful consideration' (A-Policy), 'guidelines' (B-Policy), 'exercise discretion' (H-Policy), and 'professional judgement' (K-Policy) creates flexibility for service providers to adapt processes to accommodate families' unique contexts. Although encouraging professionals to use their individual judgement allows for flexible application of discharge policies, it is important to recognise that individual discretion may be influenced by preconceived negative judgements or unconscious bias based on family identity or circumstance. This could increase the risk of marginalised families disproportionately experiencing barriers to continued service as a result of systemic inequities such as racism, classism or ableism.

Policies enabled service providers to use their judgement regarding proceeding with discharge despite missed appointments, as allowances can be made for missed visits that are 'deemed reasonable' (O-Policy), 'justifiable' (H-Policy) or 'valid' (I-Policy). The power for upholding equity in service is held by the service providers and their value judgement on the validity of a family's reason for missing an appointment leaves room for bias in application and risks undermining the aims of equitable service. The language in some of the policies depict a commitment to making discharge from services a last resort, occurring only when 'every attempt to work through hardships or barriers has taken place' (G-Policy). Equity is also demonstrated through procedural steps aimed at engaging families who have missed appointments by adding resources such as social work services or contacting 'other agencies or service providers with consent that are part of the client's circle of care in an effort to engage the family' (L-Policy). While it may appear equitable to make attempts at understanding a family's barrier to services and to consider discharge only after problem-solving attempts, we must also consider the inherent value in any reason that a child or family has for missing an appointment and the potential harms in having those reasons judged. While social work services and attempts to work through hardships may be well-intentioned, they may also threaten child and parent autonomy in pressuring families to use services or to worry about the involvement of social work and potentially child protective services.

3.3.3 Balancing Equitable Access to Service with Management of Resources

The policy documents provide flexibility within procedures and encourage actions that support engagement of families who miss appointments while simultaneously advocating for equitable service access for families waiting for service by acknowledging finite CTC resources. Policy language attempts to justify the necessity of discharge resulting from missed appointments due to the need to efficiently manage limited resources. The need to manage waitlists (i.e., ‘M has a lengthy waitlist and thus missed appointments results in delays in other children receiving service’) (M-Policy) and resources (i.e., ‘to ensure the most effective utilization of costly and limited resources, clients are expected to attend appointments …’) (H-Policy) are used as justification for procedures that involve discharge as a strategy to address missed appointments. Service wait times and resource management are mentioned in documents shared with families to illustrate reasons why missed visits are problematic: ‘As resources are costly and limited, clients are expected to attend appointments …’ (H-Family Document). In a letter to families, waitlists were used to justify why the family was being discharged from services, ‘we have many children waiting for our service and therefore [you/client name] have/has been discharged from [name of service] at G’ (G-Family Document). With the reality of finite resources and high demands for service, CTCs attempt to balance service equity for those active in service as well as those waiting for service. However, by advocating for equitable access for both groups, the language of these documents becomes conflicted. On one hand the language allows for flexible interpretation to avoid discharge, while at the same time uses resource management to justify procedures that lead to discharge.

3.4. Perpetuating Established Power Relations Discourse – Creating Power Imbalance Through the Language of Policy

3.4.1 Institutional Power Sustained Through Controlling Access, Differing Expectations for Attending Appointments and Valuing Professional Opinions Over Family Input

Language in the policy documents places value on the judgement of the clinical professional to determine if a family remains in service after missing appointments as illustrated in statements such as, ‘It will be at the discretion of my therapist(s) to continue service’ (M – Family Document). The organisation holds the power to determine what is justifiable for missing an appointment stating that, ‘frequent cancellations without valid reason may result in the child being discharged from a service’ (I-Policy). Language of policy also indicates that the organisation has power to dictate when a family is able to access service, indicating that ‘services can be started again at a future date, when the client/caregiver are able to commit’ (H-Policy). Examples from the data indicate that value is placed on professionals’ opinions regarding when a family needs to access service for their child, such as ‘therapist/consultant felt it was important to see you’ (A-Family Document), which might influence the family to feel as though they must engage in service, limiting their sense of choice. Entrenched in the broader discourses of development and rehabilitation, service providers’ values and beliefs in the benefits of rehabilitation and the ideal course of child development are embedded in the policies. Through use of discharge policies, organisations have imbued service providers with power as gatekeepers that may grant or limit access to services to families. Families are in a relatively powerless position with limited choice in determining if they want service, to miss or pause services, or whether to return to services after a discharge.

The power relations embedded in this discourse emphasise power imbalance through the language used to describe actions taken by professionals to manage missed visits compared to stronger language used to indicate actions required by parents to comply with the process. For example, a policy indicates that a 'therapist will make a reasonable effort to communicate with the family to discuss the situation by making a special phone call' (P-Policy) or instructs that 'the professional should be discussing with the parent/caregiver a different model of delivering service that will accommodate reasons for missed appointments' (M-Policy). Comparatively, actions required by families are represented by language like 'must' (L-Policy) or 'expected' (A-Policy), which give a sense of finality and restricted choice. For example, these policies state that the family 'must be on time' (B-Policy) and are 'expected to attend all scheduled appointments' (B-Family Document). Although nuanced, comparing the language that demands specific actions from families to the suggestive tone associated with the actions of service providers illustrates that power differential can be created and maintained in policy.

Within the policy documents, a dominant view exists related to the organisation's perception that attendance at therapy appointments impacts child treatment outcomes. This value is illustrated through statements like, 'your child's goals will only be met when you come regularly to all appointments' (H-Family Document). The conceptualisation that attending therapy appointments is necessary for a child's development is noted in 13 policy documents and is utilised to motivate attendance as well as to explain to caregivers why missed visits are problematic. Statements such as, 'we are concerned that you may not be receiving the necessary therapy support to promote your child's ongoing development' (A-Family Document), or 'consistent attendance for scheduled appointments will provide the best treatment support for the child and family' (B-Policy) create the assumption that there is a causative link between attending appointments and therapy outcomes. These claims, however, are not supported by evidence within the policy documents and instead are presented as the accepted viewpoint in the field of paediatric rehabilitation. Upon critical reflection of these statements, they are interpreted as a means to motivate families to attend appointments, however, in reality they may devalue the impact families have on their child's development and can increase the pressure families feel to attend appointments. Additionally, these values embedded in policy perpetuate normative ideals of child development and disability as an impairment requiring rehabilitation. Parents may experience feelings of self-blame and guilt if they are unable to attend appointments, increasing the power discrepancy between the CTC and family as well as creating barriers to conversations about the family's values and desires related to services access and outcomes.

3.4.2 Devaluing Family Power Through Language and Expectation

In addition to the language of policies devaluing the family's impact on child development independent of CTC intervention, the language also acts to minimise the family's power in the service process. Use of punitive language in policies such as 'failure' (E-Policy) or 'consequences' (P-Policy) create the sense that the family is expected to act or respond in a way set out by the organisation with procedures in place to follow up if the family does not engage as expected. Statements such as, 'failure to make contact will result in discharge from the specified service' (F-Policy) use language to clearly delineate repercussions of a family's inaction and strips the family of the power to choose an alternate course of action that might better suit their context.

Power imbalance between the CTC and family is also illustrated through language that can be interpreted as making assumptions about the family or labelling them based on their action or inaction in accordance with the institutionally defined procedures for how missed visits are managed. Policy documents use terms like 'chronic cancellers' (I-Policy) or label families as being 'at high risk of cancelling' (A-Policy) based solely on attendance history. A family's attendance history leads to further presumptive statements related to their level of commitment to service such as, 'it appears that services may not be a priority for you at this time and as such, we are discharging …' (A-Family Document).

Language in policy documents places the responsibility for managing and attending appointments on families stating that 'clients and families are expected to attend scheduled assessment and recheck appointments' (B-Policy). Letters are sent to families with reminders that their 'failure to contact the clinician will result in discontinuation, postponement or discharge from service' (H-Policy) and associate a family's level of engagement in service with attendance at appointments as illustrated by the statement, 'our priority is to provide service to the families who are committed to treatment for their children, as demonstrated by regular attendance at therapy appointments' (M-Family Document). This language places expectations for how the organisation anticipates a family should act in the service relationship, devaluing family contribution and desires in the service delivery process. Limiting family choice and input in turn limits their power in the service relationship by restricting opportunities for their unique contexts to be acknowledged. This perpetuates the notion that families subscribe to the same assumptions of those in positions of power (service providers), that rehabilitative treatment is beneficial for the development of disabled children.

4. Discussion

The language of CTC discharge policies results in dominant practices that risk infringing on a disabled child and their family's right to choose whether to access rehabilitation. As a step toward addressing the social injustice associated with restricted access to rehabilitation, recommendations for equitable policies that enable service use are discussed below. Authors of this article acknowledge that families may elect not to use rehabilitation services and that these services are situated in traditional rehabilitative discourse that privileges notions of normal development, remediation, and service provider expertise. This positioning may not align with families' beliefs, especially when cultural beliefs are explored and systemic inequities that may be experienced in health and rehabilitation are considered. While these complexities are acknowledged, the focus of the recommendations are to provide feasible steps that CTCs can take to shift dominant practices and reconceptualise norms around discharge policy development and implementation. Much work remains in the critical examination of the intersection between service access and barriers imposed by accepted social practices and discourses. Operationalising the recommendations proposed here is a starting point toward encouraging CTCs to reflect on how current practices contribute to the maintenance of oppressive systemic barriers impacting families' access to their services.

In the literature, FCS is described as a model of care that recognises the parent as a constant in the child's life, which has been shown to increase parent satisfaction with service, reduce parent stress and increase parent emotional well-being (Rosenbaum et al., 1998; King et al., 1999; Law et al., 2003). Although rehabilitation professions identify client-centred services as a core value in their professions, little information has been solicited from clients themselves to determine what defines client-centred practice or what it means for a professional to practice in this manner (Hammell, 2013). This risks perpetuating professionally derived assumptions about what it means to practice in a family-centred way and about the value families place on family-centred service. While further critique of FCS is warranted, the policy recommendations provided below are situated in the FCS discourse that is common in CTCs.

Given that child development is impacted by family context, FCS calls for the needs of all families members to be supported (Rosenbaum et al., 1998). Raising a disabled child has the potential to increase financial strain, negatively impact parent health, increase reliance on public support and weigh into parents' decisions related to employment and education (Reichman, Corman and Noonan, 2008). Families report challenges they experience due to systems-related issues, such as navigating disjointed services, advocating for their child's services and social participation opportunities, and a lack of financial or material supports (e.g., respite services) (Hanvey, 2002; Ballantyne et al., 2015, 2019; Sapiets, Totsika and Hastings, 2020). While these systems-level issues and the impact on families' finances, health, and social participation may pose barriers to service use, current policies for addressing missed appointments are limited to how services themselves can be modified (e.g., the frequency, time or location of service provision). If FCS is extended to deeply understand families' lived experience, an intersectional lens may be usefully applied to understand the systemic barriers that limit access to a range of health and social services such as ableism, racism, classism. An examination of these inequities raises different questions about why families may decline service use and points to novel strategies that may support families' decisions about whether to access services and how to increase the acceptability of those services.

In the policy documents analysed, frontline clinicians are sometimes encouraged to initiate conversations with families who have missed appointments to discuss barriers to attending. However, within the policy documents there is little procedural detail provided to ensure these steps are implemented consistently. Current practices risk missing an opportunity to engage in conversations with families to gather information about their context and gain insight into the influence of systemic barriers on attending appointments. To truly address service access barriers, FCS needs to move beyond modifications to service into the political sphere to advocate for structural and institutional change across multiple systems (e.g., housing, employment, healthcare), a worthwhile but immensely complex venture.

Recommendation: It is recommended that policy development is informed by a family-centred approach that prioritises understanding family needs, values, desire for therapy, and the potential for systemic barriers to influence their care decisions and access. This may enable CTCs to adopt and implement policies that promote families' therapy-related choices, examine individual and systemic barriers to service use, and to work in solidarity with disabled children and families to address the systemic inequities embedded in rehabilitation, health and social services.

In Ontario, Canada there is a high demand and lengthy waitlists for paediatric rehabilitation services (Empowered Kids Ontario, 2016). CTCs are challenged to make efficient use of limited resources considering both families active in service as well as those waiting for service. Additionally, publicly-funded services are accountable to funders to meet service output targets related to the number of families serviced, time spent waiting for service, and positive therapeutic outcomes for clients (Phoenix, 2016). Both funding and limitations on service capacity have been identified as system-level barriers to families receiving early intervention services for their child (Sapiets, Totsika and Hastings, 2020). The pressure of outcome performance and finite resources may create systemic bias toward discharging families who require higher levels of organisational resources to support continued engagement in services (Cortis, 2012). These perspectives are drawn from dominant rehabilitation discourses that prioritise goal attainment, positive outcomes, and efficiency in service delivery. Ethical tensions may be experienced by children, families and clinicians when they do not ascribe to these values, yet are tasked with enacting the policies that prioritise attendance, progress, parents' responsibilities in care, and resource allocation between children who are waiting for service and efficient care delivery to those that are already involved (Phoenix, 2016).

Recommendation: Given the potential for ethical tension when enacting policies related to missed appointments, it is recommended that CTCs formalise a mechanism for applying an ethical lens when developing policy. Taking an ethical approach to organisational policy development has been shown to emphasise the shared values of the parties involved and generate policies aligning with organisational values (Ells and MacDonald, 2002).

Intersectionality is inherently concerned about the influence of power relations on creating and sustaining dominant views in society that result in the marginalisation of some groups over others (Crenshaw, 1991; Hankivsky, 2012). Power imbalance in favour of the CTC emerged from the policy documents through language placing the organisation in control of families' access to service, dictating expectations from families in relation to attending appointments and perpetuating assumptions about the value families place on services. This power differential is sustained by the creation and implementation of policies by persons in a perceived position of power. Power in health policy is described as being elite-focused, whereby power is centralised around particular influential groups (Lewis, 2006). Influence has been identified as important to the health policy process as it impacts which issues are considered during policy development (Lewis, 2006). In the CTC context, organisational structures, such as management and a board of directors, exist to govern the operation of CTCs. This leadership structure places individuals, such as members of the board or the CEO, in positions of considerable power in policy development, meaning that their standing can influence issues addressed by policy.

Given that power in health policy tends to be concentrated within an elite group (Lewis, 2006), it is imperative that methods are employed during policy development to mitigate risk of systemically biasing discharge policy to negatively impact some social groups over others. A demand for increased accountability for public decisions has resulted in increased transparency by decision-makers for processes such as policy development (Gregory and Keeney, 1994).

Involvement of multiple and diverse stakeholders, including groups at risk of systemic oppression, has been identified as critical in the development of public policy (Riege and Lindsay, 2006). Innovative policy alternatives can be developed through the inclusion of stakeholder values (Gregory and Keeney, 1994). Rights-based rehabilitation emphasises the importance of creating space for the voices of disabled people to share their experience, needs and desires regarding rehabilitation (Shakespeare et al., 2018). To achieve improved balance in power between the CTC and family it is recommended that the family voice (including that of the child or youth client) is represented at the stakeholder table during policy development. Family and client input can be included in the development, implementation and evaluation of policies (Carman et al., 2013). Including families and clients as stakeholders provides critical insight related to areas of concern that may impact policy development and assist in setting priorities for the use of limited resources (Carman et al., 2013). Through sharing of lived experience, inclusion of family and client voices in policy development creates the opportunity for deeper understanding of family needs, the value placed on therapy and the impact of systemic barriers on accessing services.

Recommendation: Procedures for the inclusion of diverse family voices and the voices of disabled children and youth should be formalised into CTC policy development processes. Dedicating resources to engage families who have historically experienced barriers to attending appointments will be necessary to promote representation of diverse family and client input in policy development. Proactively budgeting for inclusion supports such as translators and transportation costs is recommended to facilitate diverse engagement (Simons, 2012; Health Quality Ontario, 2017). Purposeful planning is needed to involve diverse groups in policy development (Simons, 2012; Health Quality Ontario, 2017). Developing a plan driven by the priorities, needs and availability of families instead of the organisation supports family and client engagement (Simons, 2012). Creative and flexible methods for collecting input from families and clients who have experienced difficulties sustaining engagement through traditional methods will need to be considered to facilitate their participation in policy discussions. Including families and clients as stakeholders in policy development enhances organisational transparency and mitigates the risk of policy practices negatively impacting access to services for some families and clients over others.

5. Limitations and Future Directions

Despite employing methods to support the trustworthiness of results there are some limitations to this study. Textual analysis focused only on policy documents and did not extend to other CTC documents that might have impacted findings (e.g., strategic plans, culture and value documents). Additionally, this study was completed in the context of publicly-funded paediatric rehabilitation in Ontario, which limits the transferability of results to other settings.

