Rehabilitation services for youth with physical disabilities and co-occurring mental health problems: Current practices, needs and future directions

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of Doctor of Philosophy

By

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Abstract

Rationale: Mental health problems are common among youth with physical disabilities. Those receiving rehabilitation services often have many needs, additionally complicated by the transition to adulthood. However, little is known about how care for co-occurring problems is delivered and how needs are met. **Objectives:** This manuscript-based dissertation seeks to better understand current practices and services targeting mental health for youth aged 15-24 receiving rehabilitation services. Specifically, it aims to 1) synthesize existing evidence about models of service delivery for youth with physical disabilities experiencing mental health problems, 2) describe rehabilitation practices and procedures addressing mental health, 3) better understand the needs, supports, challenges and potential solutions to optimize rehabilitation services from the perspectives of youth with physical and mental health problems, family members, and clinicians, and 4) gain insights on organizational contexts from managers' perspectives. **Design:** A multimethod research design, using qualitative research methods, is presented across four unique studies to provide a comprehensive perspective. **Methods:** The first objective was addressed by conducting a scoping review of service delivery models (manuscript 1). The second objective was addressed through a review of 60 charts of youth with physical and mental health problems receiving rehabilitation services from 5 sites in Montreal. Information about assessments, goals, interventions, and referrals was extracted, categories were identified using content analysis (manuscript 2). The third objective was addressed by conducting semi-structured interviews with 22 youth, parents and clinicians representing 5 sites exploring perspectives on actual and ideal care (manuscript 3). The fourth objective was addressed by conducting two focus groups with

9 managers from the same sites to gain additional insight at the institutional level, analyzed thematically (manuscript 4) as in the case of the interviews. **Results:** The scoping review identified 16 articles with 2 service delivery models and 12 key principles to guide service organization grouped into: collaboration and coordination, training and support, and delivery of care. Chart reviews revealed that youth had mental health problems such as anxiety (n=53) and depression (n=25), with many (n=36) having more than one. No mental health assessments were found, and mental health therapy goals or interventions were not evident in 43% of charts. When addressed, goals (n=98) targeted emotional management, autonomy/communication of needs, acceptance of physical condition, socialization, routines/energy levels, school/work supports, and leisure/calming environments. Interventions (n=104) included emotional management, formal individual/group therapy, links with external supports, routines/activities, reflection/acceptance, and school/work supports. Mental health services were delivered in-house (n=24) and/or externally (n=30), plus 18 referrals pending and 14 not referred. Across interviews (n=22), themes were: available clinical resources for mental health (access to mental health professionals, organizational structures and mandates, continuity of services during transition to adult care); clinician workforce capacity (mental health knowledge, tools and professional development, therapeutic rapport); and links and partnerships with key players (improved pathways to access mental health services across programs and organizations, family involvement and advocacy). Similar service organization challenges emerged with managers (n=9), confirming and complementing interview results. **Conclusions:** While mental health is a concern for this population, it is not always targeted in rehabilitation due to multiple challenges such as limited expertise

and structures available to address it. Identified principles and suggestions for ideal care can guide improved delivery and organizational change to address access issues, while clinicians can benefit from training and support. Findings enhance our understanding of the current rehabilitation landscape and highlight areas for improvement. Future studies can develop and test comprehensive service delivery models, integrate structural changes, and promote clinician capacity building to ensure youths’ mental health needs are met.

Résumé

Contexte: Les problèmes de santé mentale sont courants chez les jeunes ayant des déficiences physiques. Ceux recevant des services de réadaptation ont souvent plusieurs besoins, complexifiés par la transition vers les soins adultes. Cependant, peu est connu vis-à-vis du traitement des problèmes de santé co-occurrents. **Objectifs:** Cette thèse par manuscrits a pour but de mieux comprendre les pratiques et les services ciblant la santé mentale pour les jeunes de 15 à 24 ans suivis en réadaptation. Quatre études contribuent aux objectifs suivants: 1) synthétiser les données scientifiques existantes portant sur les modèles de service pour les jeunes ayant des déficiences physiques et des problèmes de santé mentale, 2) décrire les pratiques et procédures de réadaptation adressant la santé mentale, 3) mieux comprendre les besoins, supports, difficultés et solutions potentiels pour optimiser les services de réadaptation de la perspective des familles, cliniciens, et jeunes ayant ces problèmes co-occurrents, et 4) approfondir les connaissances sur les contextes organisationnels du point de vue de gestionnaires. **Méthodes:** Une thèse multiméthodes est entamée avec quatre études qualitatives afin d'obtenir une perspective globale. Le premier objectif est adressé par un examen de la portée sur les modèles de service (manuscrit 1). Le deuxième objectif est adressé par une revue de 60 dossiers de réadaptation de jeunes ayant des déficiences physiques et problèmes de santé mentale provenant de 5 sites à Montréal. De l'information sur les évaluations, buts, interventions, et références sont extraites et catégorisées avec une analyse de contenu (manuscrit 2). Le troisième objectif est adressé par des entrevues avec 22 jeunes, parents et cliniciens des 5 sites pour souligner leurs perspectives sur les services actuels et idéaux futurs (manuscrit 3). Le quatrième objectif est adressé par deux groupes de discussion avec 9 gestionnaires provenant des 5 sites pour obtenir des perspectives additionnelles au niveau de l’organisation (manuscrit 4). Des analyses thématiques sont faites pour identifier des thèmes (entrevues et discussions de groupe). **Résultats:** L’examen de la portée a identifié 16 articles avec 2 modèles et 12 principes clés pour guider l’organisation de service. Ceux-ci sont groupés par les thèmes suivants: collaboration et coordination, formation et support, et livraison de service. La revue de dossiers a révélé que les jeunes avaient des problèmes de santé mentale tels que l’anxiété (n=53) et la dépression (n=25), et plusieurs (n=36) en comptaient plus qu’un. Aucune évaluation de santé mentale n’a été trouvée, et les buts ou interventions en santé mentale n’étaient pas présents dans 43% des dossiers. Les buts pertinents (n=98) ciblaient la gestion des émotions, l’autonomie/communication des besoins, l’acceptation de la condition physique, socialisation, routines/niveaux d’énergie, supports pour l’école/travail, et loisirs/environnements calmants. Les interventions (n=104) incluaient la gestion des émotions, thérapie formelle individuelle/de groupe, liens avec les supports externes, routines/activités, réflexion/acceptation, et supports pour l’école/travail. Les services de santé mentale étaient livrés à l’interne (n=24) et/ou à l’externe (n=30), en plus de 18 références encore en attente et 14 non référés. Pour les entrevues (n=22), les thèmes étaient les suivants: ressources cliniques pour la santé mentale disponibles (accès aux professionnels de santé mentale, structures et mandats organisationnels, continuité de services pendant la transition aux services adultes); capacités cliniques du personnel (connaissances, outils et développement professionnel en santé mentale, rapport thérapeutique); liens et partenariats avec acteurs clés (amélioration des voies d’accès en santé mentale dans les programmes et organisations, implication des familles). Des enjeux similaires sur l’organisation des services ont été soulevés par les gestionnaires (n=9), confirmant et complémentant les résultats des entrevues. **Conclusions:** Les enjeux de santé mentale concernent cette population mais ne sont pas toujours ciblés en réadaptation dû à de multiples défis tels que l’expertise et les structures de support limitées. Les principes et suggestions identifiés pour des services idéaux peuvent guider l’amélioration des services et le changement organisationnel afin de surmonter les obstacles liés à l’accès, et les cliniciens peuvent bénéficier de développement professionnel et support adapté. Les résultats contribuent à une meilleure compréhension des services de réadaptation actuels et souligne des points à améliorer. Des études futures pourraient établir et tester des modèles de service complets, apporter des changements structurels et encourager le renforcement des capacités des cliniciens pour s’assurer que les besoins de santé mentale des jeunes sont satisfaits.

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First and foremost, I would like to express my immense gratitude to my supervisor, Dr. Dana Anaby, who has been a mentor and inspiration to me for over a decade. She has encouraged me to think critically and focus on clinically relevant research problems. I appreciate her unwavering support, dedication, and work ethic, and the multiple opportunities she afforded me which culminated in this thesis. I will always be grateful for her availability throughout the years and her unwavering belief in me and my potential.

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Preface

Thesis Organization and Overview

This doctoral dissertation includes four manuscripts (one published, two submitted, and one which is being prepared for submission to a peer reviewed journal) with the overall objective to better understand mental health practices and the organization of mental health services in rehabilitation for youth aged 15 to 24 who have a physical disability and encounter mental health problems. Chapter 1 consists of the objectives, design, and rationale underpinning this thesis. Chapter 2 introduces the topic and presents a comprehensive review of current scientific literature pertaining to youth with physical disabilities and co-occurring mental health problems and why this co-occurrence is important to consider especially for the targeted age group. Chapter 3 presents the first manuscript titled “Organization of rehabilitation services for youth with physical disabilities and mental health problems: A scoping review” which is published in *Frontiers in Rehabilitation Sciences*. It synthesizes existing evidence on models of service delivery for youth and young adults with physical disabilities and mental health problems following scoping review methodology. Chapter 4 bridges manuscripts 1 and 2. Chapter 5 presents the second manuscript titled “Mental health practices in rehabilitation for youth with physical disabilities: A chart review study” which is published in *Disability & Rehabilitation*. This manuscript describes current mental health practices in physical rehabilitation settings across 5 different sites in Montreal based on chart review methods. Chapter 6 bridges manuscripts 2 and 3. Chapter 7 presents the third manuscript titled “Services addressing mental health needs of youth in physical rehabilitation: perspectives of clinicians, youth and family members” which has been peer-reviewed by the *Child: Care,* *Health and Development* Journal for their special issue on Comorbidity and Multimorbidity in Childhood and is currently being revised by the authors to address reviewers' comments. It describes the needs, supports, challenges and potential solutions for improved mental health services in rehabilitation from the perspectives of service providers (clinicians) and receivers (youth and family members). Chapter 8 bridges manuscripts 3 and 4. Chapter 9 consists of the fourth manuscript titled "Manager perspectives on services addressing mental health needs of youth in physical rehabilitation: a focus group study" which is in preparation to be submitted to a peer-reviewed journal. Chapter 10 provides a comprehensive discussion of the cumulated findings, including implications for clinical practice, policy, and future research. Finally, Chapter 11 concludes with closing remarks.

Statement of Originality

I declare that this thesis is an original report of my research, has been written by me and has not been submitted for any previous degree. All the assistance received in preparing this thesis has been acknowledged. This project began with an initial scoping review (Lal, Tremblay, Starcevic, Mauger-Lavigne & Anaby, 2022) which revealed several gaps in the field from which stem the dissertation project, co-constructed with Dr. Dana Anaby, director of the ASPIRE Lab and Dr. Shalini Lal, director of the Youth Mental Health and Technology Lab and Canada Research Chair in Innovations for Youth Mental Health. New knowledge generated by this project is the result of my own work with the support of my supervisor Dr. Dana Anaby, co-supervisor Dr. Shalini Lal and committee member Dr. Mark A. Ferro, Canada Research Chair in Youth Mental Health. The contents of Chapters 3, 5, 7 and 9 are original and provide an important contribution to an underdeveloped area in the field of rehabilitation. This work has potential implications for researchers, clinicians, and managers to guide decision-making and client-centered care for youth with physical disabilities and mental health problems to improve the coordination and integration of services as elaborated below.

Contribution of Authors

The doctoral candidate serves as the first author of all manuscripts presented in this dissertation. Stephanie Marie Tremblay prepared the initial drafts of the manuscripts and incorporated feedback from members of the advisory committee (Drs. Anaby, Lal and Ferro) into the final drafts. Data collection and analysis were led by the doctoral candidate under the supervision of Dr. Anaby and Dr. Lal. With respect to the first manuscript of this thesis (i.e., the scoping review), Ms. Tremblay co-developed the search strategy and co-executed it, synthesized the data, and drafted all sections. Ms. Lucille Xiang took part in screening the literature for the inclusion of articles and assisted with coding and categorizing the information and editing the final version. Drs. Anaby and Lal critically reviewed the paper and provided extensive feedback to improve the quality of the manuscript for publication. Dr. Ferro reviewed the manuscript and provided feedback. The second and third manuscripts were co-authored by all members of the supervisory committee. Dr. Anaby's extensive ongoing feedback and guidance ensured that the manuscripts were of good quality. Dr. Lal advised on the methods used, reviewed the manuscripts, and gave constructive feedback to prepare the manuscripts for publication. For the third manuscript, Dr. Anaby and Dr. Lal were involved in the data analysis and validation and refining the themes, with feedback on the manuscript from Dr. Ferro. The fourth manuscript was similarly analyzed and validated with Dr. Anaby and Dr. Lal.

List of Figures and Tables

Chapter 1: Rationale, Objectives and Design

The aim of this dissertation is to better understand current interdisciplinary rehabilitation practices and services for youth with childhood-onset physical disabilities who experience mental health problems.

Rationale Supporting the Need for this Research

Approximately 20% of Canadians develop a mental illness before the age of 25 (Mental Health Commission of Canada, 2019), and there is increasing awareness of the magnitude of this problem for youth who are particularly vulnerable. According to the United Nations, the term ‘youth’ refers to individuals between 15 and 24 years old who are transitioning from childhood to adulthood, where physical and psychological maturation is needed to develop the skills necessary for success (UNESCO, 2017; Viner & Booy, 2005). Addressing mental health concerns for this targeted age group is particularly critical as this is when symptoms tend to emerge, with over three quarters of mental illnesses having their onsets before the age of 25 (Jones, 2013). Youth experience the highest incidence of mental disorders out of any age group (Gore et al., 2011), and less than one fifth receive appropriate and timely treatment (Mental Health Commission of Canada, 2019). Additionally, the timeframe already encompasses a challenging transition to adulthood aside from mental illness as teenage years mean adapting to all kinds of changes and challenges (Osgood, Foster, & Courtney, 2010).

In 2022, 20% of youth reported having one or more disabilities, which represents a total increase of 7% in the past 5 years (Statistics Canada, 2022). There is growing evidence that the co-occurrence of physical disabilities and mental health problems is common. This has been established among children and adolescents with cerebral palsy as shown in a systematic review (Downs et al., 2018) and through a large 2016 National Survey of Children's Health done in the United States (Whitney, Peterson, & Warschausky, 2019). An initial scoping review done by our team to systematically synthesize evidence on prevalence also revealed that symptoms of depression and anxiety are frequently present in adolescents with a physical disability such as cerebral palsy or spina bifida, and noted an underutilization of mental health services (Lal, Tremblay, Starcevic, Mauger-Lavigne, & Anaby, 2022). However, less than a third of the studies reported on access to mental health services and none detailed how to organize them (Lal et al., 2022). Identified gaps generated by this knowledge synthesis are therefore targeted in specific objectives below.

It is important for youth to get connected to appropriate services and receive mental health care before they transition to the adult healthcare system, considering that early intervention is key for mental health recovery (Malla et al., 2018). Additionally, adult services tend not to be as comprehensive as pediatric ones (Rauen et al., 2013). Health services utilization will be optimized if emerging mental health challenges are addressed within the structured care youth are already receiving (in their rehabilitation center) before they transition to adult care (Rauen et al., 2013). However, often psychiatric services are accessed long after the initial onset of symptoms, if at all (Malla et al., 2018; McGorry, 2017). In addition, healthcare services tend to be organized in silos which may require separate referrals to different institutions and complicate navigation, delaying treatment and leaving youth at risk of becoming more ill (Charlton et al., 2017; Gauthier-Boudreault, Couture, & Gallagher, 2021). The complex factors that lead to difficulties accessing mental health services require additional exploration.

Youth with physical disabilities present with multiple vulnerability factors towards mental illness (i.e., age, co-occurrence) and find themselves at a delicate timepoint where a transition to the adult care sector is envisaged. There is very limited information on how youth with physical disabilities who have emerging mental health problems access and use mental health services (Lal et al., 2022). Effective strategies and principles for organizing and delivering services for youth with co-occurring physical and mental health problems have not been established or reported on in a systematic and accessible fashion, with different institutions or governing bodies working in their own ways (*Gouvernement du Québec*, 2017; Lal et al., 2022; Wankah et al., 2018). Little is known about how rehabilitation services concretely address the mental health needs of youth with physical disabilities. Studies are needed to better understand rehabilitation professionals' clinical realities and actual practices within the limits of their organization, the needs of youth and family members and the barriers they face, and the perspectives of managers on how such services are currently organized.

Specific Objectives

Objective 1: To identify existing evidence about health and rehabilitation services and models of service delivery for youth with co-occurrence of childhood-onset physical disabilities and mental health problems through a knowledge synthesis (scoping review of scientific literature; Study 1).

Objective 2: To describe rehabilitation practices and procedures via chart reviews across five local rehabilitation organizations (Study 2).

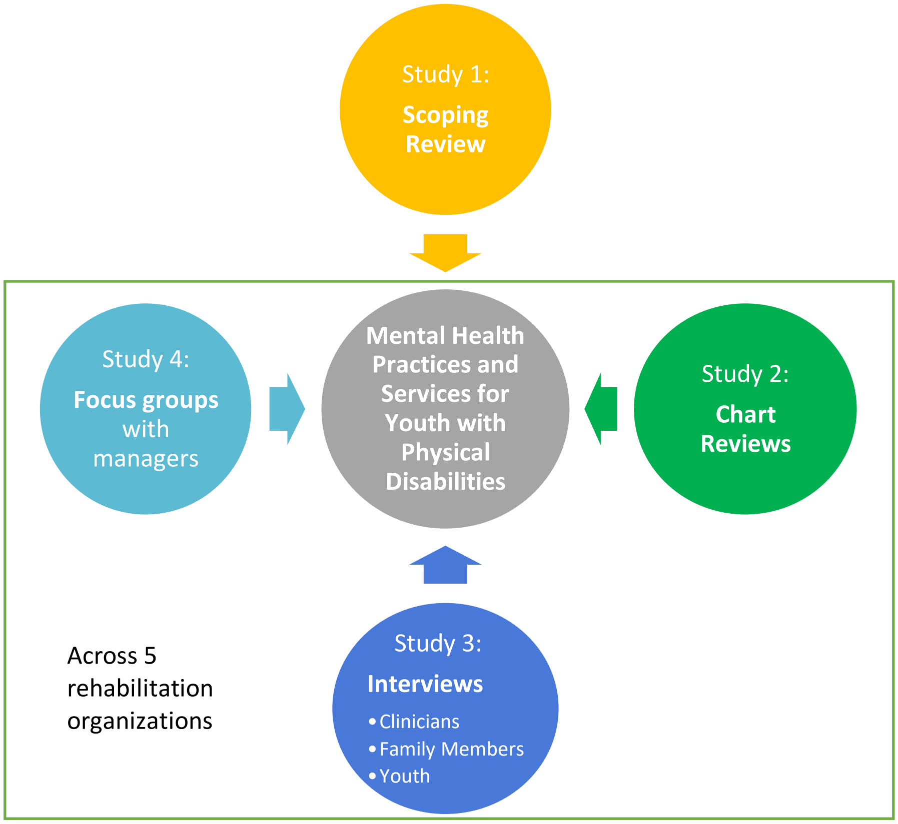
Objective 3: To better understand the needs, supports, challenges and potential solutions to optimize rehabilitation services across the five organizations through semi-structured interviews from the perspectives of service providers (clinicians) and receivers (youth, family members; Study 3).

Objective 4: To gain insights on service delivery and organizational contexts at the institutional level via focus groups with managers representing the five organizations (Study 4).

Design

A multimethod research design, using qualitative research methods, is presented across four unique studies (Creswell, 2015). This design was chosen to provide a comprehensive perspective and bring greater insight into the complex targeted problem through multiple rich sources of data, informed by different stakeholders at various levels of organization (Creswell, 2015). A multimethod design is adopted when several distinct research projects are conducted to address research questions relating to a particular topic and use multiple quantitative or qualitative methods, implemented concurrently or sequentially (Morse, 2003). However, unlike mixed methods, each study is planned and conducted independently to answer a specific sub-question or objective. The various methods used can provide different perspectives which are then brought together to offer a deeper understanding of a complex problem, as is frequently the case in healthcare research (Morse, 2003). The results deriving from the studies using different methods (methodological triangulation) can be corroborated (data triangulation) in the discussion to converge data pertaining to the same phenomenon (Green & Thorogood, 2018). See Figure 1 below for a visual representation of the four studies included in this thesis which all contribute to a better understanding of the central topic of interest.

Figure 1: Design of Thesis Encompassing 4 Data Sources



Study 1

To address Objective 1, a scoping review of peer-reviewed international scientific articles was carried out to synthesize current research and information related to the organization and delivery of services for youth ages 15 to 24 with co-occurring physical disabilities and emerging mental health problems (study 1; Tremblay et al., 2023). A scoping review is a synthesis used to map existing literature pertaining to broad, emerging topics (often with much heterogeneity) and identify present gaps (Arksey & O'Malley, 2005; Tricco et al., 2016). This was the methodology of choice to help understand the underlying phenomena regarding the organization and delivery of services for this population and identify collaborative models of care, best practices and key principles that have been established in the literature which can serve to guide improved care.