This article provides recommendations aimed at enhancing the development and implementation of policies that support equitable access to rehabilitation services for families who choose to engage with them. Further research is needed to understand the complexities associated with operationalising these recommendations in practice and the steps required to shift policy development practices in this context.

Conclusion

Disabled children and their families have the right to choose to access rehabilitation services. The dominant organisational practices associated with discharge policies related to missed appointments in Ontario's CTCs, strongly embedded in rehabilitation and developmental discourses, risk disproportionately limiting the choice to access to paediatric rehabilitation services for some families over others. Policy recommendations have been provided to support equitable service continuation and access to paediatric rehabilitation services for all disabled children and their families who choose to engage in them.

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Chapter 3. Describing Caregiver and Clinician Experiences with Pediatric Telerehabilitation Across Clinical Disciplines

As part of a larger co-design study, Chapter 3 presents a published manuscript that describes the experiences of caregivers and clinicians with pediatric telerehabilitation. Interview data was analyzed using qualitative content analysis to describe the high and low points of engaging with a pediatric telerehabilitation service delivery model. Findings highlight the importance of being informed about the telerehabilitation service model so that caregivers and clinicians can make an informed choice about engaging in telerehabilitation and feel prepared for these appointments.

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Describing Caregiver and Clinician Experiences with Pediatric Telerehabilitation Across Clinical Disciplines

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Abstract

Scope: This study describes the high and low points of caregiver and clinician experiences with pediatric telerehabilitation with consideration for the sustainable adoption of pediatric telerehabilitation beyond the COVID-19 pandemic context.

Methods: As part of a larger study, this project analyzed data from qualitative interviews to describe caregivers' (n = 27) and clinicians' (n = 27) experiences with pediatric telerehabilitation.

Findings: Caregiver and clinician experiences with pediatric telerehabilitation are described according to four touchpoints identified: (1) child engagement in telerehabilitation; (2) perceived value of telerehabilitation services and caregiver engagement; (3) preparing the people and environment for telerehabilitation services; (4) fit of using a telerehabilitation model; and (5) providing family with choice.

Discussion: Findings highlight the importance of being informed about the telerehabilitation service model, feeling prepared for telerehabilitation appointments and being responsive to families' choice. Recommendations to address these areas are discussed.

Keywords: Caregiver experience, Clinician experience, Multidisciplinary, Pediatric telerehabilitation

Telerehabilitation, therapy occurring remotely over a telecommunications platform (Parmanto & Saptono, 2009), was rapidly implemented as a model of service delivery because of restrictions on in-person appointments during the COVID-19 pandemic. In the field of pediatric rehabilitation, it is estimated that the number of clinicians using telerehabilitation to provide services grew from 4% to 75% during the COVID-19 pandemic (Camden & Silva, 2021). Although the quick adoption of pediatric telerehabilitation is closely linked to factors related to the COVID-19 pandemic, it has been recommended that the benefits of continuing to offer telerehabilitation alongside in-person appointments as part of a hybrid approach to pediatric rehabilitation be explored (Camden & Silva, 2021; Rosenbaum et al., 2021). Prior to the COVID-19 pandemic, publicly-funded pediatric rehabilitation appointments at Children's Treatment Centres in Ontario, Canada primarily occurred in-person. However, since telerehabilitation was integrated into service provision in response to pandemic restrictions, telerehabilitation continues to be available as an option for families in a hybrid model of practice. These services can include a combination of occupational therapy (OT), physiotherapy (PT), and speech and language pathology (SLP), along with other supportive services such as social work (SW) or behavioural supports.

A 2023, systematic review examining the effectiveness of telerehabilitation interventions compared to other interventions (i.e., no treatment, usual care and in-person) found that on average telerehabilitation interventions were more effective (for 46.9% of outcomes) or as effective (for 53.1% of outcomes), at improving therapeutic outcomes related to the parent and child (Ogourtsova et al., 2023). The effectiveness of pediatric telerehabilitation is further supported by a 2020 systematic review reporting that 56.1% of the outcomes evaluated improved with telerehabilitation intervention (Camden et al., 2020). Telerehabilitation interventions were found to be most effective when they supported implementation of an exercise program by the parent, targeted the parent (i.e., not working directly with the child) and when a coaching approach was utilized (Camden et al., 2020). Alongside literature discussing the effectiveness of pediatric telerehabilitation, preliminary evidence suggests that pediatric telerehabilitation is feasible within the clinical context and acceptable to caregivers (Tanner et al., 2020). The findings from a 2022 scoping review exploring the acceptability of telerehabilitation interventions provided by pediatric occupational therapists and physical therapists suggest that further research is needed to understand how acceptability is defined and evaluated in relation to telerehabilitation intervention (Dostie et al., 2022).

A body of literature has emerged that explores the perspectives of invested groups (e.g., caregivers, youths, and clinicians) about pediatric telerehabilitation. Experience of providing or receiving pediatric rehabilitation services has highlighted both benefits and challenges associated with this service model. Challenges identified include difficulties using the technology, a lack of access to the technology required for appointments, privacy concerns, and distractions in the surrounding environment (Lindsay et al., 2023). Increased flexibility, convenience, and opportunities for the child to be in their own home have been identified as some of the benefits of pediatric telerehabilitation (Lindsay et al., 2023).

At this time, much of the pediatric telerehabilitation literature explores the perspectives of invested groups in isolation of each other (i.e., either clinician or caregiver perspective) (Fairweather et al., 2021; Grant et al., 2022; Wittmeier et al., 2022) or explores the perspectives of multiple invested groups but only related to a single clinical discipline (i.e., caregiver and clinician perspectives related to telerehabilitation with SLP) (Kwok et al., 2022a). Additionally, the literature exploring the perspectives of invested groups as well as the benefits and challenges of pediatric telerehabilitation is often situated in the timeframe of the COVID-19 pandemic when implementation and adoption was rapid and essentially mandatory (Kwok et al., 2022a; Lindsay et al., 2023; Wittmeier et al., 2022).

There is a paucity of evidence describing the experiences of both caregivers and clinicians with pediatric telerehabilitation in a post-pandemic context that is inclusive of multiple clinical disciplines. This study aims to address this knowledge gap by answering the research question: How do caregivers and clinicians describe the high and low points of their experiences with pediatric telerehabilitation? The aim of reporting these findings is to identify potential priorities for change to pediatric telerehabilitation that would enhance caregiver and clinician experiences with this service model. This study was part of a larger Experience Based Co-Design (EBCD) project, with an overall purpose of improving experiences with telerehabilitation services at a publicly-funded children's treatment centre (Reitzel et al., 2023). Implications for the sustainable adoption of pediatric telerehabilitation beyond the COVID-19 pandemic context are discussed.

Methods

Study Design

EBCD uses collaborative methods to learn about the experiences of service users (e.g., caregivers) and service providers (e.g., clinicians and health service managers) to guide co-designed changes to health services (Bate & Robert, 2007; Moll et al., 2020; Mulvale et al., 2019). Guided by the EBCD methods proposed by Bate and Robert (2007) the following stages were completed as part of the co-design project: (1) setting up the project; (2) engaging clinicians and gathering their experiences; (3) engaging families and gathering their experiences; (4) co-designing meetings; (5) sustaining co-design engagement and implement change; (6) celebrating and evaluating changes to health service.

This paper focuses on reporting findings related to the experiences of caregivers and clinicians collected during stages 2 and 3 of the co-design process. The aim of stages 2 and 3 is to gain a deep understanding of individuals' experiences engaging with a health service to uncover collective touchpoints, representing the highs and lows of engaging with a health service such as pediatric telerehabilitation, and to identify priority areas for change (Bate & Robert, 2007; Donetto et al., 2015). To learn more about the full EBCD study and related co-developed solutions refer to the paper by Reitzel et al. (2023). Ethical approval for this study was received by the Hamilton Integrated Research and Ethics Board (project #14235).

Context

Thorough description of the study context improves trustworthiness of qualitative research by enhancing readers' understanding of the transferability to other contexts (Lincoln & Guba, 1986). This study was completed in partnership with KidsAbility, a publicly-funded CTC in Southwestern Ontario, Canada. At the time of this project, KidsAbility had six clinical sites providing family-centered therapy services to children from birth to secondary school exit in both urban and rural areas. Prior to the COVID-19 pandemic, most appointments at KidsAbility took place in-person. However, since the pandemic, telerehabilitation visits are offered alongside in-person appointments as part of a hybrid service delivery model. A research partnership was formed with KidsAbility in part due to author MR's history working as an occupational therapist with this organization. Aligning with the collaborative methods of EBCD, our research team, referred to in EBCD as the steering committee, guided each stage of this project and included diverse perspectives from multidisciplinary researchers, clinicians and a caregiver.

Recruitment

Recruitment for this phase of the project launched in September 2022 and closed December 2022. Caregivers with children who received telerehabilitation services from KidsAbility in the previous 12 months were recruited by self-referral. Established communication channels between KidsAbility and families such as KidsAbility's social media platforms, website and email were used to reach out to caregivers. Clinicians with experience providing telerehabilitation services at KidsAbility in the last 12 months also self-referred and were recruited through messages to their workplace emails and advertising in the internal staff newsletter. A time frame of 12 months was selected for both caregivers and clinicians to ensure that their experiences were representative of the current status of telerehabilitation service provision and not of that provided in mandatory response to the COVID-19 pandemic in March 2020. To be included in the study, clinicians were required to be actively working for KidsAbility in one of the following disciplines: board certified behaviour analyst (BCBA), instructor therapist (IT), communicative disorders assistant (CDA), occupational therapist (OT), physiotherapist (PT), speech-language pathologist (SLP) or social worker (SW). Throughout this paper the term clinician can refer to an individual from any of these clinical disciplines.

The aim was to recruit approximately 30 caregivers and 30 clinicians to maximize variation according to child's age, discipline of service, site of service, urban-rural geography, and caregivers' gender (Kuzel, 1999). Maximum variation sampling was selected in response to recommendations from KidsAbility's Parent Advisory Committee (PAC) emphasizing the importance of having a diverse sample representative of the services and families connected with KidsAbility. Consultation with the PAC was held prior to commencing recruitment planning. Transportation and language interpretation services were made available in all phases of this project to enhance the accessibility of participation.

Data Collection and Analysis

Semi-structured interviews were completed with 27 caregivers and 27 clinicians between October 2022 and December 2022. The interviews ranged in length from 20 minutes to 60 minutes. One interview was completed with the assistance of an interpreter. Interviews were completed virtually using the Zoom platform and audio recorded using the laptop microphone (Zoom Video Communications, 2023). The option for in-person interviews was made available to enhance accessibility but was not utilized by any participants. Author MR completed interviews with caregivers, while author MNP interviewed clinician participants to avoid discomfort and to aid in mitigating power imbalances related to author MR interviewing her clinical colleagues. The interview guide was developed by the steering committee with input from members bringing a caregiver and clinical perspective. The same interview guide was used for caregiver and clinician interviews. During the interview, questions were posed to elicit stories from participants about their experiences receiving or providing telerehabilitation services with KidsAbility.

The aim of this phase of analysis was to uncover touch points, which are memorable highs and lows of engaging in telerehabilitation to identify priorities for change (Bate & Robert, 2007). Data from the interviews were analyzed using inductive qualitative content analysis as described by Elo and Kyngäs (2008). The transcripts were read multiple times, and inductive open coding was used to identify codes that highlighted positive and negative aspects of the telerehabilitation experience as described by the participants. Transcripts were coded in Microsoft (MS) Word (Microsoft Corporation, 2016). Google Jamboard (Google, n.d.) was utilized as a collaborative platform to compare and group codes between caregiver and clinician data into higher order categories (Elo & Kyngäs, 2008). In qualitative content analysis, when data are analyzed at a manifest level, codes and categories are meant to capture meaning as it is explicitly expressed by participants (Lindgren et al., 2020). This level of analysis aligns with the aim of identifying touch points as described by the participants while sharing their experiences with telerehabilitation. To enhance trustworthiness, the emerging codes from five caregiver transcripts and five clinician transcripts were reviewed by two researchers on the team (MNP and MP) to validate the codes and identify possible gaps. Halfway through open coding, a summary of the emergent touch points was reviewed by the caregiver and clinical steering committee members (JLL and CL) to ensure the findings resonated with their experiences and to once again draw attention to any gaps or alternate perspectives that should be considered.

Next, author MR led the steering committee in a journey mapping elicitation activity where using Google Jamboard (Google, n.d.), touch points were mapped onto a timeline representing the journey of a telerehabilitation appointment (i.e., time before the appointment, during the appointment and follow up from the appointment). The journey mapping activity provided a visual depiction of when participants were experiencing the touch points during their telerehabilitation journey and facilitated collaborative discussion among the steering committee to prioritize the touch points that would be carried forward into the stage 4 co-design meetings (Reitzel et al., 2023). Trustworthiness was enhanced during the analytic process through use of an audit trail and analytic memos documenting decisions made by the steering committee and monthly peer debriefing meetings.

Findings

Sample

Refer to Table 1 for a detailed description of the sample. Thirty-three caregivers were enrolled and 27 participated in this phase of the study. We did not receive responses to schedule interviews from five caregivers and one was unable to participate due to an unforeseen family circumstance. Using a tool developed in Research Electronic Data Capture (REDCap) (Harris et al., 2019), demographic data were collected about 27 caregivers and 29 unique children. Caregivers were recruited from all six KidsAbility sites, 24 participants were mothers, two were fathers and one was a grandparent. Only one caregiver was interviewed from each household except for one family where both the mother and father were interviewed separately regarding their experience with telerehabilitation services. Most families (n = 24) had one child who received services from KidsAbility, however three families identified having two children who received services from KidsAbility. Twenty-three caregivers identified English as the primary language spoken at home, one spoke Urdu, one spoke Persian, one spoke Arabic and one family identified speaking both Arabic and Kurdish. All caregivers indicated having access to a reliable internet connection at home.

The age of the children receiving services from KidsAbility ranged from 0 to 18 years old, however 25 of the 29 children represented in the sample were seven years old or younger. Diagnoses represented include speech and language delay (n = 18), autism spectrum disorder (ASD) (n = 4), global developmental delay (n = 1), and other (n = 15). One family preferred not to disclose the diagnosis and eight families identified that their child had multiple diagnoses. Twenty-four families reported receiving telerehabilitation services from SLP, eleven from OT, three from Autism Services (IT or BCBA), two from PT and two from SW. Eighteen families engaged with one discipline for telerehabilitation appointments, six received telerehabilitation services from two clinical disciplines and three families reported engaging in telerehabilitation appointments with more than two clinical disciplines. Twenty-three families reported that they received telerehabilitation sessions that were completed individually with the caregiver and child, one family indicated they only participated in group telerehabilitation and three families shared that they received a combination of individual and group-based telerehabilitation sessions.

Twenty-nine clinicians were enrolled into the study and 27 interviews were completed. One clinician opted to withdraw from the study and another changed place of employment and therefore was no longer eligible. Most clinicians identified their gender as woman (n = 26) and one as a man. Five of the six CTC sites were represented in the primary work site of the clinician participants. There was no clinician representation from one of the two rural sites. The clinical backgrounds of the participants included SLP (n = 10), OT (n = 4), PT (n =4), SW (n = 4), CDA (n = 2), IT (n = 2), BCBA (n = 1). This meant that the sample included at least one member of each clinical discipline providing telerehabilitation services at KidsAbility. All KidsAbility clinical services programs were represented in the sample of clinicians who participated in this phase of the project, including services for children aged 0-3 years, services for school aged children (aged 4 years to secondary school exit up to 21 years old), autism services, and services with a specialized focus (e.g., augmentative and alternative communication). Twelve clinicians reported having 1 to 5 years of clinical experience, seven reported 6 to 10 years, one reported 11 to 15 years, three reported 16 to 20 years and four reported having over 25 years of clinical experience. Of the participating clinicians, 70 % (n = 19) reported having two or fewer years of experience providing telerehabilitation services as part of their clinical practice.

Table 1

Description of Caregiver and Clinician Sample

Caregivers		**Clinicians**	
Total caregiver participants	n = 27 Only one caregiver interviewed from each household except for one family where 2 caregivers were individually interviewed	Total clinician participants	n = 27
Total number of children connected to caregiver participants	n = 29	Clinician reported gender	Woman, n = 26 Man, n = 1
Caregiver role	Mother, n = 24 Father, n = 2 Grandparent, n = 1	Clinical discipline	SLP, n = 10 OT, n = 4 PT, n = 4 SW, n = 4 CDA, n = 2 IT, n = 2 BCBA, n = 1
Primarily language spoken at home	English, n = 23 Arabic, n = 1 Arabic and Kurdish, n = 1 Persian, n = 1 Urdu, n = 1	Clinical experience (years)	1 to 5, n = 12 6 to 10, n = 7 11 to 15, n = 1 16 to 20, n = 3 25 +, n = 4
Age of children receiving services from KidsAbility (years)	0 to 3, n = 15 4 to 7, n = 10 8 to 11, n = 3 12 to 15, n = 0 16 to 18, n = 1	Telerehabilitation experience (years)	0 to 2, n = 19 3 to 5, n = 6 6 to 9, n = 1 10 +, n = 1
Diagnoses	Speech and language delay, n = 18 Autism spectrum disorder, n = 4 Global developmental delay, n = 1 Other, n = 15 Preferred not to share, n = 1 Multiple diagnoses, n = 8		

Telerehabilitation received by clinical discipline	Autism services, n = 3 SLP, n = 24 OT, n = 11 PT, = 2 SW, n = 2
Format of telerehabilitation	Individual sessions, n = 23 Group sessions, n = 1 Individual and group sessions, n = 3

Touchpoint Identification

From data analysis, four touchpoints were inductively identified from the stories that caregivers and clinicians shared during interviews about their experiences with telerehabilitation. The four touch points identified were: (1) child engagement in telerehabilitation; (2) perceived value of telerehabilitation services and caregiver engagement; (3) preparing the people and environment for telerehabilitation services; (4) fit of using a telerehabilitation model; and (5) providing family with choice. The findings related to each touch point are presented below, synthesizing the perspectives of the caregivers and clinicians on each touch point, which are summarized in Table 2. Findings related to the codesign process that followed the identification of these touchpoints are reported in Reitzel et al. (2023).

Child Engagement in Telerehabilitation – Caregiver Perspective

Caregivers described that at times it was challenging to support their child's engagement in virtual sessions. "Sometimes he would be very reluctant to participate. There was one time when the clinician was showing him a picture of a snake and he said, 'I will say snake one time, then we are done.' and he didn't want to do anything else." (Caregiver 1) Difficulties with child engagement at times left caregivers questioning the value of the appointment, "I can remember an appointment where it felt very pointless because my son would have 'NO' days…He didn't even want to look at the computer screen. Now I don't know if that would have been different in-person. He still might have been 'no, no, no', but the fact that he didn't want to sit in front of the computer meant that there was no opportunity to do anything." (Caregiver 2)

When comparing their child's engagement in a virtual session to an in-person session a caregiver shared, that "[in-person] the therapist made them play the games together and against each other. This is more fun than playing against…the computer remotely." (Caregiver 3) A child's age was a factor some caregivers felt impacted engagement in telerehabilitation sessions. "He was just too young to engage with Zoom." (Caregiver 3) From the caregiver perspective, using only screen-based activities was felt to limit children's engagement. "Children are very tactile, and they need to do and experience things for learning. I think having the virtual only and having an activity only on a screen was a big limitation as opposed to if parents were given something tactile that the child could have that corresponded to the virtual session." (Caregiver 1) Caregivers described that incorporating the child's own toys into the sessions improved engagement levels. "After one or two sessions it was pretty clear that our therapist was okay and encouraged my daughter to get some of her toys to interact with and to do some of the exercises with. I would get the computer set-up and my daughter would run and grab her puzzle or whatever." (Caregiver 4)

Caregivers emphasized the importance of having high quality telerehabilitation materials to support child engagement, "I think I would have liked the little book game and some of the other games that he played with, that were haphazardly put together, to be better. It was as if they had taken pictures of a book they already used. Those could have been a little bit better." (Caregiver 2) Sustaining a child's engagement for the duration of a session was described to be challenging at times. "Towards the end of each session you could tell he was fading and wanting to go, so getting him to try and participate was like pulling teeth." (Caregiver 1) When it felt challenging to engage a child in a telerehabilitation appointment caregivers described sessions feeling "pointless," which was "disappointing" and "frustrating." Reducing the length of a telerehabilitation session was a strategy caregivers used to increase their child's engagement. "That [30-45 minutes] is a long time for a three- to four-year-old to sit in front of a screen so I started to ask for [the time] to be reduced so we would get more out of the session, and we did." (Caregiver 10)

Child Engagement in Telerehabilitation – Clinician Perspective

Clinicians discussed feeling that it took more time to prepare for telerehabilitation appointments compared to in-person sessions. Creativity was needed to find and adapt engaging activities for an online environment, which children tired of quickly according to clinicians. “I just found I had to be very creative with looking around for what online games and things were available because I could make a power-point presentation but that got really boring, really fast.” (Clinician 1) “There are some really good online games and things too. There are some good websites. The problem is you only get so far and then you have to start paying. It is really not cost effective to buy all of the things because the kids will only really be interested in them for maybe the next three sessions.” (Clinician 1)

Clinicians emphasized the need to be flexible when planning for and conducting engaging telerehabilitation sessions. “I think I had to learn to be a lot more flexible. I found it took a bit of thinking because…if they were in-centre, I have this toy and I’ll grab it off the shelf and I know the child is really going to like this, but mom doesn’t have that toy at home, so I need to shift my thinking to ‘What do you have at home?’ and what could we do this with right here and right now on the fly.” (Clinician 2)

Clinicians expressed the desire for ongoing training and the opportunity to learn about what other clinicians were doing in their telerehabilitation sessions to support a child’s engagement. “I would be really interested in learning about what other therapists are doing externally or internally virtually because I feel as a newer OT, I spend a lot of time trying to figure out how to provide [telerehabilitation] service…because we do not see what other people are doing. There may be other OTs who are doing something totally different... I think it would be helpful to learn what other virtual sessions look like.” (Clinician 3) “I would love to learn about the green screen and how to make use of it and other technologies.” (Clinician 1) “I think having some of that information on-going and learning more about the research into [telerehabilitation] and what best practices are related to telerehabilitation. I think that would be helpful.” (Clinician 4). Without these ongoing opportunities for learning, clinicians expressed concern that they would become less proficient with delivering telerehabilitation services, “[telerehabilitation] is one of those things that you have to continuously use it, or you get a little bit rusty.” (Clinician 5)

Connection between Perceived Value of Telerehabilitation Services and Caregiver Engagement – Caregiver Perspective

Caregiver statements such as, “I don’t know if it was just me, but it felt like a waste of time.” (Caregiver 5) indicates a perceived lack of value for the telerehabilitation service model. The level of caregiver engagement required during telerehabilitation sessions did not always align with caregiver expectations. “I felt like the virtual was more the speech pathologist teaching me and doing things with me that I could do with [my son] versus trying to address him and giving him words and telling him what to do.” (Caregiver 6) “I felt [telerehabilitation] forced me to be too involved.” (Caregiver 7) A mismatch in caregiver engagement expectations appeared to impact caregivers’ satisfaction and their perceived value of the service they received. A caregiver stated, “I felt like a lot of the onus was put on me to work with my daughter as opposed to my expectation, which was the therapist would be doing the teaching with my daughter and not teaching me to teach my daughter. I was frustrated by that sort of thing.” (Caregiver 4) “Am I the one in speech therapy or is he in speech therapy?” (Caregiver 6)

The need for caregiver engagement in telerehabilitation sessions was not a concern to all caregivers interviewed, some caregivers viewed their increased active engagement as a benefit. One caregiver shared, “I think I put more effort in being actively involved virtually. I do not know why. I think I would have maybe been a little bit more passive and more of just a supervisor [in-person] as opposed to when I was virtual. I was actively trying to be more engaged in listening and being able to carry on the things [the clinician] was doing in the meetings.” (Caregiver 7) Caregivers recalled accounts of their active engagement in telerehabilitation sessions, “[The clinician] would walk me through the things I could do with my daughter in forming the words and what not. She would teach me the touch cues so I could do that on my end with my daughter” (Caregiver 8). In-the-moment coaching and feedback during telerehabilitation sessions was valued by some caregivers. “The second part that stood out was the immediate feedback. Everybody likes a compliment, but I do not know how I am doing [with implementing strategies] sometimes until I see the specialist at the next session…I have not really had anybody until then just come out on their own and say, you are doing a good job.” (Caregiver 9) Caregivers’ perceived value of telerehabilitation services may have been higher if they felt their child was making progress towards their goals. “Our speech therapist has been absolutely amazing, and I see the improvement in my daughter with her speech and so does everyone else. She is improving all the time, so I do not think there is any real downfall for her doing it online.” (Caregiver 8)

Connection between Perceived Value of Telerehabilitation Services and Caregiver Engagement – Clinician Perspective

The perceived value that some clinicians placed on telerehabilitation was related to things like developing therapeutic connection and evidence for this service model. Some clinicians with experience providing both in-person and telerehabilitation services identified challenges with developing a therapeutic connection with families during online appointments. “Maybe it is just me, but I feel there is a limitation of the connection and rapport that you build with families... It could just be the way I build relationships, but I feel there is a trust, a closeness and a rapport that does not look the same in virtual therapy as it does when you are face-to-face. You see the body language, but you do not get all of it. You are missing part of the context.” (Clinician 5) Clinicians desired access to evidence about the benefits and limitations of telerehabilitation services to share this information with caregivers and feel validated in offering this service model. “I think the other piece again would be to have some level of validation that it is still providing the same type of change as in-person.” (Clinician 5) “The research of the benefits of virtual services so we can share that with families and say, the research is showing us that children or families make the same gains or skills in-person and virtually, and these are the benefits. At least that way, we are not doing things because we have to but because clinically it makes sense.” (Clinician 1)

Caregiver buy-in was identified as an important foundation for telerehabilitation appointments, “The other thing I think was huge was buy in…If the family didn't buy into the fact that…we could be successful virtually. Having families not understand its value or not accepting what could be provided virtually.” (Clinician 6) A shared understanding between caregiver and clinician about what to expect from telerehabilitation services was described as an important foundation to successful sessions: “I think what makes up a strong interaction is having an understanding of what is expected. So, having talked to the family that the child is not expected to sit at the computer, or what the session is going to be, that it is typically helpful when parents come prepared with questions, things that they have worked on and are wondering about.” (Clinician 3). Caregiver trust was another factor that clinicians felt impacted caregivers’ perceived value of telerehabilitation and engagement. “The families who were really hesitant about [telerehabilitation], they questioned the validity or benefits of it to begin with…but they had to trust us a little bit. I think a lot of time families do not necessarily trust that [telerehabilitation] is going to be a good approach, but I think that often goes along with services in general because often families come in with a preconceived notion that we are going to work directly with their kids, and they are going to be sitting in the corner not doing anything. They are very surprised when we tell them to come to the floor and play with us.” (Clinician 2) Telerehabilitation was viewed as a service model with potential to increase parent engagement in therapy sessions. “A big thing that we push, especially in our programs, is around that building parent capacity piece and that the parent is the one to be carrying out treatment at home. I think because there is such a focus on that coaching model, especially with certain types of skills, I think that a virtual model is really a nice supportive way to coach families and have a conversation with them.” (Clinician 7)

Preparing the People and Environment for Telerehabilitation Services – Caregiver Perspective

Caregivers described not knowing what to expect when getting started with telerehabilitation appointments. “Early days it is like your first baby. You do not have a clue. To have that guidance of ‘this is how therapy works’ and ‘this is how we are going to move forward’. Now I know what the plan is and what we are doing, but those early days I really needed a lot of instruction about what our visit was going to look like.” (Caregiver 11) Additionally, caregivers lacked clarity about what their role would be during a telerehabilitation appointment. “Perhaps I went into it with the wrong expectation that I was just going to be there to ensure that my daughter is doing what she is supposed to be doing as opposed to actually being really involved in the situation. That might be helpful for the parent to know what the expectation is and what they can expect and what these virtual sessions will look like.” (Caregiver 9).

Caregivers described feeling like there was a lot for them to manage during the telerehabilitation appointments related to the environment, sharing information with the clinician, and supporting their child’s participation. “So here I am trying to hold the iPad and hold my daughter to support her and then it was okay, put the iPad down on the floor at the bottom of the stairs and okay, but [the clinician] was not really getting the full picture of what is going on because the iPad is just not positioned right and you could only see so far.” (Caregiver 8) Another caregiver shared, “It was a lot because I had a non-speaking toddler, so I was doing a lot of the speaking and describing… Then I would also hand him things. Occupational therapy wanted to see if he would take two cars and crash them…For physiotherapy I was literally walking him around or giving him a walker. A lot of times I was running behind him with the computer to try and get a view of him walking. It was very hands on, and I was usually sweating by the end of it.” (Caregiver 2) Caregivers described a tension between wanting to play naturally with their child in the home environment while also ensuring that the clinician could see what was occurring on the screen. “I only had so much space that my camera provides. I would be in the middle of doing something with him and he would move slightly, I would feel that I needed to move my camera to ensure that the therapist could see what was going on and see if what I am doing is right…But then it would interrupt the whole natural interaction that I was having with my son to get him to do that because I would say, 'oh one second, Mommy has to grab the iPad', and at that point the moment was lost." (Caregiver 12)

Caregivers shared that at times, distractions in the home environment made telerehabilitation appointments challenging. "We did [telerehabilitation] almost exclusively while the baby was napping to not contend with the baby too often, but there are other distractions around, even their toys, the dog, snacks, and whatever is going on around them." (Caregiver 13) Despite some challenges, caregivers identified benefits of telerehabilitation appointments occurring in the home environment, such as the child being more comfortable in a familiar environment or tailored strategies from the therapist on how to use their surroundings to target goals. "She was a lot more comfortable with the surroundings she knows. The toys, the blankets and anything we were doing, she would feel more comfortable trying things because she was in the comfort of her own home." (Caregiver 5) A caregiver shared, "[Our clinician] asked me to go raid my pantry for…his favourite snacks... She had me put pieces of snacks all the way along the couch and at the beginning he reached as far as he could and then took a sidestep. That was the first step movement that he had taken. That was within a [telerehabilitation] session we had gotten him to take a step movement, so that one was huge." (Caregiver 2)

Preparing the People and Environment for Telerehabilitation Services – Clinician Perspective

Clinicians also identified distractions as a challenge with telerehabilitation appointments. "Sometimes you can have the other brothers and sisters coming in and interrupting or other people coming in or phone calls happening…It can be quite disruptive if mom is at home and other people are at home. It is not always the most focused and that can be a thing." (Clinician 8) Difficulties with the technology, such as audio quality were another obstacle clinicians described. "Sometimes the audio was tricky, especially if I was trying to do a speech assessment. I find especially with iPads, depending on the way they had the camera facing, it seemed to be that the microphone would pick up more of the noise behind the iPad than facing forward, so I would hear everything going on around, but I would not be able to hear the child that I needed to hear." (Clinician 9)

Safety was an additional environmental consideration that clinicians discussed in relation to telerehabilitation appointments. "Another difficulty is I cannot be there to do hands-on stuff. I cannot be there for safety. Things I would be more than willing to try in-centre to see if we could then use that strategy for home, you cannot. I cannot teach mom enough safety techniques for her body to be safe, or me to figure out how the [child] is going to respond to be able to transfer that skill over to mom with my words." (Clinician 8)

Similar to caregivers, clinicians also identified benefits of telerehabilitation linked to being able to see the child in their home environment. "I have had some lovely sessions that have involved eating and mealtime, because I think that virtual offers an opportunity to see the home environment that we do not get to see in-person. Sessions where I have noticed things where I might not have identified like positioning during eating or a lot of distractions in the home environment that I may not have been aware of that are affecting eating." (Clinician 3) "Being able to see home set-ups…to walk through an exercise program and say, 'I want you to hold onto the counter behind you'. Just being able to use their real-life things instead of having them on the site…I can get them to take me around and show what they are doing." (Clinician 8) "I have had some nice experiences where families will have the video set-up in the living room where there are toys or if the child has a playroom maybe. That has been good in terms of getting a more representative speech sample of a child because they are in their own space, with their own toys and they are likely to be more relaxed and more likely be able to demonstrate their abilities because they are at home." (Clinician 10)

A clinician shared that seeing a family for a telerehabilitation appointment gave them "a picture of what their life is like. It can be an eye-opener about how chaotic their lives are, and I am asking them to do more. So, it gives me the perspective of 'you have a very busy life, how can I help you incorporate our goals that we set together in a realistic way?'" (Clinician 11)

Fit of Using a Telerehabilitation Model and Providing Family with Choice – Caregiver Perspective

The importance of the fit of the telerehabilitation model with families' skills, resources and preferences were described by caregivers. A caregiver felt it was important that clinicians understood a family's familiarity with the technology needed for virtual appointments, noting that there could be cultural aspects that influence their comfort with using it. "I think it is really important to know their culture too. In my experience, we did not have enough experience with virtual. We learned it in Canada. We had to do everything over the phone, and we have never applied for anything online in Iran." (Caregiver 14).