Recruitment Settings

To address Objectives 2 to 4, five distinct sites offering public, multidisciplinary, out-patient rehabilitation services for transition-age youth with childhood-onset physical disabilities (e.g., cerebral palsy, spina bifida, juvenile arthritis, degenerative conditions) in Montreal, Quebec, were purposefully selected as recruitment sites for the subsequent studies (2, 3, 4) to conduct an exploration of their current rehabilitation services and clinical practices. Focusing on sites within the province of Quebec was decided as rehabilitation services are organized provincially. The Greater Montreal area was targeted as structures and policies for organizing services differ by region and considering contextual barriers and supports is key (*Gouvernement du Québec, 2017*; Quesnel-Vallée & Carter, 2018). Excluded sites were those providing in-patient or acute care services (as the follow-up is short-term) and private healthcare services (as they are organized differently and funded by other budgets). Five sites affiliated with two different umbrella organizations (Integrated University Health and Social Services Centre (*CIUSSS*) West-Central and South-Central) were retained as eligible (i.e., fitting all inclusion criteria and serving a large proportion of youth with physical disabilities in Montreal) and interested in participating. Institutional diversity was important since many of the aspects targeted in this research will vary with the context, therefore it is necessary to highlight the similarities and differences across settings and propose representative findings that could be adapted for different settings (Gauthier-Boudreault, Couture & Gallagher, 2021; Restall, Diaz & Wittmeier, 2020). Also, multiple sites were chosen to sample from different areas of the city, ensuring diversity in the participants with regards to languages, socioeconomic status, diagnoses, ages, and residential districts.

Study 2

To address Objective 2, a chart review methodology was selected as it can bring to light concrete information about what is currently done in a clinical site (or across several sites). In Study 2, 60 charts of youth with co-occurring physical and mental health problems from across the 5 recruitment sites were reviewed for information about current practice (related to assessments, goals, interventions, and referrals) and content analysis was used to create categories and quantify them (Tremblay, Lal, Ferro, & Anaby, 2024). Chart review methodology can serve to determine documented healthcare practices, offering an inexpensive way to research rich pre-existing data with low participant burden (Hess, 2004). Often used in medicine with large numbers of patients who are hospitalized, medical records are reviewed to estimate prevalence, etiology, comorbidities, and use of medication for specific disorders. An earlier study looked at family physicians' performance based on 25 physicians' documentation in 25 to 40 charts each (Goulet, Jacques, Gagnon, Racette, & Sieber, 2007). Although less common, chart reviews have successfully been used in rehabilitation research. To illustrate, one study aimed to identify healthcare concerns of young people with cerebral palsy by looking at 241 initial consultations for a transition rehabilitation program, and many needs were highlighted (Winger et al., 2023). Another study looked at occupational therapy practices across 16 students with physical disabilities followed in the school setting, describing the clinical reality, and exploring possible avenues for improved participation (Bonnard, Hui, Manganaro, & Anaby, 2022). Chart reviews are certainly a promising approach to providing useful research data.

Study 3

To address Objective 3, Chart-Stimulated Recall Interviews (CSRI) with clinicians, and semi-structured interviews with youth and family members were conducted. Indeed, the reasons underlying why specific needs were not addressed could not be readily captured from the charts and required different methodological approaches. Therefore, to complement chart reviews and obtain various perspectives, 22 participants (9 youth, 4 parents, 9 clinicians) who received or provided services within the 5 selected sites were individually interviewed to highlight experiences and perspectives on actual and ideal care which were subsequently analyzed thematically (Study 3). An earlier study that looked at family physicians' performance based on charts had indeed combined chart reviews and a reflective discussion with participants to elaborate on the documented practices and provide more context (Goulet et al., 2007). The CSRI method can provide information about the clinical decision-making process and rationale behind practice behaviors not necessarily captured with chart reviews. To illustrate, a scoping review on CSRI methodology has shown that it can provide valuable insights into reasoning for actions taken (or not) as well as the different (social or other) influences which do not readily get documented (Sinnott, Kelly, & Bradley, 2017). The CSRI approach has been increasingly used in medicine and medical education, particularly with residents (Mutter, Kyle, Yecies, Hamm, & Di Nardo, 2022; Rakofsky et al., 2023). It has also been used in rehabilitation research, as exemplified by the previously mentioned study of occupational therapy practices in the school setting which combined CSRI with eight occupational therapists and chart reviews (2 each) to describe their clinical reality more accurately (Bonnard et al., 2022). A downside to chart reviews as a data source is that the voices of youth and their families are seldom documented. It was therefore important to consider how their perspectives could also be accessed since they are central stakeholders. Semi-structured interviews were chosen to allow youth and family member participants the space to express themselves on their needs, challenges and hopes regarding rehabilitation services (Green & Thorogood, 2018; Whiting, 2008). The guiding methodology, qualitative description, is useful for gaining a better understanding on practical problems including opinions, perspectives and experiences of a phenomena or situation through methods such as interviews (Sandelowski, 2000, 2010). Qualitative descriptive studies do involve data interpretation, but the researcher stays close to the participants' words and looks for patterns that are present in the data.

Study 4

To address Objective 4, two focus groups were held with managers (n=9) representing the 5 sites to gain perspectives at the institutional level (Study 4). Focus groups allow participants to share thoughts on their experiences and build off each other to compare the realities, challenges and practical solutions found within and across the different settings, capitalizing on group interaction (Green & Thorogood, 2018; Kitzinger, 2006; Krueger, 2014). The focus group format therefore allowed managers to discuss clinical mandates, resources, and challenges in providing services for a complex clientele. Additionally, it has been proposed that combining interviews and focus groups can enhance data richness through their complementary strengths and help to gain an in-depth understanding of the circumstances (Lambert & Loiselle, 2008). All interviews and focus groups were conducted by one interviewer (the doctoral candidate) which has advantages for data triangulation considerations (Lambert & Loiselle, 2008). Qualitative description was also chosen as the guiding methodology for the focus groups (Sandelowski, 2000, 2010).

Results from the four studies are brought together in the discussion to summarize the current state of services and practices across different rehabilitation sites and to collectively address the overall research question. Representation of relevant parties at the micro (clinicians, youth, family members) and meso (managers representing the organization) levels resulted in diverse perspectives from different ecological levels that together provide a better understanding of the highlighted topic and inform avenues for future research.

Consultation with Key Stakeholders Across Studies

When studying rehabilitation service delivery for youth, it is crucial to have their input on the current organization of care and directions for improvement (Barbic et al., 2019; Servili, 2012a, 2012b). Considerable progress has been made in understanding the health needs of youth with mental health problems, though little attention has focused on the needs that they identify, despite a national priority to incorporate patient-oriented research into health services (Barbic et al., 2019; Malla et al., 2019). Working directly with stakeholders is central to healthcare service provision and research (Witteman et al., 2018). This project was developed with stakeholder-oriented concepts in mind. I aspired to engage youth, family members, clinicians, and managers in the research process to include their perspectives via consultation activities informing the project. As a first step, I held a meeting with four rehabilitation specialists at one of the rehabilitation centers to better understand the scope of the problem. They discussed the many challenges they faced when working with youth presenting with mental health problems within physical rehabilitation settings. Following that initial meeting, various stakeholders representing the participating organizations were engaged at different time points, including clinicians (working in a rehabilitation center providing services for those with physical disabilities and that did not have mental health service delivery as their specialty), a family member and a youth with a complex physical condition. Their specific involvement throughout the thesis, such as providing input on search strategies for the scoping review, assisting in interpreting the findings by reviewing themes (clinicians), and providing advice about presenting the findings via an infographic (clinician, youth and family member), is described in more detail in Chapters 2, 4, 6, and 8.

Positionality

The first author of the four manuscripts is a female, bilingual doctoral candidate with no lived experience of disability. She has diverse clinical and research experience in pediatric rehabilitation and mental health. Her prior clinical experience as an occupational therapist in a multidisciplinary mental health team facilitated her understanding of the barriers and facilitators experienced by the stakeholders with regards to mental health practices and services. This was helpful for the chart reviews to aid in extracting relevant information, and in the interviews and focus groups to encourage participants to delve deeper into what they had to share. The three remaining authors have extensive research experience in pediatric rehabilitation, youth mental health, and epidemiology and biostatistics focusing on pediatrics and child psychiatry, respectively. The senior researchers supported Ms. Tremblay throughout the study designs, implementation, data analyses, and writing. The team's varied academic backgrounds and research experiences collectively shaped the interpretations and analyses of this thesis.

Chapter 2: Review of the Relevant Literature

General Overview of the Topic

The World Health Organization (WHO) defines mental health as “a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community” (WHO, 2005). Youth with physical disabilities are particularly vulnerable to developing negative emotions and mental health problems, which can have an impact on their healthcare needs. There are several contributing reasons, including the high prevalence of mental health problems in youth in general, limited participation levels among this group, the COVID-19 pandemic impacts, challenges with access to mental health services, and difficult transitions to adult roles and adult care settings. The following sections will detail each factor, present current supporting literature, and highlight how they are interlinked.

With regards to definitions, this thesis includes the following constructs: mental health problems (a broad concept encompassing mental challenges and symptoms), mental disorders (syndromes with clinically significant impacts on behavior and emotional regulation which lead to distress and decreased function), and mental illness (severe problems with impaired function, diagnosable; Granlund et al., 2021).

Mental Health Problems among Youth

Diagnosed mental illnesses account for 10% of the global burden of disease, and 30% of the non-fatal disease burden (Global Burden of Disease Mental Disorder Collaborators, 2022). Mental health problems encompass a wide range of negative emotions and behaviors, and persistent mental health problems early on increase the probability of later being diagnosed with a mental illness, as described in a conceptual paper in the context of neurodevelopmental disorders (Granlund et al., 2021). Self-reported or observed and documented mental health problems and/or symptoms were therefore included in this thesis, in addition to diagnosed mental illnesses, as they are viewed as important indicators representing a heightened risk of a diagnosable mental illness and we wanted to account for widespread delays in accessing assessment which further postpones treatment (Downs et al., 2018; Lal et al., 2022).

Mental health problems are prevalent worldwide, with estimates circling around one fifth of the total population being impacted over the life course (McGorry, 2017). When considering disabilities among Canadians, those that were mental health-related in 2022 accounted for 39% (Statistics Canada, 2022). In Canada, approximately 20% of youth will develop a mental illness (Butler & Pang, 2014). Youth in general experience the highest incidence of mental disorders out of any age group and face major consequences as a result (Gore et al., 2011). Indeed, upwards of 75% of mental illnesses have their onsets in adolescence or young adulthood, before the age of 25 (Jones, 2013). Addressing mental health concerns for this targeted age group is particularly critical as this is when symptoms tend to emerge, and they should be the top priority for receiving mental health care (De Girolamo, Dagani, Purcell, Cocchi, & McGorry, 2012; Malla et al., 2018). This is therefore the prime time to assess, diagnose and begin treatment, however in reality it is not always the case. Early intervention is critical for optimal recovery, though barriers such as wait times to be assessed and diagnosed can significantly impact the possibility of rapid follow-up and intervention (Iyer et al., 2015; Kutcher, 2017; McGorry & Mei, 2018).

This is of paramount importance as mental illness is the primary contributor to the burden of disability-adjusted life years among youth in high-income countries, and globally, mental illnesses make up a quarter of years lived with disability in that age group (Erskine et al., 2015).

Co-occurrence of Physical and Mental Health Problems

In 2022, 20% of youth reported having one or more disabilities, which represents an increase of 7% in the past 5 years (Statistics Canada, 2022). Among these are congenital or acquired physical disabilities involving a mobility restriction. For example, childhood-onset physical disabilities include cerebral palsy, spina bifida, juvenile arthritis, muscular dystrophy and other congenital, progressive, or degenerative conditions. This thesis takes a non-categorical approach to physical disability, with various physical diagnoses included across the 4 studies, recognizing the commonalities across distinct diagnoses and service needs (Arim et al., 2015). This approach fits with the WHO's International Classification of Functioning, Disability and Health (ICF) emphasis on individual functioning and is representative of how most rehabilitation programs tend to be organized, based on function and common needs rather than diagnosis (Miller, Gardiner, & Rosenbaum, 2023).

People with disabilities often have multiple co-occurring types, with 43% of Canadian youth with disabilities reporting having two or three (Statistics Canada, 2022). As youth navigate rehabilitation care, their physical and mental health challenges can influence each other and require particular attention (Aarons et al., 2008; Doherty & Gaughran, 2014). This was previously an understudied area that has garnered growing interest in recent years. Evidence of mental health problems is emerging among youth with various health conditions (such as physical illnesses). A large Canadian study (n= 5947) looking at prevalence found that physical (respiratory, musculoskeletal, cardiovascular, neurological, endocrine/digestive) and mental (depression, suicidal behavior, bipolar disorder, generalized anxiety disorder) comorbidity is prevalent among young adults (Ferro, 2016). In children aged 6–16 years (n=49) diagnosed with asthma, diabetes, epilepsy, food allergy, or juvenile arthritis, comorbid mental illness was found to be common and seemingly chronic (Reaume & Ferro, 2019). Another Canadian study currently underway is following 263 children 2-16 years old with physical illness over time to establish multimorbidity, which is in line with recent government position statements that encourage taking a life-course approach to mental wellness programs with a special focus on vulnerable populations (Ferro et al., 2021).

Mental health problems are also widespread among people living with a physical disability resulting in a mobility restriction due to congenital or acquired problems. Indeed, youth with physical disabilities who receive rehabilitation services often present with many complex needs, and there is increasing evidence that co-occurrence of mental health problems is common among those with cerebral palsy (Downs et al., 2018; Whitney, Peterson & Warschausky, 2019), neurodevelopmental disorders (Granlund et al., 2021) and a range of physical disabilities (Lal et al., 2022; Maalouf, Hatoum, Atwi, & Boustany, 2010). A study from the United States of America looking at the prevalence of mental disorders among children with cerebral palsy found that psychiatric medications were frequently used to address multiple symptoms (Linhares et al., 2017). A systematic review of 28 studies found that autism and attention deficit disorders, which are classified in the American Psychological Association (APA)'s Diagnostic and Statistical Manual of

Mental Disorders (5th ed.; DSM-5; APA, 2013), were observed among those with cerebral palsy (Craig, Savino, & Trabacca, 2019). A recent study consisting of an initial evaluation of mental health problems in 33 youth with physical disabilities using the Behavior Assessment System of Children (BASC-3) found that those with a greater number of functional issues were more likely to be in the “at risk” or “clinically significant” categories (Amalfi et al., 2023).

Another systematic review of eight studies (n=1771 children and youth) used primarily parent-report mental health screening tools (i.e., Strengths and Difficulties Questionnaire, Child Behavior Checklist) to establish the prevalence of mental health conditions and problems in children and adolescents with cerebral palsy and found that it was between 28 and 35% (Downs et al., 2018). They concluded that while mental health symptoms are common, more studies are needed to confirm the prevalence of mental health disorders in this group and emphasized that evaluations targeting mental health should be incorporated into multidisciplinary assessments (Downs et al., 2018). Research targeting youth with these co-occurring health problems is important as the combination of physical and mental health problems complicates further diagnosis and treatment and can negatively impact overall prognosis. Unfortunately, mental health is often overlooked altogether when clients are being treated for chronic physical conditions, and Downs and colleagues (2018) suggest that complexities with classification of the various co-occurring health challenges could partially explain the difficulties in accessing appropriate mental health services.

To synthesize available scientific research on the prevalence of mental health problems in youth with congenital and childhood-onset physical disabilities and their access to mental health services, a scoping review was conducted by our team (Lal et al., 2022). We reviewed 33 peer-reviewed studies targeting youth with a physical disability and associated restricted mobility (e.g., cerebral palsy, juvenile arthritis, spina bifida) coupled with information on mental health assessment, treatment, or service access and use. The results revealed that the most investigated mental health problems across reviewed studies were depression and mood-related difficulties (73%) followed by anxiety (39%). Prevalence rates, based on our synthesis of reported rates, ranged between 7.8% to 53% for depression and mood-related difficulties, and between 2.2% to 31% for anxiety. Of note, only 10 out of the 33 retained studies reported on some aspect of access to mental health services. From those, four key themes emerged, namely: access, use and experiences of mental health services; stigma; mental health of family caregivers; and value of comprehensive mental health services. The underutilization of mental health services was highlighted, with less than a quarter of young people with mental health concerns using mental health services and overall delays or lack of formal help-seeking. Unmet needs included services to address sexuality, relationships, depression, and linking to peer and vocational support. Details on the type of treatment and services that few participants did receive were limited to two case studies. No article from the scoping review detailed how to organize these services. From this scoping review, our team concluded that "a better understanding of the organizational contexts of various healthcare systems or models of service delivery would be pertinent to ensure the complex needs of this population are met” (Lal et al., 2022, p. 13).

Participation of Youth with Physical Disabilities

Positive coping strategies to manage mental health include participating in sports, creative arts or volunteer work which can help reduce stress and increase self-esteem and resilience, but youth with physical disabilities face additional barriers to participation in meaningful activities (Anaby et al., 2022). Unfortunately, participation for this group is limited and most often restricted to individual activities done in the home environment (Anaby et al., 2014; King et al., 2010). This can result in less opportunities to make friends, have support, and be physically active, further exacerbating the potential for the development of negative emotions and low self-esteem (King et al., 2010). A cross-sectional study examined how social factors such as participation in activities and established friendships mitigated the risk of mental health disorders (e.g., depression, anxiety, attention-deficit/hyperactivity disorder) in 111 children and youth (aged 6-17) with cerebral palsy (and 29 909 without). Though there was an elevated prevalence of mental health disorders among the children with cerebral palsy, they found that they were partly associated with social factors that could be modified or improved (Whitney, Peterson & Warschausky, 2019). A recent study pertaining to adolescents with neurodevelopmental disorders (n = 1790) across Sweden also suggests that participation interventions can possibly protect against mental health problems, while acknowledging the barriers that youth with disabilities face which limit engagement (Augustine, Lygnegård & Granlund, 2022).

Impacts of COVID-19 on Mental Health of Youth

The COVID-19 pandemic resulted in many lockdowns and populational health impacts. These amplified barriers to participation and the overall burden of mental health problems by adding another layer of challenges for numerous youths, attributed in part to a disruption of their health services, activities, and school- or community-based supports (Magson et al., 2021). The prolonged isolation and widespread uncertainty had several negative effects for many, and a recent systematic review and meta-analysis found that clinically significant symptoms of anxiety and depression, as well as loneliness, remain high since March 2020 and are particularly prevalent and elevated in North America (Cenat et al., 2022).

The negative impacts of the COVID-19 pandemic were multiplied for youth with physical disabilities, and decreased mental health was documented across several studies in this context (Meireles & Meireles, 2020; Merrick et al., 2023; Varengue et al., 2022). In a study undertaken in the United Kingdom, 241 parents were surveyed about the mental health of their child with disabilities, and most reported that loss, worry and changes in mood due to disruption of routines and other social changes were having negative impacts on them (Asbury, Fox, Deniz, Code & Toseeb, 2021). A large survey (n=1000) undertaken in France targeting children with physical disabilities (42% with cerebral palsy) highlighted that they were negatively affected by the pandemic by stopping engagement in physical activities (44%), no longer having contact with other children (55%), and demonstrating behavioral problems (32%; Cacioppo et al., 2021). Mental health concerns were exacerbated by the COVID-19 pandemic to a greater extent than for those who had no physical health problems, emphasizing the importance of considering this vulnerable group when developing supports and interventions that integrate physical and mental health needs (Hawke et al., 2021).

Considerations for the Transition Age Range

The teenage years are a time of physical, mental, and social changes for youth in general, where some present with difficulties adapting. It is a complex and important time encompassing a challenging transition to adulthood, notwithstanding illness diagnoses, involving adjusting to changes, taking on multiple new social roles and going from a dependent child to forming an independent identity (Osgood, Foster & Courtney, 2010). Common worries about building friendships and fitting in, managing increased demands of school and part-time work, and maintaining appearances may lead to feelings of inadequacy which could bring about anger, anxiety, or low self-esteem (Singh et al., 2010). Transition-aged youth are particularly vulnerable to developing mental health problems during a developmentally sensitive period, and maladaptive behaviors to cope (such as substance use) can cause more distress and isolation. Mental health problems during this life stage can disrupt milestones including educational and vocational attainment and overall autonomy, thereby creating a vicious cycle (McGorry et al., 2022).

Transition of Care to Adult Mental Health Services

While the transition age range is a critical period for youth to receive continued support, unfortunately, many health systems are organized in such a way that they disrupt care as youth who are followed for chronic disabilities must transition from pediatric to adult services once they reach a certain age (Iyer et al., 2015; Lindsay & Varahra, 2018; Singh et al., 2010). These transitions are often abrupt and can result in a decrease or complete loss of services, or disengagement following loss of contact with their treating team, which generally lead to poor clinical outcomes (MacDonald, Fainman-Adelman, Anderson & Iyer, 2018). A scoping review on mental health services for children and youth transitioning to adult mental health care found that there were many elements to consider, and adequate transition planning was often lacking (Cleverley, Rowland, Bennett, Jeffs & Gore, 2020). One such consideration is the importance of having a strong therapeutic relationship with care providers for optimal care, which requires time, skill, and understanding to attain (Kornhaber et al., 2016). Additionally, adult healthcare services tend not to be as comprehensive and organized as pediatric care settings, making the transition extremely challenging (Rauen et al., 2013; Wenger & Niemann, 2020). Indeed, in a large survey across 11 countries, adults with complex chronic conditions (n= 18,667) reported that their care was poorly coordinated (Schoen et al., 2011). Health services utilization could be optimized if these challenges were addressed while youth are already receiving structured care (for example, within their rehabilitation center) before planning a smooth transition to adult services (Rauen et al., 2013; Sukhera, Fisman & Davidson, 2015). However, psychiatric services are often only accessed many years after the initial onset of symptoms, if at all, which significantly decreases opportunities to capitalize on the benefits of early intervention (Malla et al., 2018; McGorry, Purcell, Goldstone & Amminger, 2011).

Transition of services for youth with physical disabilities

Children with a physical disability who are reaching adolescence face additional challenges when considering the many developmental changes, as comparisons with peers are common and awareness of physical differences (e.g., using a wheelchair or walking aid) can significantly affect self-esteem (Maxey & Beckert, 2017). A qualitative study on perspectives of young adults aged 18 to 25 with cerebral palsy (n=14) transitioning to adult care reported some positive experiences but several challenges, including apprehension before the transition, lack of coordination between pediatric and adult healthcare providers, and feelings of abandonment afterwards (Larivière-Bastien et al., 2013). Recent research has targeted transition healthcare services for this vulnerable group, and barriers raised include inconsistent practices and lack of resources for healthcare providers to support the imposed transition (Nguyen et al., 2023). Proposed recommendations include having a flexible age for the transfer, addressing the situation holistically by considering aspects such as housing and employment, and undertaking gradual transitions beginning several years before the planned transfer (Nguyen et al., 2023).

Considerations for involving families in the context of transitioning to adult care

Families play a major role in helping their child access pathways to mental health care, highlighting the need to include them in decision-making and in outreach efforts to reduce treatment delays (MacDonald et al., 2018). Family involvement is known to facilitate recovery in mental illness (Corrigan et al., 2014). Although collaboration with family members is increasingly considered by many rehabilitation and healthcare programs, it must be done with sensitivity to respect confidentiality and youths' increasing desire for self-management (Singh et al., 2010). Family-centered care has also been a growing area of research for youth with a physical disability such as cerebral palsy (Li et al., 2024). The application of family-centered principles to organizational service delivery is encouraged to bring about a cultural shift at the institutional level (King & Chiarello, 2014; Li et al., 2024).

Access to Mental Health Services for Youth

Youth face multiple challenges regarding accessing mental health services. As found in a recent systematic review on the topic, pathways are generally complex, involving several contact people and multiple barriers and delays along the way (MacDonald et al., 2018). Unfortunately, adolescents and young adults, who are in the transition-age grey zone, have the worst access to rapid mental health care to address their significant, emerging needs (McGorry et al., 2022). Indeed, less than twenty percent of Canadian youth who need mental health services receive appropriate and timely treatment (Mental Health Commission of Canada, 2019).

Reasons for limited use of mental health services

In recent decades, there has been more attention directed towards youth mental health and understanding why many are not accessing mental health services (in a timely manner, or at all). Limited outreach for mental health services could in part be attributed to the stigma associated with having a mental illness (Corrigan, Druss & Perlick, 2014; Lal et al., 2022). A systematic review found that stigma related to embarrassment, problems recognizing symptoms, and a desire to be self-reliant were major barriers to help-seeking (Gulliver, Griffiths & Christensen, 2010). The immense stigma is a barrier faced by many youths, especially at an age where most want to be accepted and fit in with their peers. Moreover, one study found that reasons for not seeking treatment varied with illness severity, and those with severe mental illness tended to find that structural or evaluative barriers were the most important deterrents (Mojtabai et al., 2011). Therefore, many aspects need to be considered and addressed to improve access to care.

Initial efforts have focused on increasing awareness across different settings aimed to improve knowledge, attitudes and understanding of mental health problems in general with the hope to ultimately improve access to services and overall health outcomes (Hoven et al., 2008). For example, the Bell Let’s Talk campaign encompasses several awareness documents and programs such as social media posts to encourage dialogue, and information guides for teachers to help them confidently discuss mental health with their students (Linden, Stuart, & Fortier, 2022). Findings from the Canadian Community Health Survey over an eight-year period (2011-2018) show a rise in diagnosed mood and anxiety disorders and mental health consultations which may in part be explained by a rise in the prevalence of mental illness, or perhaps diminishing stigma and increased mental health literacy which may come from these types of awareness efforts (Wiens et al., 2020). Even so, significant stigma remains and the demands for mental health services among youth continue to rise, therefore the health care system must adapt and respond with different strategies.

Given the immense challenges listed above, there have been recent developments in multidisciplinary integrated youth services aiming to improve ease of access to mental health care for young people. Novel programs intending to provide a flexible approach to care and cater to youth with a range of needs and severity of challenges encompassing physical, sexual, and mental health as well as housing and other social challenges, are emerging. In Canada, examples include the nation-wide ACCESS Open Minds (Malla et al., 2019), Foundry in British Columbia (Mathias et al., 2022) and Youth Wellness Hubs in Ontario (Henderson et al., 2023).

Integration of Mental Health Care in Physical Rehabilitation Settings

Service integration is defined as “functions and activities aimed at the formation of a unified and comprehensive range of services in a geographical area, where the intent is to enhance the effectiveness of the delivery of services and optimize the use of limited resources”, going beyond coordination between different specialties (King & Meyer, 2006, p. 479). Integrated care is thought to be ideal, and recommendations integrating various components are slowly emerging (Fleury, Grenier, Vallée, Aubé & Farand, 2017; Schor & Bergman, 2021). Organizations are moving towards improved coordination, for example using a coordinator who oversees the entire care trajectory and ensures that all needs are met (Hillis, Brenner, Larkin, Cawley & Connolly, 2016). A scoping review from India highlighted the importance of integrating mental health care into existing primary care structures within that country in a phased manner and leveraging technology to make it accessible and affordable (Pandya, Shah, Chauhan & Saha, 2020). The WHO also emphasizes the importance of integrating mental health into general health facilities, moving away from psychiatric, hospital-based treatment approaches and encouraging young peoples’ active engagement in monitoring the quality of care (Servili, 2012a). Indeed, primary care mental health services facilitate the early identification and treatment of mental health problems and can facilitate access to services, and professionals working within these organizations are best placed to provide holistic, continuous care (Robinson et al., 2021; Scratch et al., 2020; Servili, 2012a).

Though awareness about the importance of addressing mental health problems in youth with physical disabilities is increasing, receiving complete, integrated care for physical and mental health problems within an organization is seldom common practice (Linhares et al., 2017; Scratch et al., 2020). An Australian study interviewing 13 adolescents with juvenile idiopathic arthritis and 37 parents found that holistic and integrated care encompassing psychosocial support (which included social and financial aid, mental health services, vocational guidance, and peer support) was crucial for optimal pediatric rheumatology services, but lacking (Tong et al., 2013). A study reviewing 203 clinical charts in the province of Ontario found that 84% of the young adults (over 14 years old) with cerebral palsy documented a need for better coordination of rehabilitation or multidisciplinary care, including new referrals to specialists, consultations with interdisciplinary medical teams, transitional care, or navigational support (Winger, Cassidy, Starowicz & Brunton, 2023).

Effective strategies and principles for organizing and delivering services for youth with co-occurring physical and mental health problems have not been established or systematically reported, with different institutions or governing bodies working in their own unique ways (Wankah et al., 2018). Indeed, little is known about how rehabilitation services concretely address the mental health needs of youth with physical disabilities including what clinicians do within the limits of their organization and how these youth and their families navigate the systems of care (Butler & Pang, 2014; Robinson et al., 2021). Additionally, there is a paucity of empirical research and evidence-based guidelines that focus on the implementation of mental health support and programs during the transition from pediatric to adult care systems (Cleverley et al., 2020; Sukhera et al., 2015).

Canadian healthcare services are often rooted in a biomedical model and are not currently prepared to meet the psychosocial needs of children and youth with disabilities (Scratch et al., 2020). A practical service integration pathway was recently proposed to implement mental health care directly into pediatric rehabilitation hospitals in Ontario and thereby reduce the silo effect that separates physical and mental health care in the current systems (Scratch et al., 2020). This realist framework stems from a local environmental scan of Canadian policy documents (specifically from the Ontario Center of Excellence for Children and Youth Mental Health and the Canadian Mental Health Strategy) and models to integrate holistic pediatric care in two phases, building rehabilitation staff's competency in mental health service delivery with support from an internal mental health team. The framework has yet to be studied in practice to determine the challenges of implementation in a real-world rehabilitation setting, and there are likely to be some differences between provinces. Another article surveying services for youth with traumatic brain or spinal cord injuries reported challenges in providing long-term support for psychosocial problems, and listed limited staff, time and funding, difficulties managing stigma, poor communication between service providers, and lack of services when transitioning into adult settings as major barriers (Botchway et al., 2022). Given the limited information on service evaluation, additional studies are needed to appraise the effectiveness of current practices supporting psychosocial wellbeing, referral pathways and transitions from the perspectives of rehabilitation clinicians, family members, and youth for a holistic understanding of the current context of care.

The provincial, national, and global initiatives pertaining to healthcare service reorganization, combined with budgetary restrictions, a call for more efficient services, and a greater awareness of the presence and burden of mental health problems among youth with physical disabilities provides a timely opportunity to study actual rehabilitation practices and services on a local scale.

Rehabilitation Service Delivery in Quebec

Healthcare services in Canada are structured at the provincial level, and have traditionally been organized in silos (Thiebaut, Farand & Fleury, 2014). They tend to be compartmentalized into mental and physical concerns that are addressed separately, often by different professionals located in various healthcare settings (Careau et al., 2015; Fleury et al., 2018). This makes services hard to navigate, and may require separate referrals, which delays treatment, increases frustration, and leaves youth at risk of becoming more ill (Charlton et al., 2017; Gauthier-Boudreault, Couture & Gallagher, 2021). In the province of Quebec, a major healthcare system structural reform was undertaken in 2015 with the hope of better integrating services across multiple levels, but this was not achieved fully, and many gaps remain (Quesnel-Vallée & Carter, 2018; Wankah et al., 2018). Recently, the provincial government announced another reform, with the reorganization again aiming to make the health system more efficient and improve access to care (*Gouvernement du Québec*, 2023).

Pediatric rehabilitation centers typically have programs serviced by multidisciplinary teams (often formed by physical therapists, occupational therapists, psychologists, special educators, and social workers) that are organized by age group and/or category of disability such as motor-related problems (Camden, Swaine, Tétreault & Brodeur, 2010; Perreault & Careau, 2012; Quesnel-Vallée & Carter, 2018). Strong and effective multidisciplinary work is listed as one of the strengths in Quebec pediatric rehabilitation centers (Camden, Swaine, Tétreault & Bergeron, 2009), and there are several rehabilitation services available. As they already provide structured out-patient care for their young clients, they are well placed to ensure that clients' needs are addressed holistically (Quesnel-Vallée & Carter, 2018). A Canadian article providing a synthesis and critical analysis drawing from the mental health literature emphasized the important impact that the clinician has in providing holistic care in pediatric rehabilitation (King, 2017). However, holistic care is not always offered in such a systematic, comprehensive manner across programs (Camden et al., 2009).

The psychosocial piece is often missing when looking at current physical rehabilitation practices. A study surveying Canadian physical and occupational therapists who worked with children with cerebral palsy (n=123) found that while physical or motor-related body functions and structures were well addressed, ICF elements such as participation and cognitive/emotional functions were not as readily targeted (Anaby et al., 2017). Another study of 91 school-aged children and 167 adolescents with cerebral palsy in Quebec found that rehabilitation services (most commonly physical and occupational therapy) decreased with age and severity of activity limitations and tended to consist of only weekly consultative sessions for the adolescents. It also reported that most rehabilitation services were within the school setting and that there was a general paucity of psychology services, implying that emotional problems and behavioral difficulties may not be well addressed (Majnemer et al., 2014).

Research Gaps in Service Organization and Rehabilitation Practices

There is still much evidence lacking when it comes to understanding the organization and provision of rehabilitation care for those with co-occurring physical and mental health problems, and more empirical research is needed to better understand rehabilitation professionals' clinical realities, actual practices, needs and competencies. Some work on this topic is emerging in alternative contexts. Current Canadian rehabilitation practices were examined in a mixed-methods study including a survey and ten interviews with healthcare providers working with children in an intensive care unit for complex chronic conditions, and barriers to providing optimal services (such as limited goal setting, weak communication with families and uncoordinated discharge planning) were highlighted (Kobussen, Hansen, Brockman & Holt, 2020). A pan-Canadian cross-sectional survey completed by 35 physical rehabilitation specialists working with children and adolescents that had cancer listed challenges to providing rehabilitation services such as limited space, few resources, and a lack of clinical practice guidelines (Ospina, Wiart, Eisenstat & McNeely, 2020).

A recent local scan (in the Greater Montreal area) of existing mental health services for children with neurodevelopmental disorders (such as autism spectrum disorder and intellectual disabilities) and their families was mapped across clinical settings, local and online communities and found that there were gaps related to availability of programs (Hanson, Heslon, & Ogourtsova, 2023). A subsequent study surveyed and interviewed 16 clinicians and 10 caregivers who reported a widespread need for pediatric, family-centered mental health services and a general lack of sufficient mental health resources and training (Heslon, Hanson, & Ogourtsova, 2024). As of yet, there are no published studies that describe rehabilitation practices and services for youth with physical disabilities and mental health care needs.

The scoping review done by our team (Lal et al., 2022) set the stage for subsequent research efforts to learn more about mental health practices and services in rehabilitation settings. It was determined that a second scoping review would be relevant to find published evidence on service delivery models for this population (Objective 1). Building on the initial scoping review (detailed earlier; Lal et al., 2022), the second scoping review looked at the same population but included a fourth search term pertaining to the organization and delivery of services. Three rehabilitation clinicians participated in a meeting to consult on the search strategy, key terms, and data extraction form to be used. Considering that only 10 studies out of the 33 included in the first scoping review discussed access to mental health services (Lal et al., 2022), we removed the results from the first search but screened those 10 studies to see if they matched the new inclusion criteria, as well as expanded the publication dates cutoff to include more recent publications. Published findings are presented in Chapter 3 (Tremblay et al., 2023).

It also became apparent that there was a major gap in research representing actual rehabilitation practices for professionals working with youth that have co-occurring physical and mental health problems, such as what is documented in rehabilitation charts (Objective 2; Tremblay et al., 2024). An in-depth exploration of current practices, needs, clinical reasoning, supports and barriers regarding physical and mental health services across different stakeholder groups was also envisioned (Objectives 3 and 4).

Indeed, different methods and participant groups across five recruitment sites were considered to provide a multidimensional picture of the current reality and constitute the four succeeding studies which are presented below (in Chapters 3, 5, 7, and 9).

Chapter 3: Manuscript 1, Organization of rehabilitation services for youth with physical disabilities and mental health problems: A scoping review

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Abstract

Introduction: Youth with childhood-onset physical disabilities receiving rehabilitation services often present with many complex needs. Emerging evidence confirms co-occurrence of mental health problems in this population is common, and mental health is often overlooked during rehabilitation for chronic physical conditions. For example, symptoms of depression and anxiety are frequently present in adolescents with physical disability such as spina bifida or Duchenne muscular dystrophy, and access to mental health services is often limited. Addressing mental health concerns for this age group is particularly critical as it encompasses a challenging transition to adulthood. Objectives: Building upon findings from a recent scoping review on the co-occurrence of physical disabilities and mental health problems, this paper synthesizes scientific literature related to the organization and delivery of services for youth with co-occurring childhood-onset physical disabilities (e.g., cerebral palsy, spina bifida) and mental health problems (e.g., depression, anxiety). Methods: A scoping review protocol stemming from Arksey & O'Malley's framework and updated guidelines from the Joanna Briggs Institute was developed. Four databases (Medline, PsycINFO, CINAHL, Embase) were searched. The search was limited to French or English peer-reviewed articles published between 2000 and 2021. Articles included were primary papers addressing: 1) youth aged 15 to 24 with a childhood-onset physical disability, 2) mental health problems, and 3) healthcare service organization or delivery. They were screened by two reviewers and discussed with a third to establish consensus on the inclusion criteria and resolve disagreements. Results: Sixteen articles were retained from the 1010 screened. Many (9/16) were from the USA. Two models were found: the Biopsychosocial, Collaborative, Agency-Based

Service Integration Approach (including psychiatry in a pediatric rehabilitation hospital) and the Client Network Consultation (an interagency collaboration in mental health care for children with complex healthcare needs). Twelve key principles for service organization and delivery were identified and categorized into: collaboration and coordination, training and support, and delivery of care. Conclusion: Identified principles can guide improved service delivery for this population. Highlighted research gaps include the need for developing models of collaborative healthcare delivery and subsequently evaluating their effectiveness.

Keywords: Service organization, rehabilitation, co-occurring diagnoses, mental health service, service delivery

Body

1. Introduction

Approximately 20% of Canadians will develop a mental illness before the age of 25, and less than one fifth will receive appropriate and timely treatment (1, 2). Youth with childhood-onset physical disabilities (such as cerebral palsy) who receive rehabilitation services often present with many complex needs, and there is emerging evidence that co-occurrence of mental health problems in this population is common (3-5). A large Canadian study (n= 5947) examining prevalence found that physical (respiratory, musculoskeletal, cardiovascular, neurological, endocrine/digestive) and mental (depression, suicidal behaviour, bipolar disorder, generalized anxiety disorder) comorbidity is common among young adults (6). Additionally, mental health is often overlooked when clients are treated for chronic physical conditions (3). A recent scoping review carried out by our team (4) also revealed that symptoms of depression and mood-related difficulties, followed by anxiety and social and behavioral difficulties are frequently present in adolescents and young adults with physical disability such as spina bifida and Duchenne muscular dystrophy. Despite the high occurrence of mental health disorders, symptoms or behavioral problems, few studies included in the review addressed access to, and organization of, mental health services. Addressing mental health concerns for this targeted age group is particularly critical as this life stage encompasses the transition to adulthood which brings about its own set of challenges.

Integrated care is generally considered to be ideal, yet effective strategies and principles for organizing and delivering services for youth with co-occurring physical and mental disorders have not been established (7). Indeed, little is known about how health and rehabilitation services address the mental health needs of youth with childhood-onset physical disabilities. Thus, our team first carried out a scoping review to explore the rates of co-occurrence of mental health problems among adolescents and young adults with a physical disability, and also to describe if they had access to mental health care (4). Only 10 out of the 33 retained articles addressed access to services, which led to four related themes: use, access, and experiences of mental health services; stigma; mental health of family caregivers; and the value of comprehensive mental health services. Few participants who had mental health concerns accessed services, and many unmet needs were reported. Despite a push for more, or better access to, mental health services for those with physical disabilities, no article from that scoping review detailed how such services could be organized to fit with existing systems of care (4). Therefore, it was established that the cooccurrences were prevalent, but it remained unclear how services were organized and delivered. To address this, a subsequent literature review including broader publication dates (between 2000-2021 versus 2007-2019 in the first scoping review) and a more specific search strategy (focused on the organization of services themselves, with additional keywords such as service delivery and service integration) was proposed. The additional inclusion of children with special healthcare needs ensured that articles addressing a variety of physical/chronic disabilities within rehabilitation were taken into consideration.

Healthcare services in many high-income countries are typically rooted in a biomedical model and are not presently prepared to meet the psychosocial needs of children and youth with physical disabilities (8, 9). In Canada, there are steps being taken towards integrating mental health into primary care (though as of now it remains at the level of some organizations and provinces), while other countries such as England have put in place specialized programs (such as the Increasing Access to Psychological Therapies program) to address this challenge (10). In the United States of America (USA), mental health services are not yet universally accessible either (10). More specifically, mental health care is not well integrated in rehabilitation services across countries (11). In response to the gap, the World Health Organization (WHO) has recently come up with the special initiative for mental health (2019-2023) document (12) which aims to achieve universal mental health coverage for all, focusing in particular on low-income countries and remote regions where access to care is especially complex. Its second strategic action, which promotes the scaling up of interventions and services across community-based, general health and specialist settings, includes ensuring that affordable, quality mental health care is integrated in relevant programs such as in rehabilitation care for people with disabilities, and stipulates that priority efforts are needed to integrate mental health care across all levels (12).

A better understanding of the organizational contexts of various healthcare systems and efficient models of mental health service delivery would be pertinent to ensure that the complex needs of this population are met more comprehensively. The current context of healthcare service reorganization, coupled with pressures deriving from budget cuts and increased need and demand for services, provides a timely opportunity to study actual health and rehabilitation services, to outline needs and to identify gaps to inform future service delivery methods and ensure that best practices are translated into clinical settings (13, 14).

The objective of this review is to identify what is known about existing health and rehabilitation services and models of service delivery for youth with co-occurrence of childhood-onset physical disabilities and mental health challenges.