Caregivers described alignment between the fit of telerehabilitation and their family needs when considering things like time saved travelling to the centre for appointments, eliminating barriers related to transportation and childcare for other children. "A big plus especially at KidsAbility for a parent in my situation where I do not drive and have two kids, so transportation is an issue along with childcare. If I have to, I'll hop on the bus with two kids but trust me, it is not easy when you have a baby whom I cannot leave at home as I have no childcare, so if I show up in-person and my husband is not there, it is very hard for me to focus." (Caregiver 9) "Virtually or remotely is more efficient because we don't…waste time moving to some other place." (Caregiver 3) A caregiver also discussed telerehabilitation appointments as a potential protective factor for parents experiencing mental health concerns. "There are days when I say 'yes, let's do this' …and when the day comes, I just don't want to do it. I don't want to go out... So having the option for Zoom means that I am not going to cancel those appointments last minute that are going to be beneficial for my son just because I am feeling that I do not want to step outside right now and I cannot handle people." (Caregiver 15)

Caregivers described that it was important to consider the fit of a telerehabilitation appointment with the type (e.g., assessment) and purpose of the visit. "With a virtual assessment they cannot check for tightness or mobility. They cannot check all of those things that with her specific issue they need to check for. They were trying to get me to manipulate her foot a certain way and ask me if it feels tight, but I do not know. I am an educated person, but I cannot tell you whether a calf muscle is tight or not." (Caregiver 13)

The importance of giving families choice in the service model they feel will be a fit for them was a critical point emphasized by caregivers. "I think going forward it would be valuable to offer both as options [in-person and telerehabilitation] and not require one or the other. I think if the parents are more willing to be involved, it is more successful for the children. The parents must be active participants in order for the kids to be successful. It is asking parents how can we make this easy for you? Do you want to come in-person, or would you rather do it virtually?" (Caregiver 7)

Considering the Fit of Using a Telerehabilitation Model and Providing Family with Choice – Clinician Perspective

When thinking about the fit of telerehabilitation for a family, clinicians highlighted the importance of considering the family's access to the technology required to engage. "A huge limitation is assuming that people have access to the technology and the connectivity to actually do these." (Clinician 8) Familiarity with using the technology was also discussed by clinicians. "Trying to talk people through how to do [telerehabilitation] if they are not very familiar with technology...that type of thing, it is tricky." (Clinician 12)

In addition to ensuring families had access to technology and could get connected to the visit, clinicians also identified the importance of considering the fit between a telerehabilitation approach and the goal of the visit. Telerehabilitation was identified as more difficult when a child had goals related to something physical such as fine motor skills. "I think where things got a little more challenging is when you had a child who had more physical needs and it was hard to do a full physical or fine motor assessment without really seeing them." (Clinician 7) Practicing in a hybrid model offering in-person and telerehabilitation was highlighted by clinicians as beneficial. "The hybrid model has been a really nice thing to do…I like doing the in-person where you are trying to figure out strategies, but once you figure out the strategies, following up virtually has been a really good thing for us." (Clinician 8)

Clinicians felt they could be more flexible with families when telerehabilitation was incorporated into their treatment plan. Instead of cancelling an appointment clinicians shared that "we can quickly switch over to Zoom. That was a real benefit." (Clinician 5). The importance of giving family choice of service delivery models was emphasized by clinicians. "[Telerehabilitation] is always an option, and I always ask families what they would prefer." (Clinician 10) "I do think it is important to provide [families] ultimately with the choice." (Clinician 3)

Table 2

Summarizing the Highs and Lows of Experiences with Pediatric Telerehabilitation

		Caregivers	**Clinicians**
Child engagement in telerehabilitation	High	More engaged when activities incorporated toys at home	Became more flexible to adapt activities according to what toys family had at home
	Low	Challenges with keeping the child interested in screen-based activities	More preparation required compared to in-person appointments Desire for continued training
Connection between perceived value of telerehabilitation services and caregiver engagement	High	Opportunity to receive in the moment coaching from clinicians Feeling actively involved in sessions More confident carrying out strategies at home Made progress towards goals	Supportive way to coach families Opportunity to have a discussion to establish shared expectations
	Low	Expected clinician to work directly with child Caregiver feeling they had to be too involved in session	Some difficulties establishing a connection with families Unsure of evidence for effectiveness of telerehabilitation
Preparing the people and environment for telerehabilitation services	High	Allows child to be in an environment they are comfortable in Strategies tailored to home environment to target goals	Observing child in the environments they are comfortable in (e.g., home) Tailoring strategies to the home environment and coaching caregivers on how to implement at home
	Low	Distractions in the home environment Unsure how to set up and prepare for a telerehabilitation appointment Managing multiple things during appointment (e.g., child and technology)	Distractions in the home environment Safety considerations of not being physically present with child and family
Fit of using a telerehabilitation model and providing family with choice	High	Telerehabilitation offers flexibility	Telerehabilitation offers flexibility
	Low	Fit between goal of visit and telerehabilitation Comfort with using technology Not having choice in service model	Fit between goal of visit and telerehabilitation Troubleshooting difficulties with technology Assuming families have access to technology and know how to use it

Discussion

The findings describe the experiences of caregivers and clinicians engaging in pediatric telerehabilitation. The stories of their experiences emphasize both high and low points. There is an opportunity to explore how caregiver and clinician experiences differ as well as how they align and to consider their influence on the sustained adoption of telerehabilitation as part of a hybrid approach to pediatric rehabilitation services. The experiences of caregivers and clinicians highlight the importance of being informed about the telerehabilitation service model, feeling prepared for telerehabilitation appointments, and needing to be responsive to families' choices related to service.

A desire to be informed about telerehabilitation services was highlighted in the narratives of both caregivers and clinicians. However, the type of information desired differed between these groups. Clinicians identified wanting to be informed about the evidence related to the effectiveness of telerehabilitation. However, constraints such as limited time and experience with searching for and appraising literature, prohibits access to empirical evidence that is ready for use in clinical practice (Chan et al., 2010). It is recommended that clinicians and health service organizations make use of widely available evidence-based knowledge translation resources such as the TelereHUB-CHILD (https://telerehubchild.com/) (Ogourtsova, 2023) or CanChild Telepractice resources (https://www.canchild.ca/en/resources/356-telepractice-resources) (Kwok et al., 2022b) that synthesize the evidence related to pediatric telerehabilitation assessment and intervention.

Caregivers shared experiences of not knowing what to expect when joining a telerehabilitation appointment or what their role would be. These experiences echo what is written in the literature about caregivers' expectations of therapy, where parents describe not having enough information to know what to expect when engaging with therapeutic services and bringing with them a predetermined idea of what their involvement in a session will look like (Phoenix et al., 2020). This gap in knowledge is of critical importance because a shared understanding of expectations for therapy between caregiver and clinician has been shown to increase caregiver engagement in services (King et al., 2019). Clinician narratives indicate that taking time to discuss the telerehabilitation service model and the role of the caregiver in these sessions results in more successful integration of this service model into care. Therefore, it is imperative that caregivers receive information (e.g., knowledge sharing dialogue between clinician and caregiver) about the telerehabilitation service model and their role in these sessions for them to feel informed and enter the appointments with expectations aligned with what the model of service offers. To enhance experiences with telerehabilitation, findings from the co-design work that drew from this interview data recommended that organizations have a process in place to consistently discuss the telerehabilitation service model and caregiver role in telerehabilitation sessions prior to commencing with virtual services (Reitzel et al., 2023).

Having a thorough understanding about the telerehabilitation service model and having access to related evidence is crucial information for determining whether telerehabilitation would be an appropriate fit for a child's therapy plan. Once the determination is made to proceed with telerehabilitation, training is needed for the clinician and caregiver to ensure that they feel prepared to engage in these appointments (Retamal-Walter et al., 2022). This includes familiarity with the required technology; knowledge of how to set-up the environment; and knowing how to adapt therapeutic activities to optimize engagement in telerehabilitation. Clinicians desired opportunities for ongoing training and collaboration with colleagues to foster continued skill development and confidence in providing telerehabilitation. A 2021 systematic review, examining the effectiveness of implementation approaches to support the uptake of evidence-informed interventions in allied healthcare reported higher levels of success with implementation efforts that use multiple strategies (Goorts et al., 2021). The use of opinion leaders (i.e., colleagues with telerehabilitation experience), workshops, and ongoing training are identified as strategies supporting intervention implementation (Goorts et al., 2021). Perceptions of being inadequately trained decrease the likelihood that clinicians will offer telerehabilitation as an option for therapy (Graham et al., 2023). It is recommended that pediatric health service organizations offering telerehabilitation consider utilizing these types of implementation strategies to provide clinicians with opportunities for ongoing skill development and training to enhance their experience with providing telerehabilitation services.

From interviews with caregivers, a key aspect to a caregiver feeling prepared for a telerehabilitation appointment was knowing how to set up the technology and the environment. This information should be reviewed with caregivers ahead of commencing with an appointment to ensure they feel ready to engage. Text-based resources, such as those available through the TelereHUB-CHILD (Ogourtsova, 2023) or CanChild (Kwok et al., 2022b) are available to support clinicians in training caregivers to prepare for telerehabilitation appointments. Alternately, video resources demonstrating how to set up for a telerehabilitation appointment were recommended out of the larger co-design process connected to this project as a method of sharing this information with caregivers (Reitzel et al., 2023). A 2023 evaluation of telerehabilitation with children with neurodevelopmental conditions, reports that early failures and challenges were viewed by clinicians and caregivers as a normal part of the learning process (Graham et al., 2023). Training is needed to support learning in these early phases of telerehabilitation to build knowledge, skills and confidence to persist with using this service model.

Family-centred service necessitates that caregivers have choice in what therapy services for their child look like and that their voices are heard as partners in therapy alongside the clinician (McCarthy & Guerin, 2022; Rosenbaum et al., 1998). When families make the choice to participate in telerehabilitation, their perceived value of the service increases and the transition to incorporating telerehabilitation into care is more successful (Graham et al., 2023). Conversely, telerehabilitation was perceived by caregivers as less valuable when they felt they did not have a choice about whether to engage with this model of service (Graham et al., 2023). When working with children with communication difficulties, providing family-centred telerehabilitation was identified as an important factor for engagement (Retamal-Walter et al., 2023). To be responsive to caregivers' choices, clinicians need to engage caregivers in shared decision-making regarding service models. Clinicians need to feel confident working in a hybrid model, shifting with relative ease between in-person and telerehabilitation visits.

Although this work incorporated a diverse range of perspectives (i.e., caregiver, clinicians, management, researchers) at each stage of the project, a limitation of this work is that it was conducted with participants from a single clinical organization, potentially limiting the transferability of the findings. We acknowledge that although set in the context of pediatric rehabilitation, the experiences of children and youth with telerehabilitation are not represented in this work and should be incorporated in future research in this area. Additionally, future research should explore how telerehabilitation is being used when incorporated into a hybrid service model along with caregiver and clinician satisfaction with a hybrid approach to pediatric rehabilitation services.

Conclusion

The interviews conducted with caregivers and clinicians as part of a larger co-design project bring to attention both positive and negative aspects of their experiences with pediatric telerehabilitation. Experience with telerehabilitation is enhanced when caregivers and clinicians have the knowledge and skills to prepare and engage in a telerehabilitation appointment. Furthermore, the perceived value of telerehabilitation increases when caregivers are empowered to make a choice regarding the fit of this service model for their child and family.

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Chapter 4. Co-designing solutions to enhance access and engagement in pediatric telerehabilitation

Chapter 4 presents a published manuscript of a study that used co-design methodology bringing together caregivers, clinicians and CTC management to collaboratively develop solutions aimed at enhancing access and engagement in pediatric telerehabilitation. This study builds from the experienced-based data from clinicians and caregivers in Chapter 3 to guide the co-design of solutions aimed at improving the low points of engaging in pediatric telerehabilitation. Findings highlight the impact of communication, consistency and connection on pediatric telerehabilitation experiences. Co-designed solutions target changes to organizational processes and generating tools/resources to enhance experiences with pediatric telerehabilitation.

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Co-designing solutions to enhance access and engagement in pediatric telerehabilitation

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Introduction: Prior to the COVID-19 pandemic, children's therapy appointments provided by Ontario's publicly-funded Children's Treatment Centre (CTCs) primarily occurred in-person. With COVID-19 restrictions, CTCs offered services via telerehabilitation (e.g., video, phone), which remains a part of service delivery. CTC data shows that families experience barriers in attending telerehabilitation appointments and may need supports in place to ensure service accessibility. Our study aimed to co-design innovative solutions to enhance access and engagement in ambulatory pediatric telerehabilitation services. This manuscript reports the co-design process and findings related to solution development.

Methods: This research project used an experience based co-design (EBCD) approach, where caregivers, clinicians and CTC management worked together to improve experience with telerehabilitation services. Interview data were collected from 27 caregivers and 27 clinicians to gain an in-depth understanding of their barriers and successes with telerehabilitation. Next, 4 interactive co-design meetings were held with caregivers, clinicians and CTC management to address priorities identified during the interviews. Using qualitative content analysis, data from the interviews and co-design meetings were analyzed and findings related to the solutions developed are presented.

Findings: Four topics were identified from the interview data that were selected as focii for the co-design meetings. Findings from the co-design meetings emphasized the importance of communication, consistency and connection (the 3C's) in experiences with telerehabilitation. The 3C's are represented in the co-designed solutions aimed at changing organizational processes and generating tools and resources for telerehabilitation services.

Discussion: The 3C's influence experiences with telerehabilitation services. By enhancing the experience with telerehabilitation, families will encounter fewer barriers to accessing and engaging in this service delivery model.

KEYWORDS

childhood disability, experienced based co-design, health service research, pediatric telerehabilitation, service access, service engagement

1. Introduction

In 2006, 174,810 Canadian children aged 5–14 years had a disability as per the Participation and Activity Limitations survey criteria (1). According to a report released by Statistics Canada in 2022, 13.5% of Canadian children aged 0–14 were reported to experience at least one activity limitation as a result of a difficulty or long-term condition (e.g., mobility, learning, emotional/psychological) (2). Rehabilitation services help children with disabilities achieve functional outcomes and participate in their social environments (3–5). Annually, publicly-funded Children's Treatment Centres (CTCs) in the Canadian province of Ontario provide over 750,000 rehabilitation visits to children (ages 0 to age of secondary school exit) and their families (6). These rehabilitation services include a combination of occupational therapy (OT), physical therapy (PT), speech-language pathology (SLP) and social work (SW) services. Some CTCs also employ Board Certified Behaviour Analysts (BCBA) and Instructor Therapists (IT) to provide services to autistic children. The term clinician is used throughout this paper and could refer to a care provider from any of the previously mentioned disciplines.

CTCs provide ambulatory services based in treatment centres to address home and community goals; however some also provide services in the school setting. Prior to the COVID-19 pandemic, CTC appointments primarily occurred in-person. COVID-19 restrictions limited access to in-person rehabilitation services and children's rehabilitation service providers quickly pivoted to supporting families using telerehabilitation platforms (7). Prior to the COVID-19 pandemic it is estimated that only 4% of pediatric care clinicians used telerehabilitation; this number drastically increased to 75% during the pandemic (7). Given the rapid uptake of telerehabilitation during the pandemic, there have been calls to consider its potential to be integrated into a hybrid service model, that takes into account reported benefits of offering a combination of in-person and telerehabilitation services (7, 8).

Telerehabilitation is defined as therapy occurring remotely over a telecommunication platform such as telephone or video conferencing (9). Increasingly, telerehabilitation services are being provided by allied health clinicians and are proposed as a solution to barriers encountered when accessing in-person rehabilitation services, such as the time and cost associated with travelling to appointments (7, 10). In a 2023 systematic review examining the effectiveness of telerehabilitation in children with developmental disabilities, telerehabilitation was found to be more effective when compared to no treatment for outcomes such as functional performance, hand function, visual perception, and behaviour or as effective when compared to no treatment (i.e., waitlist) and usual treatment, respectively (11). For outcomes such as, self-efficacy, self-control and social skills, telerehabilitation was found to be as effective when compared to usual treatment (11). In autistic children, telerehabilitation was found to be more effective than in-person services across 85% of outcomes and most importantly, telerehabilitation was never found to be less effective or to cause harm (11). This evidence of effectiveness aligns with findings from another systematic review that described telerehabilitation as an effective approach to supporting the development of adaptive skills in children with multiple disabilities (12). The benefits and challenges of telerehabilitation in outpatient pediatric rehabilitation services during the COVID-19 pandemic have been described and it is recommended that service organizations address barriers to optimize the effectiveness of this model of care (13).