2. Materials and methods

A scoping review methodology was selected to answer the broad research question by mapping the available evidence since existing models and services available for this population have not yet been comprehensively reviewed. Stemming from Arksey & O'Malley's framework (15) and the recommendations provided by Levac and colleagues (16), Colquhoun and colleagues (17) and the JBI Manual for Evidence Synthesis: Scoping Review chapter from the Joanna Briggs Institute (18), a detailed protocol was created and registered in Open Science Framework online in December 2021 (19). This scoping review includes 6 stages: identifying the research question, identifying relevant studies, selecting studies, charting data, collating results, and consultation. A preliminary meeting was held with 3 stakeholder clinicians to contribute ideas pertaining to additional literature and review the search strategies. One clinician from a physical rehabilitation team agreed to serve as a member of a consultation committee to help interpret and validate the results and assist in dissemination.

Scientific evidence obtained from peer-reviewed journal articles via Ovid Medline, CINAHL, PsycINFO and Ovid Embase was targeted. These four databases were chosen as complementary to encompass the inclusion criteria and retrieve the highest possible number of publications in the disciplines of biomedicine and psychological sciences (20). A university-based librarian with expertise in rehabilitation was consulted when selecting the databases and finalizing the search strategy.

2.1. Identifying the research question

Using the PCC framework (Population/Participants, Concept, Context) and building on the previous scoping review findings (4), this review aimed to answer the following research question: What is known about existing health and rehabilitation services and models of service delivery for youth with co-occurrence of childhood-onset physical disabilities and mental health problems? Additional sub-questions include: 1) How are these services organized and delivered? 2) What are the key principles of existing models of service delivery? 3) What is known about the effectiveness of identified models or principles?

2.2. Identifying relevant studies

The search terms included four topics and their derivatives: physical disability, mental health disorder, youth, and healthcare service. The initial search strategy was developed for Medline, building on previous scoping reviews (4, 21) and as seen in Table 1. It was then adapted to the other databases with input from the university librarian to specifically target the organization of services. This was an iterative process evolving over several months to result in the final search strategy. Articles already reviewed in the previous scoping review (4) were removed from the search so as to not be screened again. However, the 10 articles that were included in the previous scoping review which addressed services for this population were screened for eligibility, and those fitting the new inclusion criteria were included in this current literature review for additional analysis.

2.3. Selecting studies

2.3.1. Inclusion criteria

The inclusion criteria for the selection of articles are based on our previous review (4) and have been adapted, where applicable, to meet the objectives of this current study:

1) A mean age of participants between 15 and 24 years old, a study population including at least 50% youth between ages 15 and 24 with specific results about this group, or the term *adolescents, youth,* or *young adults* used to describe their population, if no age is mentioned. The age limits correspond with the United Nations definition of youth (22).

2) A sample diagnosed with childhood-onset disabilities (pertaining to at least 50% of the total sample). Childhood-onset physical disabilities include cerebral palsy, spina bifida, muscular dystrophies, juvenile idiopathic arthritis, or other chronic physical disabilities that mainly affect movement and mobility, or children with special healthcare needs.

3) A focus on psychological problems, mental illnesses or symptoms of emerging mental disorders. These include anxiety, depressive, personality, psychotic and neurodevelopmental disorders such as autism, and their associated symptoms, as per

the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (23). In addition, studies were included if they focused on social or behavioral difficulties (with the addition of ADHD as a search term) as these were prevalent in the previous scoping review conducted by our team and could be a precursor to a mental illness diagnosis (4). There was also an addition of the personality disorder* search term to the previous strategy as it was listed by the stakeholder clinicians as a co-occurrence that they regularly came across in their work setting (see Table 1 for the full list of terms searched).

4) A focus on the organization of services, including if they reported a healthcare service delivery principle, model, or framework. Interventions were included if they described details pertaining to the context (e.g., which professionals are involved in the delivery).

5) Published in French or English (to accommodate authors' language fluency), between January 2000 and June 2021. While Lal and colleagues' scoping review (4) had a lower limit of the year 2007, there were major shifts in thinking about healthcare reorganization happening before then. The WHO produced a World Health report (24) emphasizing that mental health care had been neglected for too long and was crucial to address in order to support healthy populations worldwide. This problem was also evident on more local scales, including in the province of Quebec, Canada, coinciding with the review of provincial healthcare service delivery highlighting lack of access to, and coordination of, care (25). Shortly after, Quebec's Ministry of Health and Social Services mental health reform mandated a reorganization of services and improvement of primary mental health care (26). Therefore, the lower limit was determined to be the year 2000. The WHO has since highlighted the importance of integrating mental health into general health facilities,

Table 1: Medline search strategy including keywords

Physical disability (Physical* disab* or Physical* handicap* or Physically challenged or Physically disabled or Cerebral Palsy or Spina Bifida or Myelomeningocele or Meningocele or Spinal muscular Atrophy or Duchenne Muscular Dystrophy or Congenital Deformit* or Juvenile Arthr*).ab,kw,ti. Advanced search: exp cerebral palsy/ or exp spinal Dysraphism/ or exp Meningomyelocele/ or exp meningocele/ or exp muscular atrophy, spinal/ or exp Muscular Dystrophy, Duchenne/ or exp disabled children/
AND
Mental Health Disorder (Mental* ill* person* or Mental health* or Psychiatric diagnosis or Psychotic disorder* or Brief reactive psychosis or Schizoaffective disorder* or Schizophreniform disorder* or Psychosis or Schizophrenia or Schizophrenic disorder* or Personality disorder* or ADHD* or Bipolar disorder* or Bipolar depression or Manic disorder* or Manic state* or Mania or Bipolar affective psychosis or Anxiety or Depression or Substance* abuse* or Substance* related disorder* or Eating disorder* or ASD or Autism or DSM).ab,kw,ti. Advanced search: exp mental disorders/
AND
Young adults and adolescents (Child* or Adolescen* or Young adult*or teen*).ab,kw,ti. Advanced search: exp youth/ or exp adolescent/ or exp young adult/
AND
Healthcare services (healthcare service* or service delivery or service delivery model* or organization of service* or rehabilitation or rehab* or care or occupational therap* or physical therap* or physiotherap* or transitional care or transition or model* or framework* or guideline* or service integrat* or coordinat*).ab,kw,ti. Advanced search: occupational therapy/ or physical therapy/ or health services/ or adolescent health services/ or community health services/ or health services for persons with disabilities/ or mental health services/ or student health services/ or Transition to Adult Care/ or "Continuity of Patient Care"/ or "Delivery of Health Care"/

encouraging a shift away from historical psychiatric hospital-based approaches to treatment (27).

2.3.2. Exclusion criteria

The following exclusion criteria were applied: the article does not give sufficient and pertinent information to be analyzed; the document solely describes the prevalence of the conditions; the document describes services solely provided in the school setting (as they have distinct organizational structures and are funded and monitored by ministries outside of health and rehabilitation); the document does not describe the service program/model targeting both physical and mental health in enough detail. Reviews were not included, but their reference lists were hand-searched for relevant articles fitting the inclusion criteria. Non-peer reviewed articles (such as theses) were also excluded.

2.3.3. Process of study selection

The searches were imported into Endnote X7 and duplicates were removed. Articles were then uploaded to the Rayyan QCRI web application for the initial abstract screening to facilitate collaboration by enabling blinding of decisions to include or exclude between reviewers and labeling reasons for exclusion (28). First-level screening based on title and abstract was completed by two reviewers. They scanned 10% of the Medline articles independently and achieved 90% agreement on whether articles should be excluded, after which a discussion with a third team member helped to clarify the inclusion and exclusion criteria. The remaining articles were screened by one reviewer based on title and abstract, and reasons for exclusion after first-level screening were recorded. A subsequent full text (second level) screening of the retained articles was completed independently by two reviewers, and disagreements were resolved with discussion between the reviewers and additional members of the research team. Validation of all included articles and a random selection of 20% of excluded articles was completed by a third reviewer. Reasons for the exclusion of articles after full text screening were also recorded.

2.4. Charting the data

2.4.1. Data charting process

A flow diagram based on the PRISMA-ScR checklist guidelines (29) was completed to report the total number of sources of evidence screened, total number assessed for eligibility at each screening stage, reasons for exclusion, and total number of studies included in the final review (30, 31) as illustrated in Figure 1. A summary data extraction chart of the selected articles was created by the research team using Excel software and inspired by templates from previous scoping reviews (4, 21). Two reviewers independently extracted data, and the information was later merged and discussed together, and then again with a third reviewer. Only data pertinent to the main objectives of the scoping review was extracted (e.g., methods and results describing mental health or access or use of mental health services for youth with co-occurring disabilities).

2.4.2. Data items

Data selected for extraction included the study characteristics such as the author(s), year of publication, title, country, study population, purpose of study or objective(s), research design, and main findings pertaining to the three research sub-questions (including key principles, services, models, and frameworks; see Table 2).

2.4.3. Critical Appraisal of Individual Sources of Evidence

Scoping reviews do not typically include a critical appraisal of the evidence as they describe rather than analyze and report (18). Additionally, given the large variability of study designs and research approaches likely to be found in a scoping review, a critical appraisal is challenging, and it is unclear whether it has an impact on the uptake of results (16), therefore it was not undertaken in this review.

2.4.4. Consultation

Consultation with stakeholders brings valuable input with regards to the needs of youth, families, and clinicians as well as the clinical realities faced and their wishes for integrated health and rehabilitation services (24). A first meeting was held in consultation with three clinician stakeholders (from physical rehabilitation teams) to contribute ideas pertaining to additional literature to investigate and review the search strategies. In a second interaction, stakeholder consultants (one clinician and one youth) reviewed preliminary findings to ensure that the results were coherent and presented in a meaningful way, and the suggestions generated were integrated.

2.5. Collating, summarizing, and reporting the results

Counts, proportions, and tables were used to synthesize study characteristics such as country, study design, and study population characteristics (e.g., type of diagnosis, age). Findings related to mental health services among the study population were coded into themes of principles through inductive content analysis (32). Main ideas were extracted based on the 3 sub-questions (How are these services organized and delivered?; What are the key principles of existing models of service delivery?; What is known about the effectiveness of identified models and principles?), and keywords were determined based on if they were strategies or structural elements that facilitated service organization. These keywords were transposed into a table and organized into principles across articles by two team members independently, then compiled by grouping similar terms together. The key principles were described (with a comprehensive definition and examples from the articles for each) and were grouped into overarching categories of themes. The frequency of principles addressed across articles was tallied and presented in percentages. The table was then reviewed by two senior team members independently for validation, and consensus (on the key principles, themes, definitions, and their frequency) was reached through discussions with the whole team.

Table 2: Data extraction form with included articles

Authors, Title, Year, Country	**Study Population and Research Design**	**Purpose**	**Main Findings**	**Service Organization, Delivery & Needs**	**Key Components of Care and Models**
Bachmann et al. Integrating children's services in England: national evaluation of children's trusts 2009 UK	147 managers and professionals working in the children's trusts for disadvantaged children with complex needs (lead children's trust managers and directors of child services) Prospective observational	Describe and compare implementing programs integrating children's services in all 35 children's trust pathfinders (for 20% of children in England)	35 local areas were chosen as children's trust pathfinders to pilot coordinating and providing children's services. The national evaluation found that they had established a board for coordinating services, had a children and young people's plan, coordinated local and national budgets, wider scope of services, better coordination between agencies and outreach to communities leading to increased access to	Multi-agency collaboration, pooled finances, information-sharing systems, shared geographical boundaries	Multi-agency, interprofessional work, shared budgets, shared information, streamlined referrals, training in complex care, key workers to coordinate, enthusiastic local leaders

	mixed methods		services (improved outcomes for families)		
Berens et al. Transition to Adult care 2020 USA	Children and transition-aged youth with CP Descriptive, conceptual	Examine topics and provide relevant resources about the transition to adult-based health care for individuals with CP		Structured approach including mental health screening, discussion with youth about psychosocial considerations (and who should be involved in those discussions)	Start planning the transition early, partner with family, shared decision making, transition supports in an electronic medical record, individual plan, transition primary care first, care coordinator, and systematic approach to evaluating psychosocial components
Butler et al. Shared decision making (SDM) among parents of children with mental health conditions compared to children with chronic physical conditions 2015 USA	Parents of children 2-17: (1) with a chronic physical illness but no mental health condition; (2) with a common mental health condition but no chronic physical condition; and (3) with comorbid mental and chronic physical conditions. Retrospective cohort cross-sectional study	Examine how parent reported SDM varies by child health status (physical illness, mental health condition, and comorbid mental and physical conditions) and examine the impact of medical home care on these differences	Mental health stigma, negative parental perceptions about mental health treatment options and complexity inhibit parent participation in SDM in child mental health care, but medical home care can help.	Implementing components of the medical home care	Shared decision-making (including behavioural interventions), partnerships between parents and providers, decision aids, workshops for parents, skills training for clinicians
Colver et al. How well do services for young people with long term conditions deliver features proposed to	374 young people aged 14 years to 18 years 11 months who used child healthcare services in a range of UK locations, including 150	To describe whether service providers offer 9 beneficial features of transition services (from providers	The 9 services (age-banded clinic, meet adult team before transfer, promotion of health self-efficacy, written transition plan, appropriate parent involvement, key worker, coordinated team, holistic life-skills training, transition	Many services did not provide the proposed beneficial features. The only features that were experienced by youth with CP was appropriate parent involvement and promotion of health self-efficacy	Age-banded clinic; meet adult team before transfer; promotion of health self-efficacy; written transition plan; appropriate parent involvement; key worker; coordinated team; holistic life-skills training;

improve transition? 2018 UK	with type 1 diabetes, 118 with ASD and 106 with CP Longitudinal cohort + subsample interviews mixed methods	and youth with long-term conditions transitioning to adult services)	manager for clinical team) were not well provided (even when services said they did, youth reported discrepancy). Many were against the written transition plans (more paperwork)		transition manager for clinical team
Glassgow et al. Behavioral Health Disparities Among Children and Youth with Special Health Care Needs 2017 USA	Children and youth with special healthcare needs including chronic complex conditions Conceptual perspective	To describe mental, emotional, and behavioral problems and disorders and disparities in mental health services among children and youth with special healthcare needs		Objective mental health assessments not common	Early mental health screening and intervention, family-centered approach
Hanson et al. * Experiences of employment among young people with juvenile idiopathic arthritis: a qualitative study 2018 UK	13 interviews and 3 focus groups (n = 9,4,3) with young people (16–25 y) and adults (26–31 y) mean age 22 with JIA and interviews with (n = 9) health professionals Qualitative description	To explore expectations and experiences of employment among young people with JIA and the role of health professionals in promoting positive employment outcomes	Lower employment rate for those with JIA due to physical and psychological impacts of the disease like pain, which was not evident for employers, and they had anxiety with regards to disclosure (or not) regarding their disability and attitudes of their employer	Multidisciplinary team involvement in promoting employment, psychosocial interventions, and few mental health professionals available. Training for professionals on complex care is needed	Disease management, flexible convenient care, information, emotional and social support, skills training, advocacy
Houtrow et al.	CSHCN with disabilities (one age	To compare health services	CSHCN with disabilities had higher rates of need and	More unmet needs (including accessing mental health	Early mental health screening and

Profiling health and health-related services for children with special health care needs with and without disabilities 2011 USA	group 14-17 years) Secondary review of national survey data	characteristics for children with special health care needs with and without disabilities and examine factors associated with unmet need	unmet need than other CSHCN for specialty care, therapy services, mental health services, home health, assistive devices, medical supplies, and durable medical equipment, despite more severe health conditions	services) for those with disabilities, little coordination of care	intervention, medical home model
Lindsay et al. * Enablers and barriers of men with Duchenne muscular dystrophy transitioning from an adult clinic within a pediatric hospital 2017 Canada	16 participants (7 clinicians, 5 parents, 4 youth) with Duchenne muscular dystrophy Qualitative	To explore the enablers and barriers of clinicians, young men, and parents as they transition from an adult DMD clinic within a pediatric hospital to an adult health facility	Clinicians, youth and their parents experienced several enablers and barriers in transitioning to an adult health care center. Clinicians reported that structural factors (leadership and advocacy) supported the transition. Clinicians and parents found that the availability and continuity of care both enabled and hindered the transition. Parents and youth found adjusting to the model of adult care and accessing resources challenging. All reported difficulties maintaining mental health for youth with DMD transitioning to adult health care	Leadership, advocacy, inter-agency partnership, no cross-appointed clinician, holistic comprehensive model of care only in pediatrics, support for relationships, sexuality and depression was missing	Emotional support (peer and clinical), family involvement, inter-agency collaboration, cross-appointed clinician, funding, leadership advocacy, staff training
Park et al. Health care services and the transition to young adulthood: challenges and opportunities 2011	Adolescents with special healthcare needs in transition to adult care Conceptual review paper and national survey analysis of	To describe a role for integrated health care services in transition		There are gaps in access and quality of care for those with mental and physical health problems. There is inadequate coverage of needed adolescent mental health services, mental health services are put apart in separate systems, a shortage	Medical home model, interprofessional work, early screening, shared decision-making, training in complex care, self-management of chronic conditions (increasing responsibility), adequate insurance,

USA	key outcomes			of mental health professionals trained to serve adolescents	community-based, considers transitions
Roman et al. Analysis of Care Coordination Needs for Families of Children with Special Health Care Needs 2020 USA	Children and youth (age 0-21) CSHCN served by the Medical Home Initiative program at the Center (2682 participants) Analysis of service use data	To identify the diverse services needed/requested by families of CSHCN and identify the specific CC efforts for different diagnoses	The most frequently required sectors across the study population were education, financial, medical/dental, social connections, and advocacy. Children diagnosed with autism spectrum disorder had the highest needs across all sectors. Most CSHCN and their families use a substantial amount of CC time and effort to secure services from diverse sectors	Coordination of care that is patient- and family-centered, assessment-driven, team-based, with collaborations across multiple sectors, but many associated challenges (ex. lack of a universal release of information, incompatible electronic health record systems, and regulatory requirements)	Assessment, family-centered planning, implementation, evaluation, monitoring, support, education, and advocacy. Social workers as coordinators. Multi-agency cross-sector collaboration (health and education).
Scratch et al. Mental Health Care in Pediatric Rehabilitation Hospitals: A Biopsycho-social, Collaborative and Agency-based Service Integration Approach 2020 Canada	Models and guidelines (Canadian and international) relating to mental health services in pediatric rehabilitation hospitals Conceptual environmental scan of best practice guidelines	To describe a practical and holistic framework for pediatric rehabilitation hospitals to meet the health care needs of children and their families		Two-phase approach: build staff capacity for MH (referrals to internal MH team) to eventually have MH staff fully integrated into rehabilitation team	Interdisciplinary healthcare team, staff capacity, screening & identification of biopsychosocial factors, efficient referrals in-house to MH specialists, holistic care plan. Assessment of family function and consider assessing family mental health **Biopsychosocial, Collaborative, and Agency-based Service Integration Approach** inspired by biopsychosocial model of care, collaborative mental health model and psychiatric consultation service models
Tong et al. * Consumer Perspectives on Pediatric Rheumatology	37 parents and 13 adolescents aged 14-20 with JIA Qualitative	To elicit parental and adolescent perspectives on pediatric rheumatology care and	Five main themes were identified for the model and was extended to include consumer-focused concerns. A well-coordinated network of	Optimized service efficiency, transitional care, psychosocial support, informational needs, school-based	Integrated clinics, faster diagnosis, peer and sibling support, psychological services, family functioning, financial

Care and Service Delivery 2013 Australia		service delivery and to describe the impact of this process on a proposed model of care addressing pediatric rheumatology service delivery	services, timely and accurate information about the illness, treatment and support services, adequate pharmacy support, and school-based advocacy are proposed to be needed to ensure pediatric rheumatology services that are accessible and responsive to the needs of patients and their families	support, and advocacy	aid, access to information, school-based support, and advocacy
Van Dongen et al. A protocol for interagency collaboration and family participation: Practitioners' perspectives on the Client Network Consultation 2018 Belgium	23 clinicians working with children having complex healthcare needs in child disability or mental health care settings Exploratory	To develop and evaluate a standard protocol on the structure, content, and impact on interagency collaboration with family involvement based on the wraparound principles (collaborative planning process for individualized treatment plan)	Focus groups evaluated the CNC by eliciting practitioners' views on the structure, content, and impact of collaborative interagency protocols with family involvement. Thematic analysis revealed four core themes: (1) Empowering the child and the family; (2) Utilizing the strength of the collective; (3) Being considerate versus constructive a dilemma for participants in CNC; and (4) The structure of a protocol offers opportunities and challenges	Client Network Consultation 3 phases: preparation (conversation with child and parents to identify strengths, needs, cultural elements, and long-term goals), individualized care plan development (care manager for coordination) and implementation of plan and care team (progress reviewed and changes can be made to plan). The structure also includes strategies to make conversations between families and practitioners possible.	Inter-agency collaboration, care manager for coordination, wraparound principles (collaborative planning process with family for individualized treatment plan and discussions, strengths-based, adapts over time, culturally competent) **Client Network Consultation** - Phase 1 - Engagement & Team Preparation - Phase 2 - Care Plan Development - Phase 3 - Implementation of Care Plan
Warfield et al. Unmet need and problems accessing specialty medical and related services among	2220 families of children under 18 (mean age 8.9) with special healthcare needs 20-state survey	To extend what is known about parent reports of their child's need for specialty medical services, unmet need, and specific	Unmet needs were greater for older children and those with complex problems, and access to mental health and home services were less likely	High need and limited access to mental health services, need more outreach and screening	Care coordination, medical home, family-centered care

children with special health care needs 2006 USA		types of access problems among children with special health care needs			
Witt et al. Mental health services use among school-aged children with disabilities: the role of Socio-demographic, functional limitations, family burdens, and care coordination 2003 USA	4939 community-dwelling children with disabilities, ages 6 to 17 years Analysis of National Health Interview Survey Disability Supplements (NHIS-D)	To examine the use of mental health services and correlates of receiving services among community-dwelling children with disabilities	Only 41.8 % of those with disabilities and poor psychosocial adjustment accessed mental health services	Low access to mental health services, but providers involved in care coordination improved this. Engaging family and healthcare professionals in the process	Care coordination, multi-agency collaborations (family-health-education), family-oriented care, family and staff training, reimbursement for coordination of care services, having a coordinator
Woodward et al. * Assessing the health, functional characteristics, and health needs of youth attending a noncategorical transition support program 2012 USA	198 parents of youth with special health care needs (including CP 36%, SB 10%, mean age 17.5) attending the transition clinic for chronic conditions Local survey and comparison to national survey of CSHCN	To assess the health, functional characteristics, and health care service needs of youth and young adults with special health care needs attending a compre-hensive, non-categorical transition program	Youth attending our transition program had more functional limitations, poorer reported health status, different diagnosis distribution, and higher levels of needed health services. Few parents identified needs for other recommended adolescent preventive services. Noncategorical transition programs currently in development will need the staff and skills to address the multiple needs of a medically complex population of patients	There were unmet needs for durable medical equipment, therapies, and medical supplies. Overall a structured approach, service delivery model and skilled staff are required	Nurse care coordinators, social work care coordinators, multidisciplinary team, staff training for complex care

*Articles from earlier scoping review conducted by our team (4)

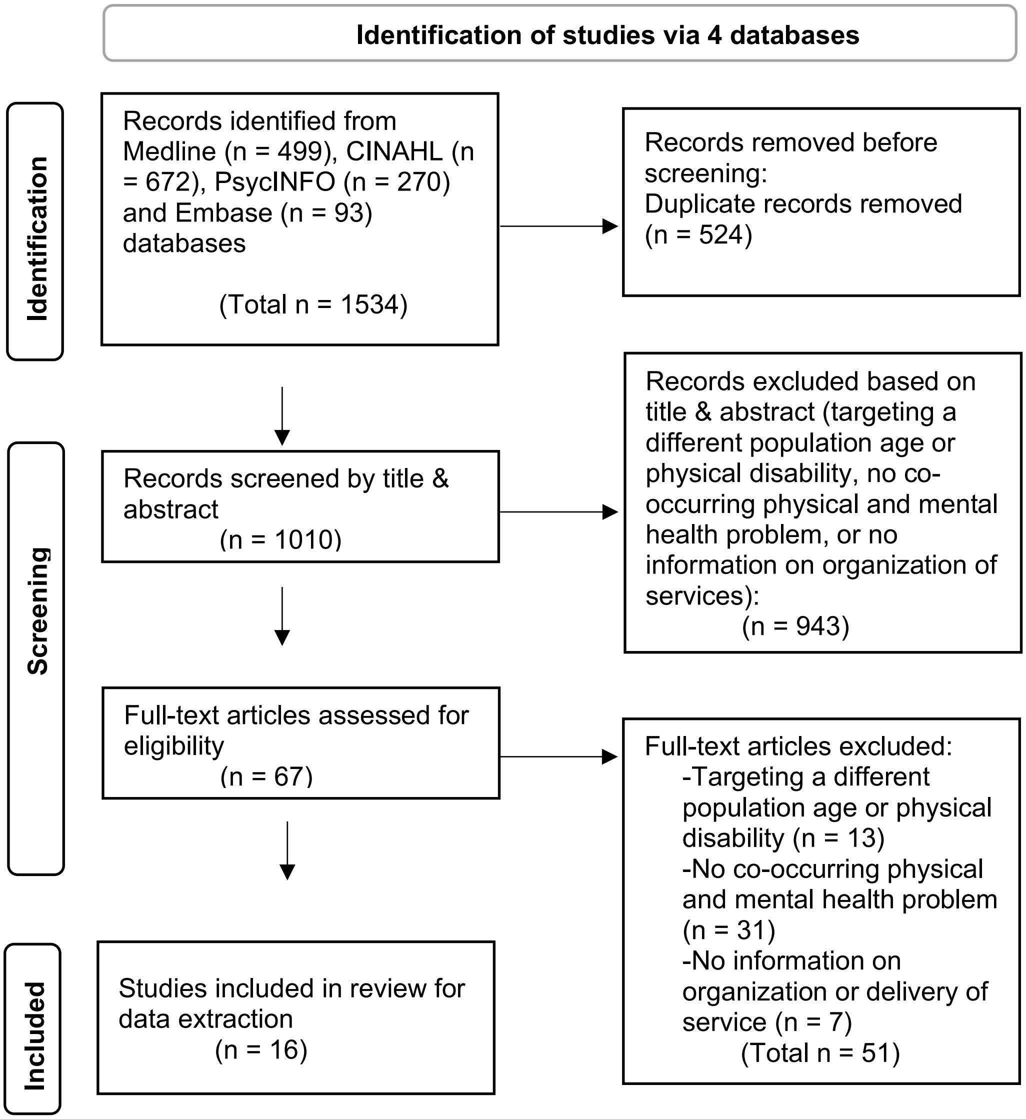
3. Results

3.1. Overview of studies reviewed

A total of 1534 articles were retrieved from the 4 databases, and 1010 remained after removing duplicates. After first-level screening, 943 articles were excluded because they did not meet the established inclusion and exclusion criteria (as they were either targeting a different population age or physical disability, had no co-occurring physical and mental health problem, or included no information on organization or delivery of services). Next, 67 articles underwent second-level screening, and 16 documents were selected for data extraction (33-48). The 51 articles that were excluded during the second-level screening were either targeting a different population (in terms of age or physical disability), did not explicitly address a co-occurring mental health problem, or did not include enough information related to the organization or delivery of rehabilitation or healthcare services. A PRISMA flow diagram is presented in Figure 1 (31).

Details pertaining to the 16 articles that were retained for data extraction are provided in Table 1. Articles originated from five different countries, with the largest proportion (9/16) published in the USA, followed by 3 in the United Kingdom (UK), 2 in Canada, 1 in Belgium and 1 in Australia. The 16 selected articles used a variety of designs, including 6 quantitative cross-sectional studies, 4 qualitative studies, 4 conceptual papers and 2 mixed methods studies. The largest portion of the articles focused on a general group of youth with complex or special healthcare needs or a mix of childhood-onset physical conditions (including cerebral palsy, spina bifida and muscular dystrophy; n=11), followed by study populations consisting entirely of youth with cerebral palsy (n=2), juvenile idiopathic arthritis (n=2) or muscular dystrophy (n=1).

Figure 1: PRISMA flow diagram of included articles



3.2. Service organization and delivery approaches

When looking at how services were organized and delivered (research sub-question 1), several (n=6) articles (33-35, 43-45) described what was currently being done in practice to address the high need for mental health services. These will be detailed further below. In contrast, most (n=10) articles highlighted the lack of structure, organization, and access, and focused on recommending future directions to address pressing needs. Some reported that objective mental health assessments were not commonly used with youth with chronic conditions or special healthcare needs (36, 37), and that more outreach and screening was needed in populations who already have diagnosed physical disabilities (46, 47). Others highlighted missing structural elements such as lack of a universal release of information on charts, incompatible electronic health record systems across sites, regulatory requirements (42) and structured approaches (48) that brought challenges when attempting to share information between collaborating centers wanting to work efficiently. Gaps in access and quality of mental health care for those with co-occurring mental and physical health problems were prevalent, and the various healthcare services needed were seldom coordinated for populations with complex healthcare needs such as seeing a psychologist or receiving therapy (39, 41). Comprehensive organization of care was even less evident after the transition from pediatric to adult settings, and support for relationships, sexuality and depression was missing altogether (40). Overall, an inadequate coverage of needed adolescent mental health services was expressed, either being made available in completely separate systems which were hard to access (i.e., not where the youth was already receiving care), or not at all available (41).

3.3. Formal models of service organization and delivery

Only two formal models of service delivery for co-occurring physical and mental health problems were described across the retained articles (43, 45). The first model found through this review was the Biopsychosocial, Collaborative, and Agency-based Service Integration Approach, developed in Canada and presented in a conceptual paper by Scratch and colleagues in 2020 (43). It described a 2-phase process to include and fully integrate psychiatry services within a pediatric rehabilitation hospital treating developmental and other chronic disabilities. Recommendations from clinical guidelines and national strategy documents were combined to develop a service integration approach built into a multidisciplinary rehabilitation setting with clinicians from varied backgrounds (ex. psychology, physical therapy, occupational therapy, speech language pathology, social work, nursing). The first phase of the model targets building staff capacity around recognizing and treating mental health needs in children and their families including structured cross-referral from the rehabilitation team to a newly formed internal mental health team who can provide integrated treatment recommendations and support the rehabilitation team in providing comprehensive care. Phase II focuses on creating and evaluating a comprehensive model of health care provision where the capacity of staff on the rehabilitation team in relation to mental health and psychosocial needs increases, and mental health specialists are fully integrated as interdisciplinary rehabilitation team members. The second model of service delivery found through this review was the Client Network Consultation (CNC) model developed in Belgium by Van Dongen and colleagues in 2018 (45). Described in a qualitative paper, specialist clinicians from different teams (including child welfare, psychiatry, and rehabilitation) participated in 3 focus groups to inform and evaluate an interagency collaboration in mental health care for children with complex healthcare needs. It includes three phases (engagement and team preparation, care plan development, and implementation) based on the wraparound principles (including collaboration and cultural competency) and details a collaborative planning process with staff, families, and their support network to create an individualized strengths-based treatment plan which can adapt to needs over time. They came up with four core themes (Empowering the child and the family; Utilizing the strength of the collective; Being considerate versus constructive, a dilemma for participants in CNC; The structure of a protocol offers opportunities and challenges) which illustrate clinicians' perspectives towards putting the model into practice.

Figure 2: Key principles across articles

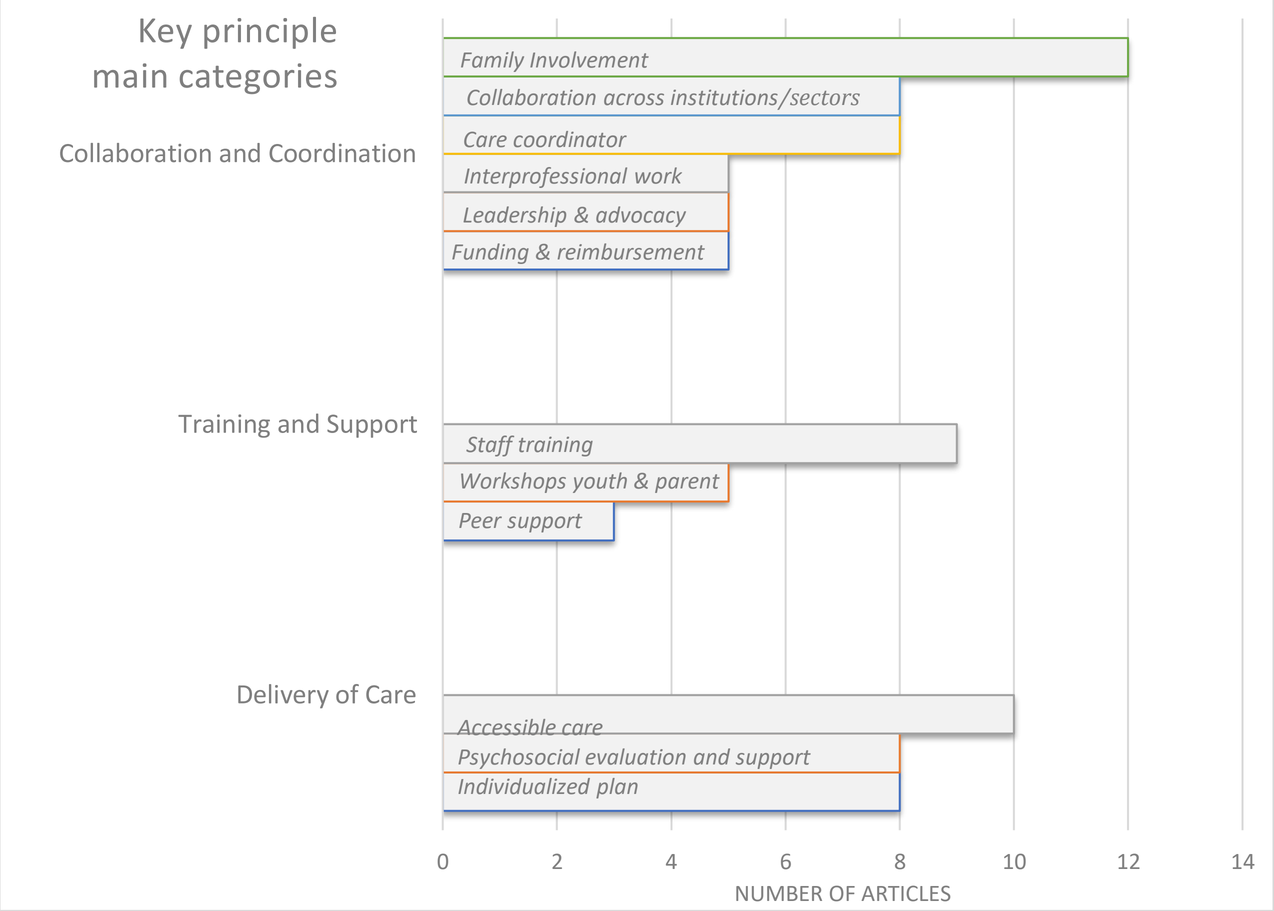


Table 3: Key principle themes and subthemes with definitions across articles

Theme	Key Principle	Definition	Articles which included the key principle
Collaboration and Coordination	Family involvement	Involving the family and youth in shared decisions about care, consulting with all stakeholders	(34-37, 40-47) n= 12
	Collaboration across institutions/ sectors	Collaborating across several institutions spanning different sectors (i.e., education, health, and social services) and settings (home, school, community)	(33, 34, 38, 40, 42, 44, 45, 47) n= 8
	Care coordinator	Also referred to as a key worker, a designated person who coordinates with family, youth and treating team, familiar with the case and with relevant resources	(33, 34, 36, 40, 42, 45, 47, 48) n= 8
	Interprofessional work	Team including different types of healthcare professionals working together	(33, 36, 41, 43, 48) n= 5
	Leadership and advocacy	Having someone or a group of people advocate for changes to improve services	(33, 36, 38, 40, 44) n= 5
	Funding allocation and service reimbursement	How money is allocated to fund different programs and services, whether it is covered by insurance	(33, 40, 41, 44, 47) n= 5
Training and Support	Staff training	Workshops for clinicians so they feel well prepared to work with clients having mental health problems	(33, 35, 38, 40-43, 47, 48) n= 9
	Workshops for youth and parents	Information delivered in group settings to help understand the complexities of care and be better prepared to make decisions	(35, 36, 38, 41, 47) n= 5
	Peer support	Access to support and guidance from others with lived experience	(38, 40, 44) n= 3
Delivery of Care	Accessible care	Having flexible and convenient care provided in a customized way to adapt to client needs, working towards integration	(33, 34, 36, 38, 39, 41, 43-46) n= 10
	Psychosocial evaluation and support	Formal evaluations to assess mental health, diagnose	(34, 37, 39-44) n= 8
	Individualized plan	Having a formal plan established and written out with team, considering culture and personal values/beliefs	(33-36, 41, 43, 45, 46) n= 8

3.4. Key principles for service organization and delivery

Key principles within these two existing models of service delivery as well as the other included articles were extracted to address research sub-question 2. Across the 16 articles, there were 12 key principles that were synthesized via qualitative content analysis and grouped into 3 main categories or themes, namely: Collaboration and Coordination; Training and Support; and Delivery of Care (see Table 3). Each article encompassed between 2 and 8 key principles spanning the different categories. As for the two models described above, the Biopsychosocial, Collaborative, and Agency-based Service Integration Approach included 6 and the CNC model included 5 key principles.

<u>Collaboration and Coordination</u>: There were 6 key principles that fit into this first main category, namely *Family involvement (present in 75% of articles); Collaboration across institutions/sectors (50%); Care coordinator (50%); Leadership and advocacy (31%); Funding allocation and service reimbursement (31%);* and *Interprofessional work (31%)*. The key principle of *family involvement* meant involving the family and youth in decisions about their care, thus ensuring consultation with all key stakeholders. Twelve articles discussed the importance of regular family involvement and integration into the team, making it the most common principle across articles (34-37, 40-47). Included in this are the concepts of shared decision-making, where families are true partners in the process (34, 35, 41) and family-oriented care (36, 42, 46, 47). One example of shared decision-making, which included discussing treatment options, providing information and opportunities to ask questions, and exploring parents' ideas of management, was presented in a retrospective cohort cross-sectional survey by Butler and colleagues (35),

but they found that it was much more complex to put into practice for those with mental and physical comorbidity versus just one or the other. In a quantitative study by Roman and colleagues (42), pediatric care coordination was described as a patient- and family-centered activity designed to meet the needs of youth while improving the caregiving capabilities of families as a whole, making their involvement crucial.

Collaboration across institutions related to (informal or formal) partnerships between several institutions, sometimes even spanning beyond healthcare into different sectors (i.e., education and social services) and settings (home, school, community). Eight articles pertained to this key principle and highlighted how coordination was crucial (33, 34, 36, 40, 42, 45, 47, 48). For example, this was done by building collaborations between the family, medical, psychological, and educational systems of care to improve access to services (47), or by creating inter-agency partnerships between different pediatric and adult healthcare settings to facilitate a smoother transition during this particularly precarious time for youths’ mental health (40, 45). Actions such as sharing clinical information across healthcare sites (33, 38, 42, 44) and using a transition registry when moving to adult care (34) supported these collaborations.

The key principle of *Care coordinator*, also sometimes referred to as a key worker (33, 36) or cross-appointed clinician (40), was described as a designated person who serves as an easily accessible point of reference, coordinating with the family, youth and treating team, and being familiar with the case and with relevant resources. Eight articles mentioned the use of a care coordinator in their settings (33, 34, 36, 40, 42, 45, 47, 48), with two specifying that nurses (48) and social workers (42, 48) were particularly well-suited for this position. Many articles specified that the role was filled by clinical providers (34, 40, 42, 47, 48), while others held a management position (45). Colver and colleagues (36), in a mixed methods study following 374 young adults with disabilities longitudinally from different services as they transitioned to adult care, discussed the role of a key worker as one of nine proposed beneficial features. However, only half of the young adults confirmed experiencing this feature when the service stated that it was provided (which was only in 43% of services across conditions, and 15% for those receiving services for cerebral palsy specifically).

The principle of *Leadership and advocacy* pertains to a person or a group of people who advocate for changes to improve services. Five articles described leadership qualities or actions that contributed to improved care, including the importance of advocating when barriers to accessing care were present (33, 36, 38, 40, 44). In a large mixed methods study spanning services across the UK, Bachmann and colleagues (33) highlighted the necessity of enthusiastic local leaders to bring about change, in addition to local cultures and experiences of cooperation that could overcome organizational and professional barriers.

The principle of *Funding allocation and service reimbursement* was addressed in five articles (33, 40, 41, 44, 47). It included how money is allocated to fund different programs (40) and professionals, such as ensuring adequate reimbursement for providers who actively coordinate the care of children with disabilities as found in an American national survey of 4939 children and youth with disabilities (47). It also examined whether services are covered by insurance (41, 44) which is of particular importance in the USA. Shared budgets were a strategy that allowed for better coordinated care across different sites within the healthcare system and reduced barriers to inter-institutional collaboration as identified by 147 managers and policymakers in the UK (33).

Finally, *Interprofessional work* involved being followed by a healthcare team made up of different types of professionals working together. Five articles explicitly stated the importance of interprofessional work (33, 36, 41, 43, 48), and encouraged increased capacity in mental health screening and identification of biopsychosocial factors as well as the possibility for efficient referrals to mental health specialists in-house. Three teams conducted large studies in the UK (33, 48) and the USA (36) and discussed the integration of specific elements of interprofessional work, highlighting that many were not well integrated into practice. Only about half (56%) of young adults (n= 304) in the American study reported being adequately followed by a coordinated team of professionals (36).

Training and Support: There were 3 key principles that related to the category of training and support resources for youth, families, and the care team, including *Staff training (56%); Workshops for youth and parents (31%);* and *Peer Support (19%).* Nine articles brought up *Staff training*, which in the context of this review specifically referred to workshops for clinicians to enhance their skills to work with clients having mental health problems, in contrast to strictly physical rehabilitation (43). These workshops should be provided in the workplace to facilitate team training (33, 34, 40, 42, 47, 48). Park and colleagues (41) described the importance of having training in areas such as primary care and new models of interdisciplinary mental and behavioral health to help address the shortage of clinicians trained to serve adolescents. Hanson and colleagues (38) echoed this, stating that there were unmet training needs for professionals in the UK working with a population having juvenile idiopathic arthritis (JIA) regarding childhood-onset chronic conditions and their impacts on their mental health and emphasizing that training on complex care was needed.