Evidence demonstrates that therapy outcomes and experiences are enhanced when families are actively engaged with the services they receive (14–16). Family engagement in therapy is supported through a shared understanding of expectations, collaboration and positive relationships with therapists (15, 17). To date much of the telerehabilitation literature examines its effectiveness (11, 18, 19) and the acceptability of this service model from the caregiver perspective (7, 20), however qualitative research has started to explore parent engagement in telerehabilitation as it relates to the parent-therapist relationship (10). In 2022, a qualitative systematic review described engagement in early intervention telerehabilitation for young children with developmental disabilities and provided recommendations to establish and maintain engagement with these services (21). Despite this emerging evidence related to engagement in telerehabilitation, little is known about whether telerehabilitation can assist families in attending appointments and improve engagement in their child's therapy. The Phoenix Theory of Attendance, Participation and Engagement (the Phoenix Theory) has provided substantive knowledge regarding the barriers families experience accessing, participating and engaging in CTC services when offered in-person (15). This theoretical framework and associated research findings have been used successfully at our partner CTC (KidsAbility) to inform organizational policies and services affecting families who miss in-person appointments to reduce barriers to service access and engagement.

Missed appointments are defined as appointments missed without prior notification to the CTC and have been problematized as inefficiently using clinician time and organizational resources and may impact therapeutic outcomes (22, 23). For this project, we partnered with KidsAbility Centre for Child Development (KidsAbility), an Ontario CTC to explore missed telerehabilitation appointments, defined by KidsAbility as appointments occurring by phone or video. Since commencing with telerehabilitation services in March 2020, KidsAbility continues to report high numbers of missed appointments. From 2022 to 2023 14% ($n = 1{,}652$) of telerehabilitation appointments were missed, which was comparable to 15% (10, 349) of in-person appointments that were missed at KidsAbility. A total of 456 telerehabilitation appointments were missed without prior notice, limiting opportunities for clinicians to effectively use that client time. These metrics indicate that families experience barriers to service use, even when services are offered via telerehabilitation.

The aim of this project was to co-design innovative solutions that will enhance access and engagement in telerehabilitation in the context of publicly-funded pediatric rehabilitation for children with disabilities. We have collaborated with KidsAbility and a parent-partner to address the following research question: What co-designed solutions can be developed to improve families' access and engagement in pediatric telerehabilitation services? The scope of this paper focuses on describing the co-design process and reports findings related to the solutions developed.

2. Materials and methods

2.1. Study design

Experience based co-design (EBCD) is a highly collaborative approach to research that focuses on the lived experience of service users and service providers to develop innovative solutions to health service issues (24, 25). EBCD necessitates authentic engagement with invested parties (caregivers, clinicians, health service organizations) throughout research development, implementation and evaluation (25, 26). With its origins in design sciences, EBCD has been proposed as an approach to create or modify health service experiences through integrating patients as partners in service design projects (27). EBCD has been utilized to design health services in the public sector with the potential for authentically engaging vulnerable populations (24, 28–30).

EBCD prioritizes collaboration, partnership between invested parties and researchers, lived experience as expert knowledge, capacity building and creativity in generating solutions (25, 27, 29). Integrating qualitative methods, this project is guided by the six stages of the EBCD approach proposed by Bate and Robert (2007). For the purpose of this project, the stages of EBCD were conceptualized as: (1) setting up the project; (2) engaging clinicians and gathering their experiences; (3) engaging families and gathering their experiences; (4) co-design meetings; (5) sustain co-design engagement and implement change; (6) celebrate and evaluate changes to health service.

Stages 1 through 4 all contribute to the overall co-design process. This paper will provide a detailed account of the methods and findings for the stage 4 co-design meetings, when the co-designed solutions were developed. Stages 1 through 3 will be reviewed briefly with a focus on how they informed the stage 4 co-design meetings. **Table 1** provides a summary of key information linked to stages 1 through 4 of the co-design process as related to this project. Ethical approval for this study was received by the Hamilton Integrated Research and Ethics Board (project #14235).

2.2. Study context

The study context is described in detail to aid readers in determining the transferability of our findings to other settings. This study was completed at KidsAbility in Ontario, Canada. KidsAbility has 6 sites (5 permanent locations and 1 rural satellite clinic) providing publicly-funded children's rehabilitation services across a highly multicultural region that includes both urban and rural communities. In response to restrictions associated with the COVID-19 pandemic, KidsAbility pivoted to providing telerehabilitation services, which continue to be offered as part of a hybrid service model combining both in-person and virtual visit options. A partnership was formed with KidsAbility for this project because author MR worked there as a clinician, facilitating a deep understanding of the culture, services, provision of telerehabilitation and characteristics of the families served. Author MR examined the impact of her dual role as a clinician and a researcher who is closely connected to the study context by engaging reflexively with literature on this topic, keeping reflective memos and by debriefing with the steering committee, to ensure multiple perspectives were included in all project decisions.

2.3. Stage 1: setting up the project

The need to reduce barriers in accessing telerehabilitation services was identified from the results of a survey administered by KidsAbility in 2020. Survey results aligned with concerns that were raised by the KidsAbility's parent advisory committee

TABLE 1 Summarizing stages 1 through 4 of co-design process.

	Experience Based Co-Design Process			
	Stage 1—setting up the project	Stage 2—engaging caregivers and gathering their experiences	Stage 3—engaging clinicians and gathering their experiences	Stage 4—co-design meetings
Purpose	Establish channels to advise project directions from the perspective of multiple invested parties	Understand experiences with receiving telerehabilitation at KidsAbility	Understand experiences with providing telerehabilitation at KidsAbility	Co-design solutions to enhance telerehabilitation experience
Participants	Steering committee: parent ($n = 1$), clinicians ($n = 2$) researchers ($n = 4$), KidsAbility Parent Advisory Committee: (PAC) ($n = 6$ members consulted)	Caregivers ($n = 27$)	Clinicians ($n = 27$)	Caregivers ($n = 9$), clinicians ($n = 12$), managers ($n = 3$) Groups ranged from 5 to 7 participants
Data collection	Parent Advisory Committee: Single point of consultation during project conceptualization Steering committee: Consultation throughout the project to develop the research question, methods, and participate in data collection and analysis	Interviews	Interviews	In-person co-design meetings ($n = 3$) virtual codesign meeting ($n = 1$)
Outcome(s)	Research methods and findings tailored to KidsAbility practice context	Touch point identification to inform co-design meetings	Touch point identification to inform co-design meetings	3Cs (communication, consistency, connection) impacting telerehabilitation experience and co-designed solutions to improve access and engagement in telerehabilitation

related to families' equitable access and engagement in telerehabilitation services. The parent advisory committee is a voluntary committee of caregivers whose children are currently engaged with services at KidsAbility or had received services in the past. Open discussion forums were held with the parent advisory committee to guide the development of the research question, objectives, and to identify meaningful indicators of access and engagement in telerehabilitation services. Insights from six committee members emphasized the importance of diverse family representation in the study including geography, ethnicity, family composition, and characteristics of the child (e.g., severity of needs and age) presuming that barriers to telerehabilitation would vary according to these factors.

A multi-disciplinary steering committee including four interdisciplinary researchers, two individuals with clinical experience providing telerehabilitation services and a parent whose child had received KidsAbility services was assembled. The steering committee meets regularly and is responsible for collaboratively participating in all aspects of the project, including but not limited to defining the research question, establishing methods for data collection, engaging in data collection, facilitating co-design groups, supporting data analysis and contributing to knowledge sharing activities (e.g., presentations, manuscript preparation).

2.4. Stages 2 and 3: engaging clinicians/caregivers and gathering their experiences

The data from semi-structured interviews completed with 27 caregivers and 27 clinicians about their experiences with telerehabilitation will be reported in a separate paper. These interviews informed the co-design process by eliciting the touch points, which are emotionally powerful and memorable highs and lows of engaging in telerehabilitation (27). Interviews were completed virtually and audio recorded using the Zoom platform (31) between October 2022 and December 2022. Inductive qualitative content analysis was completed to identify, describe and visualize the touch points. Following this analysis, MR led the steering committee in a journey mapping elicitation activity where Google Jamboard was used (32) to further categorize touch points based on commonalities and to map them onto a timeline representing the journey of a telerehabilitation appointment (i.e., time leading up to the appointment, during the appointment and follow up from the appointment). The purpose of this task was two-fold. First, mapping the touch points provided a visual depiction of when participants were experiencing the touch points during their telerehabilitation journey. Second, through collaborative discussion, journey mapping allowed for the prioritization of the touch points that would be carried forward into the co-design meetings aimed at developing solutions to enhance the telerehabilitation experience. An audit trail was kept to document decisions made by the steering committee during all data collection and analysis phases of this project. Analytic memos documenting reasoning for decisions and directions taken during this project were kept by author MR. Peer debriefing was practiced during monthly meetings with the steering committee to guide project related decisions.

2.5. Stage 4—co-design meetings

2.5.1. Sampling

Caregivers with children who received telerehabilitation services from KidsAbility in the previous 12 months were recruited by self-referral using established communication channels between KidsAbility and families (e.g., KidsAbility's social media platforms, website and email list). Direct emails to clinical staff and advertising in the internal staff newsletter were used as additional strategies to recruit clinicians via self-referral who had provided telerehabilitation service KidsAbility in the previous 12 months. The timeframe of 12 months was selected for both caregivers and clinicians to ensure that they had relatively recent experiences receiving or providing telerehabilitation. The desire was for experiences to be representative of the current status of telerehabilitation service provision and not of that which was provided when CTCs were required to pivot to this unfamiliar service model in response to the COVID-19 pandemic in March 2020.

Participants were recruited to take part in one of the four co-design meetings. Given that our aim was to maximize the diversity of perspectives, caregiver and clinician participants did not have to complete an interview in stages 2 or 3 to participate in the stage 4 co-design meetings. In addition to clinicians and caregivers, managers who directly supervised staff providing telerehabilitation services were also recruited for this stage of the co-design process. Managers were recruited through the same internal communication channels as clinical staff (i.e., internal newsletter, email). Although managers did not have direct experience providing telerehabilitation services at KidsAbility, co-design approaches recommend including those in positions to influence service delivery decisions (25). Therefore, our steering committee felt it was important that managers be included in the development of solutions to the touch points identified in stages 2 and 3. Including managers ensured their voice was heard in the process and encouraged investment in the co-designed solutions, enhancing implementation and sustainability efforts. Recruitment for this phase of the project launched in February 2023 and closed April 2023.

2.5.2. Participants

Sixteen caregivers were enrolled into this phase of the study and 9 attended a co-design meeting as planned (one parent could not be reached to schedule into a meeting, one parent cancelled prior to the scheduled meeting and 5 did not give prior notice that they would not be attending). Demographic data were collected using a form developed in Research Electronic Data Capture (REDCap) (33). Caregivers were recruited from 3 of 6 KidsAbility sites, with one family reporting that they lived rurally. Seven families identified that the primary language spoken in the home was English, while the two other families spoke either Telugu or Bilen. All families identified having access to reliable internet at home. Seven mothers and 2 fathers participated in the co-design meetings and all families identified having one child who received telerehabilitation services from KidsAbility. Children of the caregiver participants ranged in age, 0–3 years old ($n = 4$), 4–7 years old ($n = 4$) and 12–15 years old ($n = 1$). Caregivers identified their children as having the following diagnoses: speech and language delay ($n = 5$), global developmental delay ($n = 3$), autism spectrum disorder ($n = 2$), cerebral palsy ($n = 1$), and other (sensory processing differences, epilepsy) ($n = 2$). Two families reported that their child had more than one diagnosis. Six families engaged in telerehabilitation appointments with SLP, 5 with OT, 2 with PT, 2 with SW and 1 family was unsure of the clinical discipline they interacted with. Four families received telerehabilitation from more than one clinical discipline and all families reported that these were individual sessions with their child. One family indicated receiving both group and individual therapy.

Thirteen clinicians enrolled and 12 participated in a co-design meeting (one clinician was unable to attend due to a change in their availability). Representation of clinical disciplines included SLP ($n = 7$), CDA ($n = 2$), IT ($n = 1$), OT ($n = 1$) and PT ($n = 1$). Years of clinical experience of the clinical participants ranged from 1 to 5 ($n = 5$), 6 to 10 years ($n = 4$) and 11 to 15 years ($n = 3$). Six clinicians identified having 0 to 2 years of experience providing telerehabilitation services and 6 identified having 3 to 5 years of experience. Three managers were enrolled and participated in a co-design meeting. The participating managers reported having at least 16 years of clinical experience in their discipline, while management experience ranged from 1 to 5 years ($n = 1$), 6 to 10 years ($n = 1$) and 11 to 16 years ($n = 1$). Between clinicians and managers, participants represented all clinical programs at KidsAbility (e.g., early intervention services, school aged and school-based rehabilitation services, autism services, and specialized services such as augmentative communication services).

2.5.3. Data collection and analysis

Four co-design meetings, each two hours in length, were conducted between April 2023 and May 2023. Three of these meetings were conducted in-person, at three different KidsAbility sites and one was held virtually over Zoom (31) to accommodate those who were unable to attend in-person. Three of the four co-design meetings had caregiver, clinician and management representation. One in-person group did not have a manager participate. All sessions were audio and video recorded to facilitate subsequent transcription and analysis of the data. Authors MR and MNP co-facilitated all meetings alongside a parent facilitator. All parent facilitators had experience being members of a research team and/or facilitating group discussions with other caregivers. The parent co-facilitator worked closely with the caregiver participants to validate their experiences, encourage idea sharing and create a safe space for collaboration. Transportation and language interpretation services were made available in all phases of this project to enhance the accessibility of participation.

The co-design meetings were run in an interactive focus group format. Each co-design meeting focused on a different touch point that emerged from interviews. The aim of the co-design meetings was to bring multiple invested parties (caregivers, clinicians and management) together to collaboratively develop solutions and prototypes for the touch points impacting experiences with telerehabilitation at KidsAbility. Each co-design meeting was divided into three sections: (1) introductions, orientation to the touch point and aims for the session; (2) solution development; and (3) prototype development. The COMPASS for Relational Safety in Co-design/Production and the corresponding MAPS framework guided the structure of the group to work toward creating an atmosphere where all participants felt comfortable collaborating toward a common goal (34).

(1) Introductions, orientation to the touch point and aims for the session—The meeting began with introductions and an ice breaker activity in the hopes of creating relatable moments between participants (34). Guidelines for engagement were discussed to ensure all participants had a common understanding of suitable ways to engage in discussion and idea sharing. Participants were oriented to the touch point of focus for their meeting using multimedia tools. These tools included an animated video depicting the positives aspects of telerehabilitation services as reported by caregivers and clinician during the interviews as well as a poignant image with a voice over of a caregiver and clinician speaking about the negative aspects of telerehabilitation in relation to the touch point. Once familiar with the touch point, the aims of the session and the activities were reviewed with the participants.
(2) Solution development—Next the participants were presented with the task of developing solutions to the touch point. A modified 1-2-4-all Liberating Structure was used to guide this activity whereby participants started with independent idea generation, shared ideas in small groups and then engaged in a full group discussion about the favourite ideas generated by each small group. Liberating Structures are a set of interactive methods used to facilitate inclusive engagement of multiple and diverse voices working toward a collective purpose and have been used to support change in health services research (35–37). Specifically, the 1-2-4-all Liberating Structure is an effective way to engage multiple people at the same time to generate ideas (36). Every participant was given a sticker to place beside their favourite idea and the idea with the most stickers was brought forward for further discussion in the prototyping phase.
(3) Prototype development—The idea that was prioritized for prototyping was the focus of section three of the meeting. Participants broke into their small groups and used arts-based methods (e.g., paper, sticky notes, markers, coloured stickers, etc.) to design low fidelity prototypes of what it would look like to implement the prioritized solution into the policy and practices of KidsAbility. Tools available in Jambord (32) (e.g., white board, sticky notes, labels) were used to support prototyping during the virtual meeting. Low fidelity prototyping is a technique described in the EBCD process (27). The participants then reconvened as a full group to provide verbal descriptions of their prototypes.

The aim of data analysis during stage 4 of the co-design process was to describe the solutions prioritized and the prototypes developed by participants in the co-design meetings. Data from the co-design meetings were analyzed using inductive qualitative content analysis as described by Elo & Kyngas (38). Data sources from the co-design meetings included sticky notes from the idea generation phase, the prototype materials (e.g., sketches) and transcripts from group discussions. Transcripts were read multiple times by author MR to make sense of the data. During a collaborative analysis session, authors MR and MP engaged in open coding and categorization of data from the transcripts, sticky notes and prototypes. Additionally, transcripts were coded and categorized by author MR using NVivo software (39) through line by line reading of the transcripts. Data from the transcripts contextualized the arts-based data (sticky notes and prototypes) by integrating explanations of the participants who generated the ideas. Data across all four focus groups were analyzed to explore similarities and differences in the solutions developed as well as potential opportunities to blend similar prototypes. Categorized was synthesized into narrative form by authors MR and MP via the use of analytic memos. Iterations of the narrative synthesis were reviewed during peer debriefing meetings between author MR and senior researcher MP. Member checking with the participants in the co-design meetings was not completed, however the categories and synthesis were reviewed and validated by authors JLL and CL through the caregiver and clinician lens respectively and feedback was incorporated into the findings. Their feedback did not result in altering the coding or categorization structure.