Workshops for youth and parents encompassed information provided in various forms (such as in-person group sessions) to better inform service users and their families about the complexities of care so they could be better prepared to make decisions. Five articles suggested that workshops for youth, such as holistic life skills training (36), and parents (35, 47) were important. Disease self-management for chronic conditions was seen as useful and empowering, for example in a group of youth living with JIA (38). A conceptual paper by Park and colleagues (41) highlighted that adolescents with special healthcare needs should assume increasing responsibility to manage their health with appropriate clinical guidance, and that providing confidential care also enabled development of skills in self-disclosure, especially for sensitive topics that frequently emerge during adolescence, such as sexuality and substance use.

Finally, *Peer support* was described as having access to support and guidance from others with similar lived experience. Three articles, based on qualitative investigations, encouraged peer support groups for youth with disabilities to help them navigate the associated complexities (38, 40, 44). To illustrate, in interviews with 16 clinicians, parents and youth with Duchenne Muscular Dystrophy in Canada, all participants reported the difficulties of maintaining mental health for these youth transitioning to adult health care and encouraged peer support groups to help deal with isolation and depression (40). Similar results were found regarding the need for emotional and social support from peers when interviewing 37 parents and 13 adolescents with JIA in Australia (44), and through interviews and focus groups with 38 clinicians and young adults with JIA in the UK (38).

Delivery of Care: Finally, there were 3 key principles pertaining to the elements of care delivery, including *Accessible care (63%); Psychosocial evaluation and support (50%);* and *Individualized plan (50%)*. *Accessible care* is related to having flexible and convenient care provided which could be adapted and customized to the client's needs, working towards a seamless integration of services. Ten articles described how accessible care could be provided (33, 34, 36, 38, 39, 41, 43-46), with 3 suggesting a medical home which brings the services to the family directly and facilitates partnerships with parents (39, 41, 46). Based on qualitative findings from focus groups conducted by Van Dongen (45), care must be strengths-based, able to adapt over time, and culturally competent. Flexible healthcare scheduling was suggested by youth with JIA receiving services in specialized programs throughout UK hospitals to ensure convenience for the client so they could attend their various appointments while still maintaining their regular routines such as going to school (38).

Psychosocial evaluation and support pertained to formal evaluations to assess mental health and screen for, and diagnose, psychiatric disorders early. Eight articles reported on the importance of specialized psychosocial care, and many emphasized early screening to address concerns before they worsen (34, 37, 39-44). Tong and colleagues

(44), via interviews and focus groups, brought to light consumer (adolescent and parent) views on how combined clinics for integrated care could lead to a faster diagnosis of mental illness in a population followed in pediatric rheumatology clinics in Australia. Glassgow and colleagues (37), in their conceptual paper, stated that early identification in children and youth with special healthcare needs across the US by way of integrated screening into primary care followed by mental health intervention is key.

Lastly, the *Individualized plan* was described as having a formal plan written out in collaboration with the clinical team, user and family which considers the client's culture and personal values/belief systems. Eight articles described how they included formal individualized plans in their care delivery built around the needs of the child and their family (33-36, 41, 43, 45, 46). The use of decision aids (in-house guidelines used to help plan treatment) was suggested by Butler and colleagues (35) in a national survey of over 21,000 parents of children with physical and/or mental health problems across the USA. Having a formal plan in place to organize care was particularly important when anticipating transitions from the pediatric to adult care settings (36, 41). Considering local cultures (33) and providing culturally effective care (46) were also emphasized when planning care delivery for children having complex healthcare needs.

3.5. What is known about the effectiveness of identified models or principles

Very little information was found about the effectiveness of identified models and principles (research sub-question 3), with only three articles mentioning that efficacy was not yet assessed. The CNC model developed by Van Dongen and colleagues (45) is the only study in this review that evaluated (by qualitatively examining) the experiences and perspectives of clinicians on implementing a model (or key principles) using focus group methods. This was done with specialist clinicians who had implemented it in their clinics, eliciting their views on the structure, content, and impact of collaborative interagency protocols with family involvement. They mentioned several strategies (including making tasks and expectations clear, creating a positive and structured environment, working collaboratively with specialist colleagues) as well as challenges (such as navigating time constraints to put the protocol in place, being transparent with the child and family when discussing delicate matters, and accepting their professional limitations).

4. Discussion

This review generated key principles for organizing health and rehabilitation services for youth with a range of physical disabilities who also presented with mental health or behavioral challenges.

4.1. Principal Findings

Only two models of service delivery were described across the retained articles, this being despite the acknowledgement that formal models are important guides for organizing complex care delivery (48). Several of the principles generated in this synthesis were present within the two formal models of service delivery. Both included the principles of *Family involvement, Individualized plan,* and *Accessible care.* The model proposed by Scratch and colleagues (43) additionally included *Interprofessional work, Staff training,* and *Psychosocial evaluation and support*, whereas the CNC model (45) also included *Collaboration across institutions/sectors* and *Care coordinator*. The 12 key principles described in this paper can be used in practice in varying combinations and can be drawn upon to tailor to specific clinical contexts. They can also guide the development of models of service organization and delivery that are relevant for various settings. Some of the principles described are well known and well documented in the literature, such as *Care coordinator* (49), while others are more unique and worth reflecting upon further, as detailed below.

Staff training was prevalent as a principle, highlighting that many clinicians felt unequipped and unprepared to address mental health problems when working with youth having physical disabilities. Needed healthcare services such as receiving therapy were seldom coordinated for populations with complex healthcare needs (39, 41). This can be partially explained by a finding from Hanson and colleagues' article (38) describing the low availability of professionals with mental health training working in physical rehabilitation settings with youth, for example those with JIA. The ability to identify mental health problems is crucial to early intervention, though little information is available in the physical rehabilitation and health services literature to guide mental health training options for their multidisciplinary teams. Whitehurst and colleagues (50) identified this gap in a similar population and created an in-house, 2-day training program (including information on mental health diagnoses, assessments, interventions, etc.) offered to all frontline staff in a residential school in the UK catering to young people between the ages of 6 and 19 with severe intellectual disabilities. Staff must have the necessary knowledge and screening or assessment tools and feel competent in identifying and addressing emerging mental health problems (or referring to other professionals) so that the youth and their families have direct access to required services (51).

Accessible mental health services are an essential component to comprehensive care, especially considering growing needs in youth mental health (52). The findings from this synthesis complement what was found in a previous scoping review (4), namely the 4 themes regarding access to services. Indeed, studies from that review found that few participants having mental health problems were receiving care for it, and there was a lack of or delay in help seeking and receiving care influenced by stigma, which in turn contributed to feelings of anxiety and impacted decisions to disclose their disability to others (4). In addition to these noted challenges, flexibility of services that could be delivered at a convenient time and location for the youth and their family (either integrated into the services they were already receiving or provided in the community or at home) was recommended. Adaptability over time to consider changing contexts and realities was also suggested.

The importance of family involvement is well-known in rehabilitation literature (53). Twelve of the retained articles emphasized the importance of family involvement, making it the most common key principle found in this review. Beyond being present for the care of their child, a recent scoping review confirms that families of children with neurodisabilities play a key role in delivering interventions to address comorbid mental health or behavioral problems (54), though training programs may vary in their aims, degree of involvement, content, and delivery methods. The associated burdens on family members should therefore be considered. The family and caregivers also need mental health support and services, delivered as a component of services for young people with disabilities (55). In addition to peer support for youth with physical disabilities, which is acknowledged by clinicians and youth as a potentially helpful resource and a way to reduce isolation (4, 55), peer support for their families is also very helpful. A recent study looking at families of children with neurodisabilities found that peer support (combining self-reflection and emotional expression) provided empathy and bridged communication between families and service providers when navigating complex healthcare systems which had a significant positive impact (56). Indeed, parents from included studies in this synthesis often felt overwhelmed and helpless, particularly when their child experienced severe depression, and emphasized the importance of accessing psychological intervention for themselves (44). Providing support to families can therefore ensure that they are capable of being there and forming a stronger support network for their child throughout the journey.

The literature included in this synthesis mainly discusses needs for better organization and delivery of health and rehabilitation services. Therefore, the challenges associated are quite clear, but the solutions are less obvious as there are many factors to consider. Every institution works in its own way, even within the same country, province, or city (57). Organizational culture emerged as important to consider in terms of cooperation, trust and values within, and across sites (33), and would be worth exploring further. Examining interagency collaborations and their dynamic interactions can help provide a better picture of the complete system of care. At the individual level, it is important to look at frequent users of rehabilitation services from a holistic perspective in order to address all of their needs over time (58). Having *individualized plans* that are not only holistic and created collaboratively with the user and family, but also accessible to relevant professionals and teams within and across organizations as necessary (such as via electronic records) could help with a better continuity of care. Different programs and institutions are encouraged to collaborate and communicate (such as with the help of *care coordinators*) to avoid gaps in care and complement each other with their strengths and specialties. It may also be useful to reduce the silos and have more flexibility within each program, not solely focusing on physical rehabilitation aspects of a disorder but instead having programs for youth with physical disabilities run by a *multidisciplinary team trained* to address multiple facets and challenges that come with living with a disability, which would include having mental health specialists integrated into the rehabilitation teams (43). The WHO is currently developing a ‘Package of Rehabilitation Interventions’ which will focus on evidence-based strategies organized by age that will aid health ministries in planning, budgeting, and integrating rehabilitation interventions into health systems (59). Better integration of care will be critical to achieving universal health coverage and reaching as many individuals and families as possible to support health and wellbeing (12).

4.2. Identified gaps in current knowledge and future directions for research

As very few articles described formal models of organization and delivery of services, this is an area for continued research. Intensive services and treatment programs for this population are also uncommon given the complexity and diversity of the target population, and their effectiveness has not been previously reported. However, some literature is beginning to emerge on this topic. An American study recently described an intensive day treatment program for children with co-occurring chronic medical disease and emotional problems with 175 children followed over 3 years and reported significant improvements in depression and anxiety among others (60). A research protocol was also recently published in Canada on the impact of a transition readiness program for youth with physical health conditions in the presence of a mental health comorbidity, to explore the experiences of adolescents and young adults with co-occurring conditions as they exit pediatric services (61). More studies such as these with a focus on mental health are needed to advance rehabilitation research.

Effectiveness of current and future models and principles of service organization and delivery should also be assessed across different contexts. Although the principles discussed in this synthesis were not directly tested in their respective articles, they are based on previous research in the field. Now that co-occurrence of mental health problems and physical disabilities is acknowledged, the described principles can be evaluated with this complex population specifically.

4.3. Strengths and limitations

Strengths of this review include revealing a true gap in this specialized area via a comprehensive search strategy across multiple databases, systematic data extraction, clear eligibility criteria and focus on the organization of services for co-occurring physical disabilities and mental health problems. However, the heterogeneity in methodological, participant, outcomes and results resulting from the review's inclusive approach diminished the potential for meaningful comparisons across articles. The targeted population was youth with childhood-onset physical disabilities that were identified as having primarily motor problems, though broadening our scope to include other disabilities (e.g., neurodevelopmental) could have yielded additional results to better understand the landscape of complex rehabilitation service delivery for co-occurring problems. Furthermore, we included only scientific studies, while gray literature could have also provided rich data. Finally, most of the studies were carried out in high-income settings, while up to 80% of people living with disabilities reside in low- and middle-income countries (62) for which most evidence lacks representation and generalizability, and which may not be feasible in resource-limited settings. This also implies that there may be sociocultural influences on attitudes regarding mental health and service trajectories that are yet to be explored.

5. Conclusion

This scoping review maps the current literature and synthesizes emerging principles to guide improved service delivery for this population as well as models of collaborative healthcare delivery described in the literature. A genuine disconnect between empirical evidence on prevalence of mental health problems among those with physical disabilities and the available services for youth with complex needs was observed, emphasizing an urgency for increased inclusion in clinical research. The findings from this review may lead to highlighting key attributes to include in a proposed model of service delivery (for replicability), with the potential to improve access and overall efficiency of services for youth across Canada and abroad, as well as inform the development of new programs to support these complex cases. This scoping review also identifies several gaps in the current literature (including formal integrated models of care and their effectiveness) that can inform future lines of inquiry in health and rehabilitation research.

6. Protocol registration and publication

The current protocol was registered online in Open Science Framework in December 2021 (19). Preliminary results were presented at national (Canadian Association of Occupational Therapists) and international (European Academy of Childhood Disability) scientific conferences in May 2022.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author/s.

Author contributions

ST conceived the idea for this scoping review building on the team's previous work, and its methodology, implementation and reporting were decided on in collaboration with SL and DA (co-senior authors). ST, SL and DA wrote the initial protocol, and all authors contributed to its finalization. Preliminary data collection was conducted by ST and LX. All authors contributed to the article and approved the submitted version.

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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.

Publisher's note

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Chapter 4: Bridging Manuscripts 1 (scoping review) and 2 (chart reviews)

The first study of this thesis, presented in Chapter 3, sought to address Objective 1: to identify existing evidence and knowledge about health and rehabilitation services and models of service delivery for youth with co-occurrence of childhood-onset physical disabilities and mental health problems through a knowledge synthesis (scoping review of scientific literature). Following the analysis, members of the consultation team (including a youth with a complex physical disability, a mother of a youth with a physical disability and a rehabilitation clinician) provided feedback on a summary of the results and an infographic, which was circulated thereafter on several platforms to disseminate findings and spread awareness on the gaps in the literature (see Appendix 1).

Indeed, the scoping review identified several gaps (such as the need to develop models for collaborative healthcare delivery for this population and evaluate their effectiveness) as well as 12 key principles to guide service delivery (organized into collaboration and coordination, training and support, and delivery of care categories). It concluded that additional research should highlight current services and treatment programs for youth with physical disabilities and mental health problems despite the complexity and diversity of this population group. Before building on the identified key principles, it is important to have a better understanding of current practices within the local context (in this case, Greater Montreal) as policies vary across regions and may affect organization and provision of services. Contributing additional data to the small body of literature on this topic by identifying specific practice needs can guide the design of appropriate interventions to address clinical priorities (for example, by offering additional training in mental healthcare provision to rehabilitation clinicians). Such knowledge translation activities would ensure that the findings are shared with relevant settings and implemented within the local rehabilitation community.

Chart reviews can be a useful tool to provide a snapshot of the current reality. This methodology can bring to light concrete information about what is currently done in a clinical site (or across several sites). We therefore decided that this would be an appropriate starting point to delve into the local rehabilitation practices pertaining to our population of interest and address Objective 2: to describe documented interdisciplinary rehabilitation practices and procedures. The knowledge synthesis findings inspired the content of the data extraction sheet by proposing pertinent variables to extract. This chart review study is presented in Chapter 5.

Chapter 5: Manuscript 2, Mental health practices in rehabilitation for youth with physical disabilities: A chart review study

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Abstract

Purpose: Evidence on co-occurring mental health problems in youth with physical disabilities is growing, however how services are provided remains unclear. This study examined current interprofessional rehabilitation practices for physical and mental health services. Methods: Youth (aged 15-24) followed for a physical disability that had mental health problems were identified. Chart reviews were used to identify practices. Mental health-related diagnoses/symptoms, assessments, goals, interventions, and referrals were extracted for inductive content analysis. Results: Sixty charts were reviewed. Mental health problems included anxiety (n=53), depression (n=25), neurodevelopmental (n=19) and personality disorders (n=8), often (n=36) citing more than one. No mental health assessments were found, and in 43%, no goals or interventions were evident. Relevant goals (n=98) targeted emotional management, autonomy/communication of needs, acceptance of physical condition, socialization, routines/energy levels, school/work supports, and leisure/calming environments. Interventions (n=104) included emotional management, formal individual/group therapy, links with external supports, routines/activities, reflection/acceptance, and school/work supports. Mental health services were received in-house (n=24) and/or externally (n=30), plus 18 referrals pending and 14 not referred. Conclusion: Many had more than one mental health problem, suggesting the complexity of their condition. While some mental health goals/interventions are documented, problems may often not be reported or addressed in this context.

Key words: rehabilitation, mental health, multidisciplinary practices, integrated care, co-occurrence, chart review

Body

Introduction

Youth with physical disabilities receiving multidisciplinary rehabilitation services (e.g., physical and occupational therapy) often present with complex needs, and increasing evidence attests to co-occurrence of mental health problems (1-7). Recent scoping reviews revealed symptoms of depression and anxiety were frequent in adolescents with physical disabilities (6), though models of service organization to address them are not well-established (8). Little is known about whether mental health is an integral part of the physical rehabilitation care plan (8, 9), particularly pertinent following the COVID-19 pandemic (10, 11).

Youth aged 15 to 24 (12) should be considered top priority for receiving mental health care as this is when symptoms often emerge (13). Over 75% of mental illnesses begin before the age of 25 (14), a timeframe encompassing a challenging transition to adulthood (15). However, mental health services are frequently accessed long after the initial onset, if at all (16). Though awareness about this is increasing, integrated care within an organization is seldom common practice (8, 17, 18). A study surveying rehabilitation therapists working with children with cerebral palsy found that while physical aspects were well-addressed, emotional functions were not readily targeted (19). Another study examining rehabilitation charts in inclusive schools found that attention was directed to participation, but not mental health needs (20). Participation levels are often low for youth with physical disabilities (due to factors such as stigma, lack of inclusivity and limited resources to address specific needs), resulting in decreased opportunities to socialize and engage in meaningful activities, which can in turn contribute to the development of mental health problems (15).

Current clinical guidelines and Canadian strategy documents support the integration of mental healthcare professionals within physical rehabilitation settings to meet youths' needs more holistically as mental health may have significant impacts on health outcomes (17). However, evidence on rehabilitation care provision for co-occurring problems is lacking yet necessary to better understand clinicians' practices, clinical realities, and needs (8). How rehabilitation practices address mental health needs of youth with physical disabilities, including what clinicians do within organizational limits, whether they have adequate training, skills, supports and tools to target aspects of mental health and know when and where to refer, and how youth navigate the system, remains unclear. Additionally, there is a paucity of studies and guidelines on the implementation of mental health supports for the pediatric to adult care transition (21, 22). A service integration pathway proposing to embed mental healthcare into pediatric rehabilitation hospitals can inspire new directions but has yet to be evaluated (17). The purpose of this study is to portray documented interdisciplinary mental health practices and procedures in several physical rehabilitation centers to begin investigating practices for co-occurring conditions. Specifically, it describes current rehabilitation practices in terms of assessments, goals, interventions, and referrals pertaining to mental health. This will allow for a better understanding of present service gaps to inform how rehabilitation practices and procedures can be improved so youth can receive comprehensive care where they are followed.

Methods

Study design and sampling procedure

An exploratory cross-sectional chart review study was conducted following 9 steps (see Table 1) of chart review methodology (23). Chart reviews are practical, reliable, inexpensive and involve minimal response bias (23, 24). A large Canadian city was chosen to access major centers providing rehabilitation services (25). Organizations were approached if they were public pediatric or adult rehabilitation centers providing out-patient services for transition-age youth with chronic physical disabilities (e.g., cerebral palsy, spina bifida, juvenile arthritis or degenerative conditions). Rehabilitation programs are serviced by multidisciplinary teams (i.e., physical therapists, occupational therapists, special educators, psychologists, social workers), organized by age group or disability category (25, 26). We excluded recruitment from in-patient or acute care services (due to short-term follow-up) and private healthcare services (that are organized and funded differently).

Charts were identified by clinicians, clinical coordinators, and managers from 5 organizations, thereby ensuring diversity. Organization characteristics were as follows: one physical rehabilitation program within a specialized school setting for children ages 4-21 including occupational therapy, psychology and social work; one transition program for youth 15-25 within a pediatric rehabilitation center including occupational therapy and social work; one transition program for youth 16-25 within an adult rehabilitation center including occupational therapy, social work, psychology; one physical rehabilitation center for adults 18 and over (including musculoskeletal programs) with access to social work and psychiatry; and one physical rehabilitation center for adults 18 and over (including

Table 1. Gearing et al.'s 9 steps of chart review methodology (23)

Steps	Action taken
1. Conception	We (A1, A2, A4) designed the research question, incorporated clinical judgement and experience in pediatric rehabilitation and youth mental health throughout discussions and consulted with others (A3, consultation committee).
2. Literature review	We searched several databases (Embase, PsychINFO, CINHAL, Medline) to find out about prevalence of physical and mental health problem co-occurrences as well as models of service to address them, and published the findings (6, 8).
3. Proposal development	The research protocol was developed and written by A1, A2 and A4.
4. Data abstraction instrument	We created a data extraction form in Microsoft Excel based on the study aims and discussed with team members to reach consensus on the final version (23). Of particular interest were symptoms associated with mental health challenges or behaviors, goals and interventions to address them, who provided these services, and if any assessments were done or referrals were made. Internal validity was enhanced by the standardization of the data collection method with the structured form.
5. Develop protocols and guidelines for abstraction	We established a clear protocol for data collection and revised as necessary. Information was extracted in the language of documentation (i.e., English or French).
6. Data abstraction	We chose data collectors with relevant experience in rehabilitation and mental health, 1-hour online training session about how to extract data from charts, determined limits to chart access, managed conflicting data through discussion.
7. Sample	We considered sampling method, inclusion and exclusion criteria. To determine pertinent goals, those that were related to strictly physical aspects (e.g., assistive devices, ambulation, and orthopedic procedures) were excluded, and all others were included. Priority was given to active charts, though archives were also used for those that had recently received services before the age of 25 to reach a larger sample.
8. Ethics	We obtained permission from the Research Ethics Board of the *Centre de recherche interdisciplinaire en Réadaptation du Montréal métropolitain* (CRIR; MP-50-2022-1348)
9. Pilot	A pilot study involving randomly selecting 10% of the charts for separate review by A1 and a research assistant (RA) independent of the study was done. Inter-coder reliability was documented by having both extract data from the charts independently and compare to ensure agreement (23, 34). The rest of the charts were reviewed by A1, with regular team meetings (A2, A4) to discuss the findings, returning to the charts for more details as necessary in an iterative process.

rheumatology and musculoskeletal programs) with occupational therapy, psychology and social work. Charts were included if they represented: 1) youth aged 15-24; 2) with a chronic physical disability diagnosis resulting in mobility restrictions; and 3) who presented with a mental illness or related symptoms (e.g., anxiety, excessive worrying, depression), observed and documented (to include youth who may not have been evaluated and diagnosed), and/or were referred to mental health services. Charts were flagged by the clinicians or managers for youth known for presenting with mental health challenges. Mental health symptoms in children and youth can be viewed as important indicators representing a heightened risk of a diagnosable mental health disorder and were included to account for widespread delays in accessing assessment, thus further delaying treatment (3). All flagged charts were reviewed between March 2022 and January 2023. Identifying terms were coded to ensure anonymity, and retrieved information was stored on a secured online platform (Microsoft TEAMs).

Data sources and extraction

All available sources (paper and electronic medical records) were searched for clinicians' evaluations, progress notes, admission, and discharge documentation. Demographic and diagnostic information were extracted (see Table 2). Information about psychiatric diagnoses based on the American Psychiatric Association (APA)'s *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM–5) criteria (27), mental health-related symptoms or behaviors, and associated assessments, goals, interventions, and referrals were manually searched for and extracted. All therapy goals and interventions documented by any rehabilitation professional and not related to strictly physical aspects were retained.

Table 2. Data extraction table template

Chart	Date of birth	Sex	Education and occupation	Living arrangements & family members involved	Physical diagnosis & date	Functional mobility, assistive devices	Mental health problem, diagnosis & date	Mental health concerns or symptoms	Assessments & who did it	Goals	Interventions	Referrals

Analysis

Chart characteristics were presented using descriptive analysis (i.e., youth's age, sex, diagnosis). Data were collated, coded by column, categorized, and compared iteratively across cases to identify emerging categories of actual practice (i.e., assessment, goal setting, intervention, referral). Category frequencies were plotted and described using percentages and proportions (across number of data extracts) to illustrate patterns of practice. We used an inductive approach to content analysis involving reviewing the data, finding patterns, and identifying categories (28). We initially familiarized ourselves with the data to identify key descriptors. For mental health assessments, we noted their presence and type (i.e., standardized). For referrals to mental health services, data extracts were categorized by whether they were within the physical rehabilitation center or to another institution (offering specialized mental healthcare) and whether the referral was successful. Goals and interventions related to mental health were transferred to an online platform (Miro) to be represented on virtual post-its, then reviewed by a research assistant (RA). Codes were grouped into categories and named collaboratively through discussion for a thorough content analysis. To increase credibility, several meetings were held between A1, A2 and A4 over the span of

6 months to discuss the coding process and come to a consensus on final categories and subcategories.

Results

Sample characteristics

Sixty charts of youth aged 15-24 (mean=21.2, median=21.5, SD=2.6) followed by a multidisciplinary team for a chronic physical disability (56 of them actively) that noted symptoms or diagnoses of mental illness were identified. Just over half the sample was female (n=31). The youth had several primary diagnoses for which they received rehabilitation services, including cerebral palsy (n=16), muscular dystrophy (n=6), juvenile idiopathic arthritis (n=5), spina bifida (n=5), or other physical disabilities (e.g., arthrogryposis, spinal muscular atrophy, osteogenesis imperfecta; n=28). Frequently documented mental health problems and related symptoms included anxiety (n=53), depression (n=25), neurodevelopmental (e.g., ADHD, ASD; n=19) and personality disorders (n=8; see figure 1). Many charts (n=36; 60%) cited more than one (including 2 that listed six). Some had a psychiatric illness diagnosed by a psychiatrist from another institution (n=18) which was noted in their rehabilitation chart, while many were awaiting an official diagnosis, had unclear diagnostic history or had not yet been investigated (n=32).

Assessments

We did not identify the results of any mental health or psychiatric assessment documented in their charts.

Figure 1. Presence of different types of mental health problems across charts

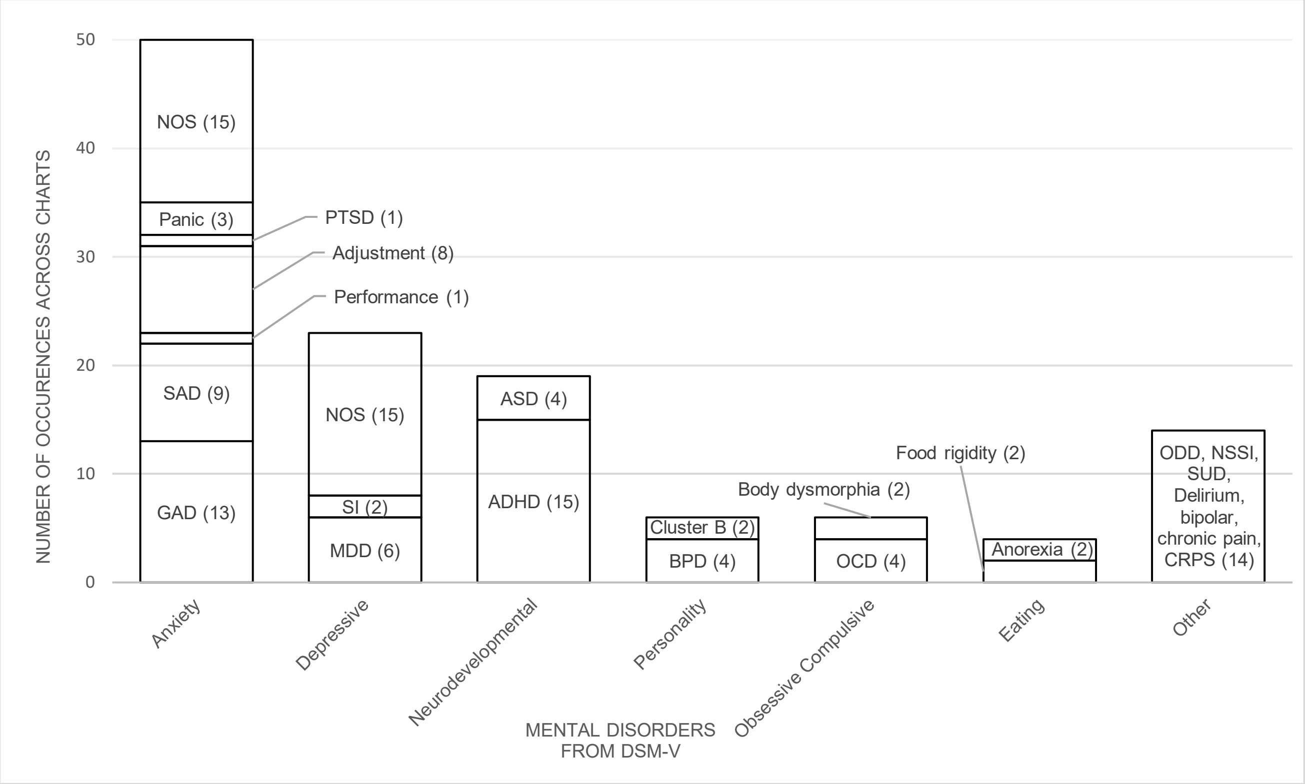

Figure 1 Legend: (27) NOS: Not otherwise specified, meaning here that the chart was lacking specificity (e.g., noting depression instead of major depressive disorder); PTSD: Post-traumatic stress disorder; SAD: Social Anxiety Disorder; GAD: Generalized Anxiety Disorder; SI: Suicidal Ideation; ADHD: Attention Deficit Hyperactivity Disorder; BPD: Borderline Personality Disorder; OCD: Obsessive Compulsive Disorder; ODD: Oppositional Defiant Disorder; NSSI: Non-suicidal Self-Injury; SUD: Substance Use Disorder

Goals

Some charts had a range of mental health related goals (47%) to be worked on in rehabilitation, but 10% had only one and 43% had none. For those that addressed mental health (n=98 goals/data extracts), 7 main categories were identified (see Table 3), namely: emotional management (n=28), autonomy and communication of needs (n=18), acceptance of physical condition (n=16), socialization (n=16), routines and energy levels (n=8), school and work supports (n=6), and leisure and calming environments (n=6). *Emotional management* was the most frequent category, present in almost half of the

Table 3: Examples of goals extracted from charts per identified categories (n=98)

Categories of goals	n	Example 1	Example 2
Emotional management	28	Learn to better deal with emotions	Learn coping skills for anxiety
Autonomy & communication of needs	18	Make choices about daily tasks to be empowered	Develop assertiveness skills to express needs
Acceptance of physical condition	16	Improve self-acceptance related to physical disability	Share concerns related to having a rare disease
Socialization	16	Improve school engagement and discussions with peers	Decrease loneliness with same-age friends
Routines & energy levels	8	Establish a daily routine to have a better balance	Manage fatigue to reduce falls and effect on mood
School & work supports	6	Put in place support for a transition out of school	Access socio-professional support for adapted employment
Leisure and calming environments	6	Engage in hobbies outside of the home	Improve calm in home environment by designating a space to go to when upset

charts. Goals within this category included learning specific skills to identify and manage negative emotions (such as anger management) and improve emotional regulation (such as recognizing signs of frustration). *Autonomy and communication of needs* encompasses goals focusing on increasing independence, such as developing autonomy to move out of the family home to live with a partner and learning assertiveness skills to adequately communicate needs. *Acceptance of physical condition* refers to goals about coming to terms with the implications of having a chronic physical disability, such as sharing emotions and challenges related to their disability with others and increasing selfconfidence with regards to their appearance and abilities. *Socialization* includes goals aiming to reduce isolation and loneliness and increase time spent engaging with others, for example, integrating and discussing with peers at school and making same-age friends. As for *routines and energy levels*, goals pertained to energy conservation strategies to manage fatigue and establishing a daily routine with proper eating, exercise and sleeping habits. *School and work supports* imply assistance surrounding transitions out of school and into the workplace as well as developing interview and other work-related skills. Finally, *leisure and calming environments* refers to the spaces used to participate in recreational activities or seek calm (such as when upset). These goals were documented by social workers (n=33), psychologists (n=24), occupational therapists (n=22), special educators (n=14) and physical therapists (n=5). In 35% of goals, progress was monitored and documented (often in a formal, multidisciplinary progress report).

Interventions

Almost half of the charts (45%) had several mental health-related interventions to be worked on, but 12% had only one and 43% had none. As for pertinent interventions used (n=104 data extracts), there were 6 main categories identified (presenting some overlap with the goals; see Table 4), namely: emotional management (n=28), formal individual or group therapy (n=25), links with external (peer, family and online) supports (n=20), routines and activities (n=12), reflection and acceptance (n=10), and school and work supports (n=9). Just as with the goals, the most common intervention targets were related to *emotional management* (present in almost half the charts), such as developing mindfulness skills. Next, *formal individual or group therapy* included different methods used by clinicians such as cognitive behavioral or acceptance and commitment therapy or group therapies. *Links with external supports* indicated when rehabilitation professionals connected youth to supports external to the rehabilitation setting, such as facilitating access to a community peer support group or support for their families (e.g., the Incredible Years program for parents) or suggesting online resources for information and support. Only half the suggestions had documented follow-up or established links confirmed, with no report on progress. *Routines and activities* spoke to interventions targeting workload and energy management as well as soothing activities to relax and recenter. The category of *reflection and acceptance* included tasks such as self-reflective journaling and positive visualization to help accept the disability process and work through

Table 4: Examples of interventions extracted from charts per identified category (n=104)

Categories of interventions	n	Example 1	Example 2
Emotional management	28	Practice breathing techniques for surfing panic attacks and sleep paralysis	Write concrete steps to cope with stress on Q-card
Formal individual or group therapy	25	Use strengths and solutions-focused psychotherapy approach for weekly session	Provide weekly group therapy for social and mindfulness skills
Links with external (peer, family and online) supports	20	Participate in a community peer support photography group	Connect mom to community psychosocial support
Routines & activities	12	Participate in improvisation and theater classes	Use a vibrating carpet to relax
Reflection & acceptance	10	Journal thoughts and self-reflection	Think positive thoughts when frustrated by tasks
School & work supports	9	Attend transition to high school workshop	Suggest workstation adjustments

challenges. Finally, *school and work supports* included integration to after-school or transition programs and connecting with mental health services at their future school or workplace. Most were delivered by psychologists (n=14), social workers (n=12), or occupational therapists (n=9) within the rehabilitation center.

Referrals

With respect to 'on-site' services and referrals, four charts had documented mental health services within the physical rehabilitation center only, being delivered by their rehabilitation team (in most cases, with an in-house psychologist). In six charts, there were documented referrals to mental health services within another health-related institution (offering specialized care), and in two, external referrals and documented services were noted. However, in most of those cases, follow-up was not (yet) confirmed or received (due to being on a waitlist, refusing follow-up, or no further documentation available within the referring institution). Fifteen charts documented external mental health services only, provided by a variety of partners (e.g., specialized programs in children's hospitals, private centers). Ten noted that they were receiving both, and four were receiving internal and external services plus had other referrals in process. However, 14 other charts had no mental health services or referrals documented. Evidence of collaborations across institutions within the health and education sectors was present in five charts.

Discussion

The most common physical and mental diagnoses in the charts were cerebral palsy and depression and anxiety, respectively, which is in line with current literature and suggests the importance of rehabilitation professionals being made aware of the co-occurring prevalence (6). As documented, youth had a range of mental health problems, supporting emerging evidence on the presence of multiple mental health challenges experienced by youth with physical disabilities (6, 15, 29). Yet, no evidence of assessments done by physical rehabilitation professionals to screen or evaluate them was found. However, it was documented that some youth were seen by a mental health specialist, such as a psychiatrist or psychologist, though the results of their assessments were not available in the rehabilitation charts. Our team's previous research identified 35 types of assessments used in the literature to assess mental health of youth with physical disabilities (6). Nonetheless, this study did not identify any, which raises the question of the extent to which available mental health assessment tools are being used in these settings. Rehabilitation specialists may benefit from guidance on how to approach specific situations where mental health problems of the youth they follow (such as lack of motivation or low mood) limit their adherence to rehabilitation programs or impact their performance of functional activities. Indeed, training was a key principle that emerged in a scoping review on the organization and delivery of services for youth with physical disabilities and mental health problems (8). This, combined with support for appropriate and timely referrals to services specialized in mental health if required, would ensure comprehensive, goal-directed rehabilitation care for all youth. Additional research can help to understand the underlying reasons explaining why screening and assessment of mental health problems was not documented in physical rehabilitation settings. Training to build clinician workforce capacity in mental healthcare delivery and improve preparedness to approach challenging situations and consolidate therapeutic rapports are warranted.

Seven types of goals were identified, where coping with emotions and developing skills to deal with challenges was the most prevalent. The social aspect also came up frequently, emphasizing the importance of community participation in mental health (30, 31). Few addressed leisure or transitioning from school to work, as there was more focus on personal factors and skill development rather than participation and engagement in activities or the environment, which are linked to better quality of life and wellbeing (15). Like goal categories, emotional management was the most prominent for the 6 interventions. Peer support was another important aspect that has been gaining more recognition in the literature, and specialized programs and online platforms such as Horyzons are being created to make it more accessible to those who are dealing with mental health problems (32).

Despite the overlap, goals and interventions were often not directly associated within a given chart. It was also sometimes difficult to differentiate between treatment plans and delivered interventions, highlighting the gaps in charting, and, possibly by extension, in care. Some received services within the rehabilitation center, while others were referred externally, implying that while there was some effort to address mental health needs, physical rehabilitation centers may not have the necessary resources, competencies, or mandate to do so. Challenges could include limited staff, time and funding, stigma, poor communication between service providers, and lack of transition services (33). Pertaining to the 43% of charts that had no mental health goals or interventions reported, the high number may be because they were simply referred or are currently receiving services elsewhere, though this was not always evident (as the charts might not capture everything, such as psychologists' notes or appointments in the private sector). Similarly, follow-up of referrals was not systematically documented, so it is unclear if the links were established, or rather left as suggestions for families to follow through with. This begs the question of how care is coordinated and how difficult it is to access services spread over different institutions across the city (that is, if they have access at all). Individual interviews (with youth, families, clinicians, and managers) reflecting on charts are needed to better understand practices and learn about competencies of rehabilitation specialists and their specific knowledge needs. This can in turn inform the development of knowledge translation strategies to bridge gaps in mental health within physical rehabilitation. Physical and occupational therapists were less often setting and addressing mental health goals, therefore specific strategies can be developed with these clinicians in mind.

Limitations

While the sample of charts from 5 organizations was diverse, it was relatively small, and limited to one Canadian city. As such, it may not be entirely representative of all youth receiving services in rehabilitation settings and provides initial findings. The sampling method may also be prone to research bias since some charts could have been missed as we relied on clinicians and managers to flag them after explaining the inclusion criteria. However, they are in regular contact and are well-placed to suggest pertinent charts (including of those who were not yet diagnosed). While recruiting from different sites was a strength, it also meant that charts were organized differently which made data extraction challenging. To remedy this, we used a structured extraction form, did data extraction training, and met regularly to discuss progress. Despite efforts, charts remain imperfect in telling the full story due to factors such as missing or illegible notes and complexities in capturing multidisciplinary work. This exploratory study provides initial findings of current practices that require confirmation from further controlled studies.

Conclusion

Practices addressing mental health varied across rehabilitation professionals. Many youths identified with more than one mental health problem, suggesting the complexity of their medical profile. In 43% of the rehabilitation charts, goals/interventions were not documented, indicating that mental problems may not be reported or not addressed in this context. Our study provides an initial overview and first step towards understanding current physical rehabilitation practices addressing mental health problems. Future studies can combine chart reviews with interviews to elicit reasoning behind current practices as well as facilitators and barriers to providing integrated services for those with co-occurring conditions.

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Chapter 6: Bridging Manuscripts 2 (chart reviews) and 3 (interviews)

The chart reviews highlighted several gaps in current rehabilitation practices across sites. The results of 43% of charts having no mental health related goals or interventions among youth who would benefit from this aspect being targeted was something to explore further. Concurrently, it is important to note that there is a possible subset of youth with physical disabilities followed in the rehabilitation settings that may have undocumented mental health problems, which is a limitation of the chart sample (as lack of documentation does not ensure that there were no mental health challenges).

While some charts documented mental health services provided within the physical rehabilitation program by different professionals such as psychologists, social workers and occupational therapists, others had been referred elsewhere to address mental health components. Additionally, 18 referrals to external mental health services were still pending (some for over one year) in addition to 14 charts which had no documented referrals or received services, despite the need.

The reasoning underlying why specific needs were not addressed in addition to whether procedures were in place to facilitate access to services could not readily be captured from the charts and required additional approaches. Also, documents available in the rehabilitation charts are prepared by clinicians and it is important to include the perspectives of youth clients and their family alongside a deeper exploration of the reasoning behind actual practices based on clinicians' perspectives. This can be done through individual interviews.

Therefore, it was decided to address Objective 3: to better understand the needs, supports, challenges and potential solutions to optimize rehabilitation services across 5 organizations from the perspectives of service providers (clinicians) and receivers (youth, family members) through semi-structured interviews (see Appendix 2; Hinton & Ryan, 2020), with chart-stimulated recall for clinicians (see Appendix 3). The resulting study is presented in Chapter 7.

For Study 3, clinicians were recruited from different professional backgrounds as they each have a different knowledge base and overall competence in mental health service delivery. This reflects rehabilitation practice and service organization in Quebec (and elsewhere), where multidisciplinary team members work together to address their clients' needs. Youth with a variety of physical diagnoses and some of their family members were also recruited to ensure a range of experiences and varying perspectives across interviews (Arim et al., 2015).

The interview guides were shared with different members of the consultation group for feedback prior to commencing data collection. One clinician member of the consultation group also provided feedback on the coded interview results and helped to validate the final themes and subthemes. The submitted study is presented in the following chapter (Chapter 7).