3. Results

The results of this research are described in four sections below. First, touch points identified from the interviews completed with caregivers and clinicians in stages 2 and 3 are summarized. A full account of the interview findings falls outside of the scope of this paper and will be reported in a future manuscript. Next, the findings from the analysis of the data collected from the stage 4 co-design meetings are described as the 3C's (communication, consistency, connection) in telerehabilitation experience. The co-design solutions developed to address the 3C's prior, during and after therapy are presented.

3.1. Touch point identification through sharing stories of telerehabilitation experiences

Four touch points were inductively identified from the caregiver and clinician experiences with telerehabilitation that were shared during the interviews. The four touch points identified were: (1) child engagement in telerehabilitation; (2) perceived value of telerehabilitation services and caregiver engagement; (3) fit of using a telerehabilitation model and providing family with choice; (4) preparing the people and environment for telerehabilitation services. Each touch point served as a topic for the four co-design meetings.

3.2. The 3C's in telerehabilitation experience—communication, consistency, connection

Open coding of the transcripts and analysis of the arts-based outputs (e.g., drawings, chart paper, sticky notes) from the four co-design meetings led to the identification of three interconnected categories identified as impacting the telerehabilitation experience. These three categories are communication, consistency and connection (the 3C's). All invested parties (i.e., caregivers, clinicians, management) involved in the co-design meetings identified examples of how challenges with the 3C's impact experiences with telerehabilitation at KidsAbility. A desire to improve how the 3C's are experienced by caregivers and clinicians is apparent in the co-designed solutions and related prototypes. **Table 2** summarizes key information from analysis that describes the subcategories and categories related to the 3C's.

3.2.1. Communication

Caregivers, clinicians and managers recognized significant deficits in how the details of telerehabilitation as a service model were communicated. General information such as what is a telerehabilitation appointment (i.e., over video or phone), what occurs during a telerehabilitation appointment and what technology/set up is required for a telerehabilitation appointment was not adequately reviewed with caregivers prior to commencing with service. “Communication is the biggest key in all of this, it's lacking at some point or points. A new person coming in, jumping right to virtual…with no further communication, they're going to be lost.” (Caregiver P1-2). A caregiver recalling her initial telerehabilitation appointment shared, “I remember my first session, and it was just chaos… (Caregiver P2-2). Without adequate communication prior to initial and subsequent telerehabilitation appointments, caregivers expressed feeling unprepared for the sessions, which impacted how meaningful the session was perceived to be, “If there was some sort of communication prior: this is what speech needs to see, this is what OT needs to see, let's do this activity because we can see both…. There was none of that, and it was overwhelming, and at the end of it, I was like, “Okay, cool, what

TABLE 2 Key components of the 3C's impacting experiences with telerehabilitation services.

	Categories		
	Communication	Consistency	Connection
Subcategories	About the telerehabilitation service model	In sessions between clinicians (e.g., format, quality)	Between treating clinician and family
	About the aims of the telerehabilitation session	In providing choice and flexibility in service	Should be established early on in service
	Should be multimodal and tailored to the family		Impacts buy-in and engagement in telerehabilitation services

did we accomplish?" (Caregiver P1-2). "If they had sent an email ahead of time that said, 'Hey, you can have snacks or something ready?' Then yep, I could have had it in place" (Caregiver P2-2).

Clinicians also identified the importance of communicating the aims of the session so that families could join feeling prepared, "having the family aware, if I want to see your kid in a walker, it can't be in storage, you have to have it ready for the session. So, preparing everyone beforehand, and then giving them the tools based on what we're hearing" (Clinician P7-4). Specific mention was made about the importance of ensuring clear and accessible communication about telerehabilitation services for families when English is not the primary language spoken. The need for "supporting parents for whom English is a second language…all the way through" (Parent Facilitator P3-3) including support for communicating with KidsAbility, accessing technology for telerehabilitation and teaching strategies for supporting caregivers to engage children in telerehabilitation appointments.

Communication impacted caregivers' expectations of therapy services. Caregivers identified feeling that there was a lack of communication provided to help inform them of what to expect with regards to wait times for visits and how many visits they could expect to receive, "I was on a waitlist for about a year, and I got one online session for an hour and that was it. I thought this was a long wait for nothing…My expectations were up to here. I got shafted." (Caregiver P3-4). A lack of clarity was also identified regarding the caregiver's role during a virtual appointment. Sharing one of her experiences with a telerehabilitation appointment, a caregiver stated, "I remember I did one therapy session, and they needed me to actually measure his spasticity. I was not prepared for this,…nobody told me that's what I'd be doing this virtual session." (Caregiver P4-1). All stakeholders identified the need for communication between the clinician and caregiver prior to commencing with a telerehabilitation session to help ensure all involved felt prepared and shared the same expectations for the appointment. "There's pre-work for the child and pre-work for the household and pre-work for the clinician. Are the 2 entities aligned in what's to be expected?" (Caregiver P4-1). The importance of matching therapy expectations is highlighted in these statements from clinician and manager participants, "Before you start a therapy, we [participant group] thought not only that the parents recognize the expectation that if this is a virtual service, you're going to need to do XYZ, but also, in return, that we're understanding what they're expecting from the service." (Clinician P1-3). "If everyone has the same expectation and is able to have done the work beforehand for that session, then you're going to be able to have a lot more success with the session rather than one person be disappointed." (Manager P2-1).

The mode of communication was also highlighted by caregivers as critical to consider when establishing effective communication between KidsAbility and families. When discussing modes of communicating one parent expressed, "My biggest point that I keep saying here is that emails get lost… Trying to go back for something that took place 3 months ago in emails, like where is that document? I know it's here somewhere. It's hard, right? So I wouldn't suggest an email touching base by any means. I think a phone call would be more efficient, ahead of time, before you got on to the link [for the telerehabilitation appointment]." (Caregiver P1-2). A clinician participant shared the following reflection about their experience sending emails to caregivers prior to telerehabilitation appointments, "…less and less parents are prepared because I think what's happening is there's just too much information. So, I think having that discussion versus an email would be helpful to really make sure we're on the same page about what this is going to look like." (Clinician P3-2). The importance of a "multimodal approach to communication" (Clinician P7-4), was recognized with an understanding that "some people may want to phone call, some people want to email,…asking how they best communicate… Adding a multimodal approach is what you'd need, considering how we can best deliver the information" (Clinician P7-4).

In addition to establishing a preferred mode of communication, tailoring the amount of information shared was also discussed as an important aspect of communication impacting experiences with telerehabilitation. A lack of communication prior to a telerehabilitation visit left caregivers feeling unprepared, while high volumes of information shared in follow up to an appointment was expressed to feel overwhelming. One mother shared this narrative about information that was provided after a telerehabilitation session: "My baby is medically fragile—that's one set of needs. And my eldest is on the spectrum [autism]. After one particular session, I was just inundated with information, and it was so overwhelming at the time because I had a baby and then a 2-year-old…But I was told, go watch this video, go on to this link, and then there were multiple attachments of 50-page documents of resources. I was so overwhelmed, but so desperate to have my husband and I help our 2-year-old" (Caregiver P5-4). Another caregiver said "I did get an email after my one call, with a whole bunch of resources…I thought this may be relevant and that, but it was so big that I just thought I would get back to that eventually, and I never did because it was overkill" (Caregiver P3-4).

3.2.2. Consistency

The importance of consistent practices and processes related to telerehabilitation services across clinicians and KidsAbility programs was identified by co-design meeting participants as another area instrumental in influencing experiences engaging with these services. Some caregivers had experience engaging in telerehabilitation services with multiple clinicians and reported that practices across clinicians varied. "So, I've done Zoom with 4 [different clinicians], and they are all completely different, and there is no consistency whatsoever in the way that they do it." (Caregiver P1-2). During a co-design meeting, a clinician shared the approach they took to support families in preparing for a virtual session, which according to caregiver participants, varied greatly from what they experienced with the clinicians they worked with, "It's just crazy that other people did it so differently, and it was so much more beneficial" (Caregiver P1-2). "I'm just going to say, from a parent's perspective, if there was that kind of training, it might help us on the consistency that we thought we would get" (Caregiver P2-2). Clinicians acknowledged inconsistencies in practice, "I don't even know what happens in other virtual sessions. I know what happened in my virtual sessions, but you're right. If there was some consistency…it would be more clear for everyone." (Clinician P4-2). Clinicians also recognized value in there being a "clear stepwise process, internally, for therapists, so that it's more consistent" (Clinician P4-2).

A desire for consistent choice and flexibility integrated into telerehabilitation service delivery was highlighted by caregivers and clinicians when discussing service experiences. A clinician described using a flexible approach to learn about how caregivers would choose to design telerehabilitation, "I had some success in the past with discussing with the parents and saying, 'How do you like to learn? How do you want this session to go?'… Do you like to learn the strategy on your own in a discussion format just with me and then the next week, your child can attend?" (Clinician P3-2). In contrast to the flexibility described by the clinician, a caregiver attributed their negative experience to a lack in choice regarding how telerehabilitation visits were conducted, "So, I do joint speech and occupational therapy at the same time… And I've tried very hard to get out of having to do my sessions together, to do them separately, which I've not been successful with. They keep doing it." (Caregiver P1-2). "There was also some discussion around when KidsAbility calls to make an appointment, whether the parent could decide at that time, 'I'd like this appointment to be virtual, or I think I can make it in person,' whether that level of flexibility could be provided, so that isn't a decision that we're making blanket from the beginning. But when the appointments are scheduled, we can sort of think through whether at that time it might be more appropriate to do a virtual or in person." (Parent Facilitator P3-3).

3.2.3. Connection

Developing a connection between the clinician and family early on in service engagement was identified by caregivers as being critical to their experience with telerehabilitation services. Caregivers described connection as feeling like their clinician knew about their child and family beyond the therapeutic context, that the clinician valued caregiver input and the clinician collaborated with the caregiver in a partnership. "There has to be some connection built with the families as a whole. The parents and the children. You can't, for your first time, go on virtual, which we did, and expect the kids to listen and to cooperate and be comfortable to move forward" (Caregiver P1-2). Prior to commencing therapy involving the child, caregivers identified opportunities for building rapport with the clinician through early communication in the form of conversations about topics like what they are hoping from therapy, preferences for how visits occur and goal setting. "There still needs to be that connection with your therapist, more from the get-go" (Caregiver P1-2). When discussing goals, a caregiver shared, "So I think the goal setting is really important. The clinician obviously has that background, they are the professional, and they know what the goals are, but as a parent, that might not be the goal that you have for your child. It's probably still on there, but it might be number 10 on your list, but number one for your daily life and for the success of your child and your family unit might be a different goal that you're [the clinician] hoping to gain." (Caregiver P5-4). The importance of following the family's lead in identifying priorities for therapy was also recognized by KidsAbility staff, "what do the parents want? What are you trying to get out of this? That's what we need to focus on" (Manager P2-4).

When caregivers feel that they are in a safe space with a strong connection to the therapist they were more confident in sharing information about their child (e.g., interests, likes, dislikes) and therapy preferences. It is important that clinicians invite this connection-building dialogue with caregivers as caregivers may fear repercussions for speaking negatively about their experiences with services. "I didn't want to rock the boat because I had waited for so long that I didn't want to lose that opportunity for her [child]" (Caregiver P2-2). A caregiver participant recognized that often the invitation to have these initial connection-building conversations are not consistently extended to families, "We don't ask the parents what's overwhelming about this for you? It's all overwhelming, but what feels possible?… sometimes we don't check in on what do you [caregiver] need… Because if the parents are checked out,…you're not getting the child" (Caregiver P4-1). By taking the time to connect with caregivers, clinicians can learn things about the child that may enhance engagement in therapy sessions. As an example a caregiver shared, "whenever my kid is excited, accomplished even a small task, sitting next to her, you just high-five. That may be something that parent and clinician can talk about…so that can keep them pumped and motivated to be engaged" (Caregiver P3-1).

The impact of connection on experience with telerehabilitation services was also recognized by clinician participants. "If we're asking questions, then hopefully, we're getting information. And then they're feeling that buy-in" (Clinician P8-4). "It sends the message that KidsAbility cares about your family, if they're wanting to know things that aren't necessarily to do with their specific therapy. It's about you and your family and your child" (Clinician P1-4). Clinicians felt that service would be improved by "making that a standard, so that everyone just does these things to build rapport with your families, and really tailoring their service to that individual, feeling them out and building a relationship" (Clinician P1-4).

3.3. Co-designed solutions for improving the 3C's to enhance experiences with telerehabilitation

Solutions were co-designed by participants to address the 3C's (1) before; (2) during; and (3) after the visit. The solutions and related prototypes developed during the co-design meetings targeted these three parts of the journey, with a heavy emphasis on what can be done to support families and clinicians before the visit takes place. "That first pre-work will determine the format, the style, the extra things to get your child's attention. So for me, you've got to start at the beginning of the journey" (Caregiver P4-1).

The co-designed solutions are presented according to where participants felt they fit into the telerehabilitation journey. The solutions target either modifying the process related to engaging in telerehabilitation services at KidsAbility or developing a tool/resource that facilitates information sharing/gathering.

3.3.1. Before the visit

Both process and tool/resource solutions were co-designed to promote consistent connection and communication between clinicians and caregivers when beginning telerehabilitation. To ensure there was a consistent opportunity for early communication and connection development, participants recommended implementing a process whereby clinicians book an initial appointment (likely by phone or video) with only the caregivers present. Caregivers expressed that this type of appointment would give them an opportunity to share information about their child as a person (e.g., likes, dislikes, motivators, interests, personality traits) and speak openly about their concerns and priorities for therapy. Clinicians saw additional value in the opportunity to connect with caregivers prior to commencing with telerehabilitation as it would give them a chance to have a conversation about the options for service models, learn about the caregiver's preference for services (examples identified by caregiver participants included: gender of clinician, ethnicity of clinician, appointment time/frequency/length), and make a service plan tailored to the family. In addition to occurring prior to commencing with therapy, participants recommended that this type of parent only appointment take place any time there is a change in treating clinician or when families are moving from in-person appointments to a telerehabilitation platform.

Participants prototyped tools/resources that included questions and discussion topics that clinicians could use during the pre-appointment conversation. Questions included: do you have access to the required technology and a reliable internet connection? Would you benefit from having an interpreter present? What are your goals for therapy? Here is what to do if we get disconnected from our visit. It was thought that a tool like this could act as a decision support when deciding what approach to take for therapy visits. Caregivers recommended consistent use of a "get to know my child" form to support the clinician in getting to know things like the child's likes/dislikes, which then can be integrated into therapy sessions to support engagement. "That [Get to Know my Child Form] would include things like your child's likes and dislikes, knowing what their dislikes are is equally as important as going through the long list of things they do like, their favorite toys, people in their life… So we're talking a lot about how to get your child engaged to be part of these [telerehabilitation session]" (Caregiver P4-1). Low fidelity prototypes of an online portal where parents and clinicians could directly message, share resources and update documents such as the "get to know my child" form was discussed as a possible platform to enhance communication between clinicians and families.

As another solution for enhancing early communication between the organization and families, participants prototyped the idea of video and text-based resources to share information with families about what they can expect when engaging in telerehabilitation appointments. Participants envisioned these resources being provided to families to support them in making informed decisions about what service model (i.e., in-person, virtual, combination) would feel like a fit for them. Videos would include footage of what a telerehabilitation session looks like, discuss technology requirements and environmental set up as well as review the caregiver's role during these sessions. "Video tutorials meaning tutorials explaining for families what a virtual appointment could look like based on the child's age, their situation, their environment, their goals… We thought this was important because we're looking at some families thinking "virtual" means my child has to sit at the computer and engage in a computer game, and that's not always what we mean when we say virtual services for a child" (Clinician P2-3). Recommendations were made that these resources should be easily translated into a variety of languages to enhance accessibility.

3.3.2. During the visit

The primary codesigned solution for during the visit targeted the consistency in communication through a process where clinicians summarize key points from the session and develop a plan for the next session that aligns with families' priorities. The aim of this solution is to establish a process to ensure that families complete the session with strategies they felt comfortable trying at home and an understanding of what they needed to have set up to feel prepared for the next session. "It's the prep for the next visit if that makes sense. It's developing that action plan and that take-home" (Clinician P1-1). This process creates consistent opportunities for clear communication and shared expectations about upcoming appointments.

3.3.3. After the visit

Participants co-designed a process for follow-up after an appointment or block of sessions that facilitated authentic and individualized information sharing and communication methods. This solution was driven by caregivers' experiences of receiving emails in follow up to a visit with large amounts of content containing strategies and resources that felt generic. Participants recommended that in conversation with caregivers, clinicians inquire about preferred formats of receiving communication as well as the amount of information a caregiver prefers to receive. Caregivers made recommendations for "a more streamlined approach to the follow up. If it is resources and videos, ensuring that the parent has time to be able to view those and read over it. Having different ways of presenting material that isn't an email…" (Caregiver P5-4). A process to streamline how families engaged in telerehabilitation can access physical resources (e.g., loan of gait aids or positioning devices) from KidsAbility was also identified as a solution to enhance experience. Currently, families accessing services virtually need to come on site to pick up these physical materials, which one caregiver said, "defeated the purpose of online" (Caregiver P5-4).

4. Discussion

The aim of this project was to determine what solutions could be co-designed to enhance pediatric telerehabilitation experiences by understanding and incorporating the experiences of caregivers, clinicians and management. The 3C's emerged from the codesign process as key factors that influence engagement in telerehabilitation before, during and after a visit. The co-designed solutions were proposed to improve families access and engagement in telerehabilitation services. The Phoenix Theory of Attendance, Participation and Engagement (the Phoenix Theory) depicted in **Figure 1**, examined missed appointments in the context of in-person pediatric rehabilitation at KidsAbility and provided a theoretical foundation our work (15). The Phoenix Theory describes six interconnected gears that influence the process of parents attending, participating and engaging in therapy including: skills, feelings, knowledge, values and beliefs, logistics, and the parent-professional relationship (15). Additionally, the theory describes factors at the level of the child, parent, professional or organization that interact with the parent gears as either grit (inhibits gear movement) or grease (facilitates gear movement) (15). Although not developed or tested in the context of pediatric telerehabilitation, we see alignment between our findings and some

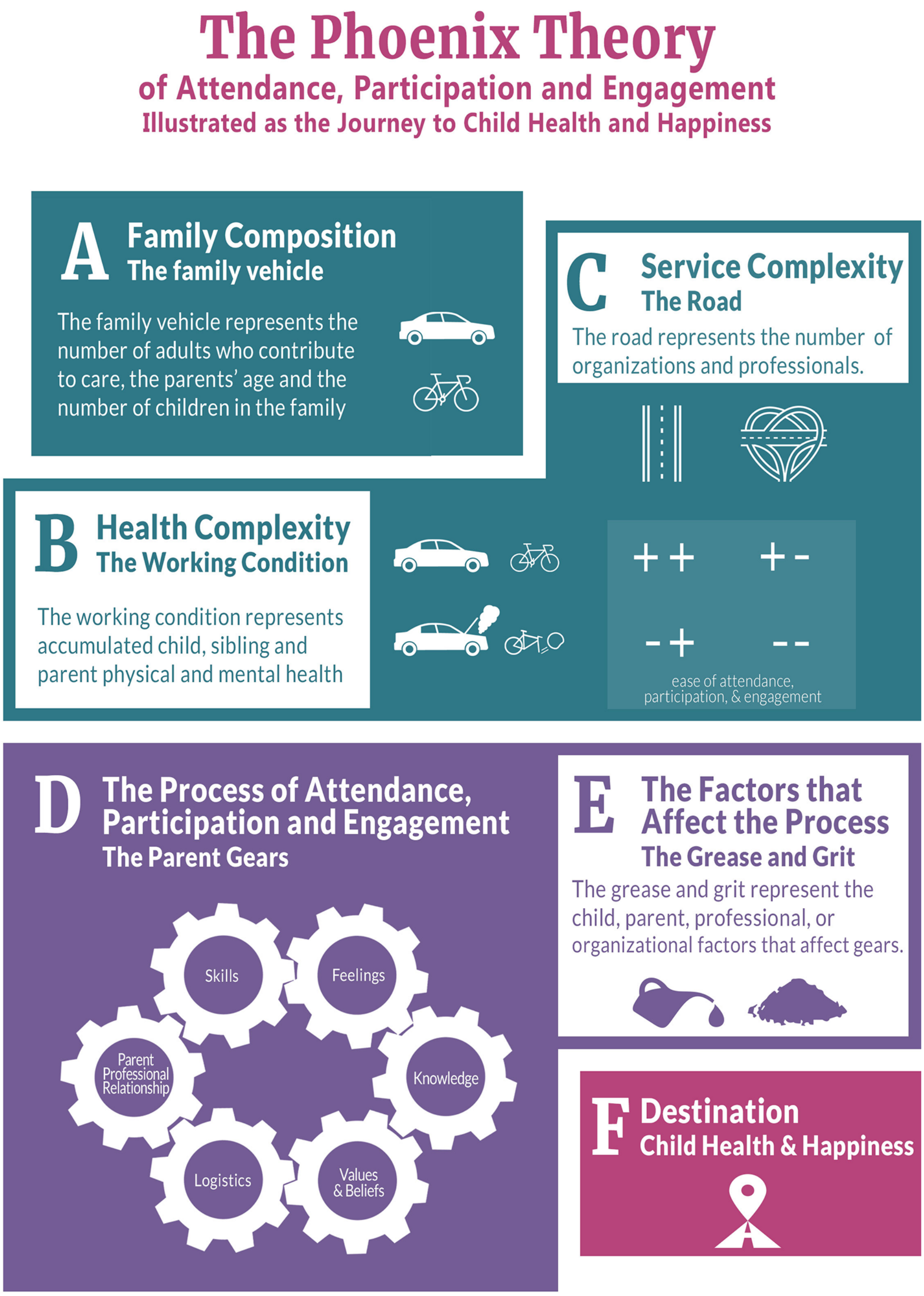

FIGURE 1
The Phoenix theory of attendance, participation and engagement (15). © 2019 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group. Reproduced with permission from Informa UK Limited through PLSclear.

the constructs of this theory. The trustworthiness of our findings, including the co-designed solutions, is enhanced through theoretical triangulation with components of the Phoenix Theory.

The connection between the clinician and the family was identified in our findings as a factor impacting experience with telerehabilitation. A desire to establish and maintain this connection is evident in the co-designed solutions developed (i.e., conversation with caregivers about their child). The element of connection discussed in our findings is akin to the parent-professional gear represented in the Pheonix Theory (15). According to the Phoenix Theory, a trust-based relationship and connection between clinician and caregiver enhances agreement between these two parties related to how to move forward in therapy (15). Relationships and collaborations have been recognized as indicators of levels of engagement in therapy (17). In a study exploring engagement and therapeutic alliance in pediatric telerehabilitation, rapport, connection and collaboration were identified as influencing caregiver engagement in telerehabilitation services (10). These findings are further supported by a qualitative systematic review exploring engagement in early intervention telerehabilitation, where building rapport between caregiver and clinician was linked to improved therapeutic outcomes, facilitating open communication and enhancing caregiver buy-in (21). This review highlighted the benefit of establishing early therapeutic rapport, suggesting relationship building should begin prior to telerehabilitation commencing (21), aligning with the co-designed solution recommending an appointment between clinician and caregiver prior to starting teletherapy with the child.

The Phoenix Theory identifies resources as one of the factors that can add grit or grease, influencing how the parent gears operate (15). Resources as described by the Phoenix Theory, include information and organizational supports, amongst other resource groupings (15). Co-designed solutions geared toward developing video tutorials and text-based resources about telerehabilitation services align closely with the Phoenix Theory's informational resources, which are factors that can influence engagement and experience with services. Examples of resources related to organizational supports are the possible adaptations and flexibility of service options (15). Our findings indicate the need for clinicians to consistently communicate service options available to families and a desire from caregivers to have a choice in their preferred service model. In a 2023 realist evaluation of telehealth in children with neurodisabilities, the importance of offering caregivers the choice to participate in telerehabilitation as part of a hybrid model (i.e., option for in person appointments, telerehabilitation appointments or both) was critical to their acceptance of telerehabilitation as a meaning option for service (40).

Communication and expectations were closely linked concepts in our findings and are represented individually as factors influencing the parent gears in the Phoenix Theory (15). Many of the co-designed solutions from our project aimed to establish consistency in the content and quality of the communication between the organization and families, with the hopes of aligning expectations for telerehabilitation service. The co-designed solutions targeted process change and resource development to achieve improvements in communication. The Phoenix Theory describes higher levels of parent engagement in services when there is alignment between what they expected the service to be like and what they received (15). Expectations are closely connected to the knowledge parent gear in the Phoenix Theory (15). In our findings, parents expressed not knowing what to expect with regards to telerehabilitation services, sharing that this knowledge was not adequate or consistently communicated and experiences with one clinician could be very different from service with a different clinician. Literature on caregiver expectations of therapy shows that caregivers enter into therapeutic interactions with expectations for their child, the clinician, the service organization and themselves (41). An ethnographic study exploring engagement in outpatient pediatric rehabilitation reported that engagement in therapy increases when expectations for therapy are aligned between caregiver and clinician, specifically when there are clear expectations about roles within the sessions (17).

Communication has been identified as one of the most important factors influencing parent engagement (15) and according to our findings is highly influential to the telerehabilitation experience. Collaborative, two-way communication, where caregivers feel listened to and feel their input is valued has been identified as critical to engagement in pediatric telerehabilitation services (10, 21, 40). With the recognition that it will take more of the clinicians' time, the use of multimodal communication approaches within and outside of telerehabilitation appointments has been identified as instrumental in facilitating engagement and connection (21). The need for using a multimodal approach to communication (e.g., using a combination of email and phone communication according to preference), tailored to each families' context is recognized in our findings and the co-designed solutions.

A limitation of this work is that the sample can only be described from a relatively small set of demographic questions focused on maximizing the diversity of the sample according to the KidsAbility context (e.g., KidsAbility site, clinical discipline, age of child receiving service, access to reliable internet connection). Additional demographic information such as income level or parent education level, was not collected and therefore potentially limits the transferability to other contexts. A strength of this work is that it included a broad range of perspectives including caregivers, clinicians, KidsAbility management and interdisciplinary researchers in all phases of the project. Due to time and resource constraint, there was not opportunity to review the co-designed solutions with participants who took part in the co-design groups, however they were validated with the steering committee members, some of which have lived and living experience with telerehabilitation services. We acknowledge that although the project is grounded in the field of pediatric rehabilitation, the child and youth voice is not represented in our work and should be incorporated into future research in this area. A possible avenue for gaining insight into youth experience with telerehabilitation is engaging with the established KidsAbility Youth Advisory Council for future projects. Although the project was completed with a single site potentially limiting the transferability of the findings, this allowed for a rich understanding of the study context and the development of solutions relevant to KidsAbility.

To date, our project has developed co-designed solutions aiming to enhance experiences with pediatric telerehabilitation. The relevance and validity of these solutions to practice has been explored through examining their relationships to theory and current evidence. Next steps of this project are to work alongside KidsAbility to implement and evaluate the impact of these solutions on organizational practices and user experience with telerehabilitation services in this setting. Evidence-based knowledge products developed to support pediatric telerehabilitation appointments, such as the Telerehabilitation Hub for Children with Disabilities and their Families (42) will be explored to operationalize the solutions developed from our co-design work in the KidsAbility context. Additionally, our team has plans for disseminating information about the co-designed solutions across an established pan-Canadian network of research and clinical pediatric rehabilitation organizations.

Data availability statement

The datasets presented in this article are not readily available. The data for this study cannot be shared to protect the privacy and confidentiality of participants. The dataset is unavailable to be requested.

Ethics statement

The studies involving humans were approved by Hamilton Integrated Research and Ethics Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

MR: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Visualization, Writing – original draft. LL: Conceptualization, Funding acquisition, Methodology, Writing – review & editing. CL: Conceptualization, Formal analysis, Methodology, Writing – review & editing. JLL: Conceptualization, Data curation, Formal analysis, Funding acquisition, Methodology, Writing – review & editing. MNP: Formal analysis, Investigation, Methodology, Writing – review & editing. BD: Conceptualization, Funding acquisition, Methodology, Writing – review & editing. MP: Conceptualization, Formal analysis, Funding acquisition, Methodology, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Publisher's note

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Chapter 5. Synthesizing and contextualizing findings to inform future directions for policy and models of service delivery in pediatric rehabilitation

Objectives of the thesis and study contributions

The first objective of this thesis is to critically examine policy in publicly-funded pediatric rehabilitation services to understand its impact on access to services. The second objective is to use co-design methodology to improve models of service delivery, with a focus on telerehabilitation, to improve access and engagement in pediatric rehabilitation services. These objectives are achieved through the research outputs of this thesis including recommendations supporting the development of inclusive discharge policies (Chapter 2) and co-created solutions aimed at enhancing experiences with pediatric telerehabilitation (Chapters 3 and 4).

Using critical discourse analysis methodology, Chapter 2 analyzed policy-documents related to missed appointments from Children's Treatment Centres (CTCs) across Ontario. The aim of this study was to identify dominant discourses related to the management of missed visits with consideration for its impact on access to pediatric rehabilitation services. From this work, recommendations were developed to support equitable and inclusive policy development in pediatric rehabilitation. These recommendations emphasized the importance of taking an ethical and family-centred approach to policy development that authentically includes and amplifies family voices.

Chapters 3 and 4 used experienced-based co-design methodology to first, describe the experiences of caregivers and clinicians with a pediatric telerehabilitation service model (Chapter 3) and then utilize this experienced-based data to co-create solutions designed to enhance experiences with pediatric telerehabilitation (Chapter 4). The solutions were developed in collaboration with caregivers, clinicians and pediatric rehabilitation service managers, all with lived experience utilizing pediatric telerehabilitation. The solutions focused on improving the 3C's of communication, consistency and connection to enhance access and engagement with pediatric telerehabilitation services.

The objective of Chapter 5 is to synthesize and contextualize the findings in Chapters 2-4 to inform future directions for reimaged publicly-funded pediatric rehabilitation policy development and service model design, guiding the practices of policy makers, pediatric rehabilitation service organizations, and researchers.

Synthesizing and contextualizing thesis findings – Implications for policy makers, pediatric rehabilitation service organizations and researchers

Opportunities for enhancing family-centred service beyond the point of care

Provision of family-centred service is a widely accepted standard in pediatric rehabilitation. The principles of family-centred service emphasize the importance of partnering with families, acknowledging the uniqueness of each family and prioritizing the expert knowledge families gain through their lived experiences (McCarthy & Guerin, 2022; Ridgway et al., 2021; Rosenbaum et al., 1998). Further, providing flexible care that is adapted to the family context (e.g., number of children in family, number of caregivers in the family, housing security, details of caregiver employment, family mode of transportation) is highlighted as an essential element of family-centred service (Kokorelias et al., 2019; Ridgway et al., 2021).

Another critical component of family-centred service is establishing a collaborative and trusting relationship between caregivers and clinicians (Kokorelias et al., 2019; McCarthy & Guerin, 2022; Ridgway et al., 2021). This aligns with the findings of Chapter 4 which highlight the impact of connection between families and service providers on their experiences with telerehabilitation services. Participants emphasized that connection goes beyond discussing priorities for therapy to encompass taking time to get to know the family and their context (Chapter 4). Similarly, in the findings of Chapter 4, communication was identified as an important factor influencing experiences with a telerehabilitation service model. This finding aligns with literature about family-centred service that highlights two-way communication between the service provider, organization and family as an essential component of family-centred service (Kokorelias et al., 2019; Ridgway et al., 2021). The importance of establishing communication and early connection with families is reflected in the co-designed solutions aimed at developing processes or tools that create consistent opportunity for relationship building between families and service providers (e.g., use of a 'get to know my child' form) (Chapter 4).

Gaining an understanding of the family context, including such things as family composition, strengths and values is another important aspect of family-centred service (Kokorelias et al., 2019). Part of understanding family context is learning about their preferences for things like appointment formats (i.e., in person, telerehabilitation, hybrid), times and locations. The increased flexibility that telerehabilitation can provide was identified by caregivers and clinicians as a positive aspect of this service model (Chapter 3). Caregivers' experiences with telerehabilitation were negatively influenced when they felt they did not have a choice of what service model was the best fit for their family (Chapter 3). Agency in choice is essential to family-centred service (Ocloo et al., 2020; Ridgway et al., 2021) and aligns with rights-based rehabilitation, an approach to rehabilitation that prioritizes the voices, values, desires and choices of disabled individuals (Shakespeare et al., 2018). Limited resources, competing priorities, high workloads and the need for additional training have been identified as barriers to implementing family-centred service that prioritizes the family voice (Ingólfsdóttir et al., 2021; Movahedazarhouligh & Banerjee, 2018; Ocloo et al., 2020). Further, a power imbalance exists whereby decisions influencing the implementation of family-centred service are driven by organization leadership without adequately considering the family voice in family-centred service improvement initiatives (e.g., family-centred policy) (Ingólfsdóttir et al., 2021; Ocloo et al., 2020). The importance of having dedicated policies and procedures for the implementation of family-centred service has been identified in the literature and a non-hierarchical approach to shared decision-making has been recommended to mitigate existing power imbalance (Kokorelias et al., 2019; Ocloo et al., 2020).

Although Ontario's CTC's aim to provide family-centred services, a discourse of power imbalance was present in the language of the policy documents analyzed in Chapter 2. Policy language devalued the family's power and agency in the service process (Chapter 2). Further, analysis of policy documents revealed a family-centred discourse, where an intention to provide family-centred service was evident but not upheld in the procedures outlined in the policies managing missed appointments. These procedures encouraged clinicians to engage in discussions with families to learn more about why they had not attended appointments, but were missing mechanisms to ensure these conversations consistently occurred (Chapter 2). These findings informed the recommendation that policy development be "informed by a family-centred approach that prioritises understanding family needs, values, desire for therapy" (Chapter 2). Further, a recommendation was made to implement formalized procedures integrating diverse family voices into pediatric rehabilitation policy development processes (Chapter 2).

Much of the current family-centred literature discusses the importance of authentically engaging families at the point of care. However, there is limited discussion of engaging families in initiatives that shape the development and implementation of family-centred service, such as policy and service model design in pediatric rehabilitation. In the guiding principles of the recently released Ontario Preschool Speech and Language and Children's Rehabilitation Service Guidelines, families are not explicitly identified as a group to be collaborated with in service provision planning (Government of Ontario, 2024). These guiding principles do, however, emphasize the requirement to provide services that are collaborative and family-centred (Government of Ontario, 2024). Engaging families in initiatives such as policy and service model design, increases the likelihood that resulting outcomes will reflect their contexts, needs, desires and choices, which aligns with the provision of family-centred service (Ingólfsdóttir et al., 2021).

Engaging families in pediatric rehabilitation policy and service model design aligns with principles of family-centred service related to partnership, communication, family agency, tailored service, and valuing lived experience knowledge. Embedding family engagement into pediatric rehabilitation policy and service model design would strengthen commitment to family-centred service by ensuring that the family perspective is integrated into all levels of organizational and clinical practices. Chapter 5 discusses family-engagement in pediatric rehabilitation policy and service model design with consideration for how co-design methodology could facilitate the integration of the family voice into these processes.

Family-engagement in policy and service model design- Implications for policy-makers and pediatric rehabilitation service organizations

There is a growing body of literature discussing the incorporation of people with lived experience, including families, into health policy and service model design. With the movement towards providing tailored and flexible health services, the need for input from interest-holders[1] is recognized as essential to informing service design (De Luca & Sangiorgi, 2024). The findings of a 2018 systematic review indicate that engaging people with lived experience can inform both health policy and enhance service delivery, noting that high levels of engagement improves outcomes related to service redesign (Bombard et al., 2018). Community engagement and participatory methods were identified as important components of a holistic model endorsed by the World Health Organization, aiming to advance health policy and systems research in the field of rehabilitation (Cieza et al., 2022). Further, engaging individuals with lived experience was identified as a recommendation in a framework aimed to guide policy action to expand access to rehabilitation services across Europe (Skempes et al., 2022). The current body of literature in this area has a heavy focus on engaging people with lived experience in mental health policy and service design (Bombard et al., 2018; Triplett et al., 2022); however, there is emergent evidence in the field of childhood disability exploring engaging individuals with lived experience to promote rights-based services (Shikako et al., 2024).

Although there is evidence supporting the engagement of people with lived experience in health policy and service design, the complexities associated with authentic engagement are

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[1] Interest-holders is used as a recommended term to replace stakeholders in health policy and research (Akl et al., 2024).

acknowledged in the literature. Managing power dynamics, tokenistic engagement, role uncertainty and a lack of organizational support for engagement have been identified as challenges associated with engaging people with lived experience health service design (Bombard et al., 2018; Murphy et al., 2021). Further, the high levels of resourcing (e.g., time, financial) required for authentic engagement have been identified as potential barriers to interest-holder involvement in health service and policy design (Bombard et al., 2018; Masefield et al., 2021; Murphy et al., 2021).

Anticipating the complexities of engaging multiple interest-holders as members of the research team in Chapters 3 and 4 of my doctoral research, I reviewed literature related to family-engagement in research best practices to proactively develop strategies to help ensure authentic engagement. For example, I used the Involvement Matrix to facilitate a discussion with the parent partner on the research team about how they envisioned contributing to the project (Smits et al., 2020). This helped avoid the pitfall of tokenistic engagement through developing a shared vision of engagement, jointly determining a plan for compensation and allowed us to tailor involvement to the tasks and activities they found most meaningful. Engaging in these open two-way conversations also helped to level perceived power imbalance between researcher and community-partner team members. Dedicating resources to authentically engage a parent as a member of the research team, helped to ensure that a parent perspective was represented during all stages of the research process. This enhanced the relevance of the research outputs to this interest-holder group, a benefit of interest-holder engagement that would be advantageous in pediatric rehabilitation policy and service model development.

A gap exists in the evidence related to engaging families in pediatric rehabilitation policy and service model development. I would implore policy makers at the local and systems levels as well as decision-makers in pediatric rehabilitation service organizations to embed as a standard of practice, the authentic engagement of families in all aspects of policy and service design. Future research should evaluate family-engaged methods and the impact of family-engagement on policy and service model outcomes, including impact on provision of family-centred service.

Co-design as a methodology for family-engaged policy and service model research – Implications for researchers

Co-design as a methodology has been used in health services research to prioritize the experiences of services users to guide health service reform (Jessup et al., 2018; Maher et al., 2017; Moll et al., 2020; Mulvale, Moll, Miatello, Murray-Leung, et al., 2019; Mulvale, Moll, Miatello, Robert, et al., 2019; O'Brien et al., 2021; Singh et al., 2023). In health services research, co-design offers an approach with flexible methods that can be adapted to the context in which the research is occurring and incorporates the voices of individuals with lived experiences throughout the process (Mager et al., 2022). By partnering with individuals with lived experience (e.g., families, disabled children or youth), co-design approaches can tailor health service design toward the priorities of individuals using the services, enhancing the acceptability and sustainability of the changes made (Grindell et al., 2022; Mager et al., 2022). Further, by amplifying the voices of service users in the service reform, individuals often considered to be a part of a marginalized community, co-design approaches seek to mitigate power imbalance between the organization and the individuals they serve (Mager et al., 2022; Moll et al., 2020; Mulvale, Moll, Miatello, Robert, et al., 2019).

Chapters 3 and 4 used co-design methodology to develop solutions aimed at enhancing caregiver and clinician experiences with the telerehabilitation service model at an Ontario CTC. The organization leadership fully supported the use of co-design for this work, recognizing the importance of integrating the perspective of those using the service model when considering adaptations for improvement. Given that the difficulties with the telerehabilitation service model and corresponding solutions were identified by people with lived experience using these services, the outputs from this research were tailored to the context and prime for quick implementation into organizational practices. Chapters 3 and 4 provide an example of how co-design methodology can be used as an approach to guide family-engaged policy and service model research within a single clinical organization.

During the co-design work completed in Chapter 4, caregivers, clinicians and mangers were brought together to collaboratively develop solutions. Recognizing the potential discomfort resulting from perceived power imbalance between these interest-holder groups, the COMPASS for relational safety in co-design and the accompanying MAPS strategies were proactively used when designing the format of the co-design focus groups to ensure a safe space for collaboration (Mulvale et al., 2021). The COMPASS emphasizes the importance of preparing the participants, building trust and fostering sensitivity to others' experiences (Mulvale et al., 2021). The components of safe interest-holder engagement were reflected in the design of the focus groups to address the importance of developing a common purpose for the co-design as well as building trust and relationships (McGowan et al., 2024; Walker et al., 2023). Strategies such as transparent communication to group participants prior to the event with a clear opportunity to opt-out, an icebreaker activity that facilitated introductions without use of title or position, and reviewing terms of engagement prior to discussions, were used to ensure safe and respectful communication during the group. Further, the COMPASS prompts gathering information about the organization's buy-in to the co-design process, requiring a demonstration of full commitment to the process before proceeding with a project (Mulvale et al., 2021). In my doctoral research, the plans for co-design and interest-holder engagement were discussed in detail with the partner organization leadership. This allowed for transparent discussion related to the resources that would be required for the process (i.e., space at their facility, administrative time, clinical time), negotiation around what resources could be committed and the opportunity to come to an agreement prior to proceeding with the project. Given the importance of leadership buy-in and that high levels of resourcing have been identified as a potential challenge in co-design (Walker et al., 2023), having this discussion prior to commencing with the co-design project was essential to ongoing smooth execution of the research. For researchers considering the use of co-design methodology, employing a framework such as the COMPASS will help with understanding the organization's buy-in, proactively considering power dynamics and prioritize participant safety in the process. Proactive planning efforts, guided by a framework like COMPASS will help to mitigate some of the complexities that come with interest-holder engagement in the co-design process.

A 2023 scoping review examining the use of co-design in health policy development reported perceived benefits related to gaining a better understanding of the community's needs, increased community empowerment, developing novel and feasible policy recommendations and increased alignment between multiple sectors (Walker et al., 2023). This review found that of the studies included, health policy co-design predominately focused on little p policy (e.g., single-organization practices such as models of service delivery), with fewer addressing big p policy (e.g., system-level change such as laws) and service innovation (e.g., new program development). The findings from Chapters 3 and 4 are an example of single organization service model co-design, aligning with the trends for use of these methods from the scoping review by Walker et. al., (2023). Reflecting on the use of co-design methodology for my doctoral work, I feel the research outputs were tailored to the context of our partner organization, with high levels of utility and feasibility within this environment. Given the specificity of the solutions to the context, the organization leadership took ownership of the solutions and was highly motivated to support implementation into their organizational practices. For example, the telerehabilitation information videos developed from the co-design work were immediately made available through the organization's Youtube channel and shared across their social media platforms. While the specificity of the solutions developed from the co-design process was advantageous for the local context of the partner pediatric rehabilitation service organization, it was difficult to conceptualize how to scale these findings beyond this context in a way that the solutions maintained their relevance and utility to other environments. The complexity of scaling co-design outputs may contextualize the Walker et. al. (2023), review findings which reported that co-design was used mostly commonly in little p policy initiatives compared to big p policy projects.

Although little p co-design policy projects, such as that in Chapters 3 and 4, generate findings specific to a context, they contribute to developing a stronger evidence-base and can inform policy and service model changes in different contexts. A novel co-design framework called Evidence-informed, Experience-based Co-design proposes an approach to co-design that emphasizes the incorporation of existing evidence alongside lived experience knowledge to address health service challenges (Morley et al., 2024). Using this type of framework, the outputs from little p policy co-design can be integrated as evidence into initiatives aiming to co-design adaptations of locally developed solutions to new contexts. Implementation science frameworks, such as the Knowledge to Action Cycle (Graham et al., 2018), can be used simultaneously to support moving the co-designed adaptations into organizational practices. Incorporating existing evidence, the Knowledge to Action Cycle, uses defined, non-linear stages to develop a tailored plan for moving evidence into a specific practice context (Graham et al., 2018). Future research should consider utilizing a model like the Evidence-informed, Experience-based Co-design framework (Morley et al., 2024) alongside an implementation science framework such as the Knowledge to Action Cycle (Graham et al., 2018) to identify, implement and evaluate the adaptation of co-design solutions to other pediatric rehabilitation contexts. Use of these types of frameworks provides a foundation for the systematic adaptation and implementation of locally developed co-designed solutions to other pediatric rehabilitation contexts, thereby enhancing the reach and impact of the findings.

Challenges related to achieving diversity in co-design participants has been identified as a barrier to co-design (McGowan et al., 2024). A 2023, systematic review examining interest-holder engagement in health service coverage identified significant gaps in how studies reported efforts made to engage marginalized communities in health service projects (Arthur et al., 2023). The importance of having diverse perspectives in the co-design process was highlighted by participants when discussing their experiences engaging in a health-related co-design project (McGowan et al., 2024). In the co-design work in this thesis, strategies such as providing transportation and interpreter services, were proactively considered to reduce barriers for participation and enhance equitable representation of the families served by the partner CTC. There was some diversity in gender, parenting role and primary languages spoken in the co-design sample and one interview was completed with assistance from an interpreter. Despite proactive consideration of strategies aiming to enhance equitable representation, limitations persisted in how effectively we could recruit individuals from marginalized groups.

Consideration for equity in co-creation methods has emerged as a recent focus in the co-production literature (Mulvale et al., 2024; Phoenix et al., 2024). It is imperative that the needs and priorities of those experiencing marginalization are represented in the co-design process; however a criticism of co-creation is the tendency to primarily engage individuals with privileged identities (e.g., white, cis-gendered, able bodied, English speaking) in these initiatives (Phoenix et al., 2024). Phoenix et al., (2024), presents a co-designed vision for equity-based co-creation, enhancing the evidence-base related to philosophies and methods aimed at embedding equity considerations into co-design research. Further Mulvale et al., (2024), present a co-produced equity-based co-creation charter outlining the tenets and processes that need to be put into practice to engage in equity-focused co-design research. The work by Phoenix et. al, (2024) and Mulvale et al., (2024) is novel in their conceptualization of foregrounding intentional considerations for enhancing equity into the planning and execution of codesign projects. Utilization of these equity-focused resources have yet to be explored in pediatric rehabilitation policy and service model research. Future research should explore the relevance of these resources to the pediatric rehabilitation setting, how they can be operationalized into developing co-design methods, report the details of how they were utilized and explore their impact on enhancing equity in co-design research.

Acknowledging the complexities inherent in co-design methodologies, the emerging evidence taken together with the findings of this thesis demonstrate promise for the use of this approach to facilitate family-engaged pediatric rehabilitation policy and service model research.

Future directions

Thesis limitations and additional considerations for future directions in research

Strengths of this thesis include the use of established methodologies, authentic community engagement, integration of theoretical foundations and embedding practices that enhance qualitative trustworthiness (e.g., use of audit trail, peer debriefings). Despite areas of strength there are limitations to this thesis that can inform future directions for research in this area.

First, the solutions developed from the co-design work were developed to enhance experiences with a telerehabilitation service model and did not explicitly account for the use of telerehabilitation as part of a hybrid model alongside in-person services. In the context of the partner organization, it is more likely that families would engage in a hybrid model of service (i.e., receive both in person and telerehabilitation appointments) than only receive services via telerehabilitation. Therefore, next steps for this work should focus on understanding the clinician, family and child experiences with a hybrid model of rehabilitation services with a focus on developing evidence that informs how best to blend these models.

Second, although there were high levels of interest-holder engagement in the co-design work, there was no formal evaluation of the engagement process or individuals' experiences taking part in the co-design process. Evaluating interest-holder engagement in research is crucial to understanding its impact on participants (e.g., feelings of empowerment) and to guide improvement in community-engaged research processes (Aubin et al., 2019). Reflecting on my own experience and learning, future community engaged research that I lead will have a mechanism for evaluating engagement embedded into the study design.

Third, although completed in the context of pediatric rehabilitation, the child and youth perspective are missing from this thesis. Future research should look to meaningfully incorporate the child and youth perspective to develop policy and services models that include the voices of these key interest-holders. Additionally, there was no family engagement incorporated into the critical discourse analysis (Chapter 2), meaning that the family voice did not inform the development of the resulting policy recommendations. Next steps for this work should involve a participatory approach to validating the policy recommendations and developing considerations for how the recommendations can be operationalized into organizational practices.

Personal future directions

My personal goal is to continue to develop my skills and confidence in becoming an independent researcher who prioritizes community engagement, co-creation and challenging the status quo to create more equitable pediatric disability and health systems. As next steps, I want to utilize the skills I have developed in policy analysis, community-engaged research and co-design methodology to take a lead role in disability systems and policy research at the national level. I will have the opportunity to focus on these goal areas during my postdoctoral fellowship. Further, in connection with my postdoctoral fellowship, I intend to develop skills in policy-oriented knowledge translation and mixed methods research.

My clinical experiences working with families in publicly-funded pediatric rehabilitation services prompted me to reflect on the impact of organizational structures on families' access and engagement with the services I provided. I became interested in learning more about the families' experiences and wanted the opportunity to think about what modifications could be made to policy and service models to make them easier to access and engage with. This prompted my entry into PhD studies and was the foundation for developing a passion for community-engaged, systems-focused childhood disability research. As my next steps shift me into macrosystems-level research, my hope is to remain closely connected to my clinical roots, engaging in research that amplifies the voices of interest-holders (i.e., children, families and clinicians) and makes impact through accessible implementation.

"Alone we can do so little; together we can do so much." (Quote attributed to Helen Keller)

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