Chapter 7: Manuscript 3, Services addressing mental health needs of youth in physical rehabilitation: Perspectives of clinicians, youth and family members

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Abstract

Background: Knowledge about services addressing mental health provided in a rehabilitation setting to youth with physical disabilities is limited. This study aimed to better understand the needs, supports, challenges and potential solutions to optimize rehabilitation services for co-occurring physical and mental health needs, from the perspectives of youth, family members and clinicians. Methods: A qualitative descriptive approach using twenty-two individual interviews with youth, parents, and clinicians from five rehabilitation centers in a large Canadian city was employed. Inductive thematic analysis was conducted. Results: Three themes were identified across the three stakeholder groups: (1) available clinical resources for mental health (access to mental health professionals, impact of organizational structures and mandates, and continuity of services during transition to adult care); (2) clinician workforce capacity (mental health knowledge, skills and professional development, and therapeutic rapport between clinician and youth); and (3) links and partnerships with key players (improved pathways to access mental health services across programs and organizations, and family involvement and advocacy). Conclusion: This study provides insights into barriers for mental health care, illustrating important aspects to address. Clinicians can be better equipped to address mental health in rehabilitation settings via training opportunities and peer and organizational support in addition to establishing links with external partners. Organizations can also ensure adequate staffing and create pathways within and beyond their institutions to deliver well-coordinated mental health services in a more accessible way.

Key words: childhood disability, mental health, rehabilitation, coordinated services

Body

Introduction

Youth with physical disabilities who experience mental health problems may receive various rehabilitation services, but whether these services adequately address their mental health needs is unclear. This is important as mental health concerns are indisputably a problem faced by many of these youth (1-4). Unfortunately, the COVID-19 pandemic has amplified this burden, in part due to a disruption to their health services, activities, and (school-based or other) supports (5, 6). Furthermore, a recent scoping review found that a major gap exists regarding the organization of services for this population, with only two models published (2).

Considering the high prevalence of mental comorbidity seen in rehabilitation settings (1), rehabilitation specialists are required to adapt to the complex needs of their clients and target a greater variety of health conditions simultaneously (2, 7). In addition to interventions targeting the physical disability, they are required to consider the various contextual factors and psychosocial stressors that can impact youths' health and development, and are encouraged to take a multidisciplinary, collaborative approach to care (8). There is an increased demand in physical rehabilitation settings to support psychosocial determinants of health outcomes. For example, a review highlighted the role of physiotherapists in providing individualized physical activity for sustainable behavioral change and emotional regulation for youth with depression as part of the interdisciplinary mental health team, despite being a profession that traditionally targets physical aspects (9). A recent chart review study found that while mental health problems were prevalent in physical rehabilitation settings, no assessments targeting mental health were found, and in 43% of charts, no mental health goals or intervention were evident (10). There is a need to deepen our understanding of practices and services by delving into reasons why certain barriers were faced, as little is known about clinician, youth, and family member perspectives regarding mental health care in physical rehabilitation settings.

Gathering information from various stakeholders involved is important to ensure challenges are understood from different perspectives so that care needs can be addressed (7). For example, an international survey study gathered input from stakeholder groups on rehabilitation services for those with physical disabilities to help inform policy (11), though it did not address mental health care. Youth need to be provided with opportunities to voice their concerns and needs, particularly when pertaining to mental health (12). Family members must also be provided with the opportunity to contribute their thoughts as they are often involved in supporting youth in navigating care, especially as many still live in the same household during the onset of symptoms of mental illness which further emphasizes the importance of family-oriented approaches (13, 14).

Eliciting perspectives from both service providers and receivers on current mental health services in physical rehabilitation can help identify barriers and inform novel strategies, assessment tools and interventions to support youth who would benefit from additional care. The aim of this study is to better understand the needs, challenges, supports, and potential solutions to optimize services addressing mental health in rehabilitation settings as perceived by youth with physical disabilities, their families, and clinicians.

Methods

As part of a larger study seeking to better understand current practices and services targeting mental health for youth in physical rehabilitation, a descriptive qualitative research design (15, 16) was employed to bring forth perspectives on the present clinical reality. Specifically, individual semi-structured interviews with youth, family members and clinicians were conducted (17, 18). The research team developed three interview guides (one for each group) and ensured limited leading questions. Clinicians participated in semi-structured Chart-Stimulated Recall (CSR) interviews (19) to elicit an in-depth reflection about their practice behaviors by drawing on a specific clinical chart to discuss their clinical reasoning (10). Interview topics included exploring their therapeutic approaches, rationales behind practice behaviors, competencies in addressing co-occurring health problems, collaborations between colleagues that would facilitate referrals, needs and areas for improvement, actual versus ideal practice, effective strategies used as well as barriers and supports within the organization. CSR interviews allow for the exploration of clinical reasoning, and combined with chart audits, can be used as a proxy of real-world performance (20). The CSR interview method was successfully used in a study looking at participation-focused, school-based occupational therapy services (21). In the present study, youth and family members were similarly interviewed about their experiences, broaching topics such as their access to services, what they felt was missing, and ideas for improvement. Examples of interview questions are presented in Appendix [2 and 3].

Ethics approval was obtained from the relevant Research Ethics Board. All participants provided written informed consent. The COnsolidated criteria for REporting Qualitative research (COREQ) checklist was used (22).

Recruitment Process

Youth were eligible participants if they had a physical disability and (diagnosed or self-identified) mental health problems. The age range of 15-24 years was selected as this group is top priority for receiving mental health care being when psychopathology often emerges, with over 75% of mental illnesses beginning before the age of 25 (23, 24). It also encompasses the transition to adulthood which can bring about additional complexities and barriers. Youth were recruited in a large Canadian city across five sites (under 2 umbrella organizations) where they currently receive physical rehabilitation services. The sites were diverse in terms of language (English or French services; both official languages), programs available, constitution of their healthcare team, age range and population served (see Table 1 for site details).

Youth, a family member, and one of their clinicians were recruited for individual interviews to provide different perspectives on their care. Eligible youth were approached by local research coordinators or clinicians to introduce the study and seek permission to be contacted by the research team if interested. Given the relatively small population of eligible youth, all those who were flagged by their clinicians were approached to reach our sample size and to ensure that there was diversity across age, sex, and physical diagnoses (25). Participants were excluded, based on clinicians' input, if they could not communicate fluently in English or French or had cognitive impairments or communication disorders preventing them from sharing opinions. Once youth agreed to

Table 1. Recruitment sites (n=5)

	Recruitment site, targeted program	Language of services	Age range (years)	Population served	Professionals available
1	**Physical rehabilitation program within a school setting**	English	4-21	Adapted school program offering on-site specialized individual rehabilitation services	Nurse, technician in specialized education, speech and language pathologist, occupational therapist, physiotherapist, psychologist, music therapist, technology rehabilitation assistant, social worker, kinesiologist, psychoeducator, orientation and mobility specialist, vision rehabilitation specialist
2	**Transition program within a pediatric rehabilitation center**	English	15-25	Complementary program for those with a physical disability impacting transition to adult life to optimize social participation and autonomy (individual and group interventions)	Occupational therapist, special care counselor, career counselor, social worker
3	**Transition program within a rehabilitation center working across the lifespan**	French	16-25	Complementary program for those with a physical disability impacting transition to adult life to optimize social participation and autonomy (individual and group interventions)	Occupational therapist, psychologist, career counselor, social worker
4	**Physical rehabilitation program for adults**	French	18+	Individual interventions in neuromuscular, return to work, driving rehabilitation programs	Technician specialized education, speech and language pathologist, occupational therapist, physiotherapist, nutritionist, social worker, kinesiologist, sexologist, psychiatrist
5	**Physical rehabilitation program for adults**	English	18+	Individual interventions in neuromuscular, return to work, rheumatology, traumatic brain injury, driving rehabilitation programs	Occupational therapist, physiotherapist, social worker, psychologist

participate, they were asked if one of their family members could also be contacted (this did not impact their own participation). Potential family member participants were nominated by the youth, and could be a parent, sibling, legal guardian, or other family relation regularly involved in their care, who spoke English or French. Eligible clinician participants were rehabilitation professionals (occupational therapists, physical therapists, psychologists, social workers, and other allied health professionals) who followed one of the recruited youths (or who provided in-house services at one of the five recruitment sites) and had at least one year of clinical experience working with that population to ensure a certain expertise and familiarity with their organization's procedures. Clinician representation was sought across different sites and professions.

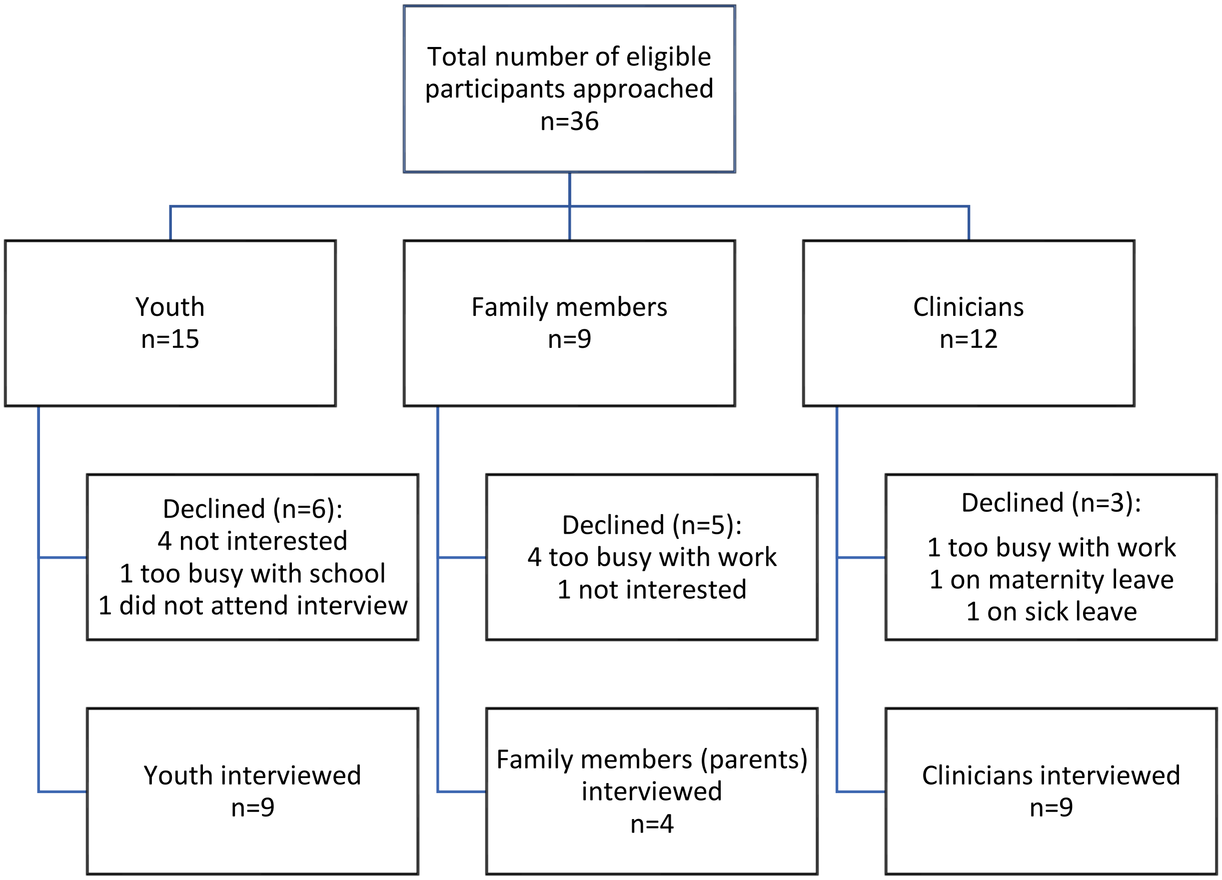
Data collection

Data collection occurred between June 2022 and August 2023. One-hour virtual individual interviews were audio recorded and transcribed verbatim using a secured online platform (Microsoft TEAMs) and reviewed by the primary author (A1), promoting dependability (26). All interviews were conducted in English or French, based on participants' preference, by A1, a female, bilingual PhD candidate and occupational therapist with qualitative research experience currently studying rehabilitation service organization. No participants had previously met or communicated with A1 prior to reviewing the study goals and consent form together. Notes were taken during and after the interview to create summaries complementing the transcripts.

Data analysis

Sample descriptive statistics were calculated with Microsoft Excel. Following Braun and Clarke's six steps for thematic analysis (27), transcript data familiarization preceded creating an initial coding list and framework based on a quarter of the sample (2 interviews from each stakeholder group, totaling 6) generated using ATLAS.ti software (version 22.0.5.0, Berlin, Germany) by A1. Two of those interviews were randomly selected to be independently coded by two senior researchers (A2 and A4) with experience in qualitative analysis, and discussed as a team, resulting in refining the framework. Three more interviews, then six (chosen to represent the different contexts in terms of sites) were then coded and discussed at two subsequent team meetings to further consolidate the framework. The remaining seven interviews were then coded by A1. In total, five iterations lead to the final (English) coding framework to be applied to the entire dataset (see [Appendix 4] Supplementary File 1). The coded data were then reviewed to inductively identify themes and subthemes representing the rehabilitation needs, challenges, supports, and ideas in relation to patterns observed across participants in the three stakeholder groups. They were then refined between A1, A2 and A4 to create a thematic map through on-going meetings to reach consensus and cross-checked with the consultation committee clinician expert. Consensus agreement across the team and detailed notes contributed to findings credibility (28). An effort was made to keep themes close to the words used by participants (16) and findings can be traced back to raw data attached to coded participant IDs, ensuring confirmability (26). Quotes below were translated to English (if applicable) and back translated by a research assistant independent of the study to ensure fidelity to the essence of the quote (see [Appendix 5] Supplementary File 2 for additional quotes).

Figure 1. Flow chart of participant recruitment



Findings

Individual interviews with youth, one of their parents, and a rehabilitation clinician were conducted for a total of 22 participants across the three groups (see Figure 1). Participants were recruited across the five sites (n=5 site 1, n=3 site 2, n=7 site 3, n=5 site 4, n=2 site 5). Participant demographics are presented in Table 2. The clinicians represented five rehabilitation professions working at one of the 5 recruitment sites (at least one from each). Interviews lasted between 34 and 75 minutes (mean 45 minutes). Half (n = 11) were conducted in English.

Table 2. Participant demographics (n=22)

Characteristics	**Youth (n=9)**	**Parents (n=4)**	**Clinicians (n=9)**
Female (%)	6 (66.7%)	3 (75.0%)	8 (88.9%)
Age (years) ± SD	21.9 ± 1.9	52.0 ± 7.8	41.2 ± 6.8
Occupation (n)	Student (8), full time worker (1)	Teacher (1), housekeeper (1), sales director (1), retired healthcare worker (1)	Occupational therapist (4), physiotherapist (2), social worker (1), nutritionist (1), psychologist (1)
Years of clinical experience ± SD			17.4 ± 7.3 (range 10-32)
Physical diagnosis	Cerebral palsy (3), Duchenne's muscular dystrophy (1), spina bifida (1), osteogenesis imperfecta (1), pediatric stroke (1), traumatic brain injury (1), neuromotor disorder (1)		
Mobility assistive device currently used	Power wheelchair (3), manual wheelchair (2), walker (1), none (3)		
Mental health problem, diagnosed or self-reported (n)	Anxiety (7), depression (7), ADHD (3), borderline personality disorder (1), PTSD (1)		

ADHD = attention deficit hyperactivity disorder; PTSD = post-traumatic stress disorder; SD = standard deviation

Themes

Participants expressed a range of barriers, facilitators, and ideas for ideal care to address mental health needs. Three themes were identified: (1) available clinical resources for mental health; (2) clinician workforce capacity; and (3) links and partnerships with key players. The first theme encapsulates 3 subthemes, while the latter each have 2 subthemes, detailed below (see Table 3).

Table 3. Interview themes and subthemes

1. Available clinical resources for mental health	2. Clinician workforce capacity	3. Links and partnerships with key players
1.1 (B, FA) Access to mental health specialists within team	2.1 (B) Mental health knowledge, tools and professional development	3.1 (FI) Improved pathways to access mental health services across programs and organizations
1.2 (B) Impact of organizational structures and mandates	2.2 (FA) Therapeutic rapport between clinician and youth	3.2 (FA) Family involvement and advocacy
1.3 (B) Continuity of services during transition to adult care		

B = barrier; FA = facilitator actual; FI = facilitator ideal

1. Available clinical resources for mental health

This first theme encompasses the availability and accessibility of various mental health resources in rehabilitation settings and how organizations structured them. Youth, parents, and clinicians identified that having access to professionals specialized in mental health was difficult due to team composition, impacted by unfilled positions and other staffing challenges. Clinicians also talked about program mandates limiting their possibilities to address mental health problems beyond what was directly related to physical disability and discouraging longer and more in-depth follow-ups. All three groups additionally felt that overall, services diminished as youth transitioned to adult care settings, where access to specialized mental health services became more complicated.

1.1 Access to mental health specialists within the team (barrier and facilitator actual)

The first subtheme pertains to the composition of the physical rehabilitation team and whether staff who could deliver mental health services were available to provide services when necessary. Participants expressed that psychologists in particular were lacking (often due to prolonged leaves of absence, unfilled positions or a decrease in program resources) and constituted a major barrier to delivering adequate services. Some youth expressed wanting to discuss certain challenges with a psychologist but having to wait months on a waitlist.

But again, that's the limited resource psychologist four days a week at 2 specialized schools. I mean, we have a whole school that barely ever has access to psychology support. 103T (clinician, school)

This left many youth and families on their own while waiting for follow-up. However, some teams had filled mental health positions, which meant that youths' concerns were addressed more rapidly and became a facilitator rather than barrier. In some cases, a psychiatrist was also present on-site which greatly facilitated timely access to specialized care.

I was seeing the neuropsychiatrist to see like what I had because (…) I remember at the end of my high school, that's when I had my depression, so the neuropsych, I saw him pretty often. 304Y (youth, rehabilitation transition program; translated)

And we can easily make a link so he meets with the psychiatrist as needed, so there are really easy exchanges between the team to establish our work plan. 304T (clinician, rehabilitation transition program; translated)

Clinicians also expressed feeling reassured when they discussed complex cases with interdisciplinary colleagues who could contribute feedback on psychosocial aspects.

1.2 Impact of organizational structures and mandates (barrier)

The second subtheme pertains to the intervention structures and program mandates or internal policies targeting solely physical disability, thereby making it difficult to provide mental health-related care. The limited number and length of psychosocial-type sessions were among the barriers experienced by youth (and additionally expressed by parents and clinicians).

Just like, the organization can't have me indefinitely. Like they say they only had a couple of meetings (with my psychologist). 100Y (youth, rehabilitation program)

It’s like they care, but they don’t want to treat that way. Cause, if I were to talk to (my social worker), she would sit, from for example 10-10:30am. That's not enough though. Because you never know what we have to say. 103Y (youth, school)

In addition to the limited sessions, another difficulty expressed by clinicians was that they were only permitted to address mental health problems directly related to (and impacting) the physical disability.

We're not called to action [to address mental health]. In fact, it's discouraged. Like I'm thinking of some of the OTs that would want to do a DCD [developmental coordination disorder] group, let's say for social skills. Like for young ones, which definitely points in the direction of mental well-being down the road. And they were not allowed, it was not granted because it didn't target physical rehab. So, the utility of trainings in mental health and the like becomes low. 101T (clinician, rehabilitation transition program)

Overall, rehabilitation programs were not set up in a way to facilitate sustained mental health care delivery, limiting what could be addressed (if anything).

1.3 Continuity of services during transition to adult care (barrier)

In the third subtheme, youth, parents, and clinicians expressed concerns over decreasing or even complete loss of the little mental health services they had transitioning to adult rehabilitation services. Youth who were soon transferring were often unsure of the process and who would be following them, while those who recently switched noted a stark decrease in overall services as well as ease of access to certain professionals. They therefore had trouble accessing specialized services across the continuum of care, often leading to feelings of abandonment by service providers. One youth mentioned: "*That's the thing, they don't tell you what to expect with the follow up. What they will say, is, we will close your file when you reach 21, but they don't say what to do. And even then, even if they say what to do, it's not 100% sure that it will be like that. And I was aware of nothing, I received a letter one day that told me that I'm on the waiting list.*" 208Y (youth, adult rehabilitation program; translated)

This discrepancy and uncertainty came up as a barrier for youth as they got older, also expressed as confusion by clinicians and worry by parents.

So, he does need to ask, but from what I understand, they work very differently there. They work by episode [of] service. So, if he has a problem, he calls, they activate his file for whatever the problem is and then they close it. It's not like here where you always have a file and we check up and see if there's any needs. And for psychology I don't think that they provide the services that we provide, I don't know if maybe there's assessments or evaluations for work, but I don't think that there's that therapy per se. So no, it would be linking him more to community resources. 100T (clinician, rehabilitation program)

I'm worried about what happens [when he transitions out of the rehabilitation center], will she take him on as a private patient and like, you know, I have insurance, I have no problem doing it, is she allowed to like, I don't know. He's been with her for three years now. 101P (parent, rehabilitation program)

2. Clinician workforce capacity

The second theme encompasses clinicians' self-perceived competence in delivering mental health services as well as finding ways to create a strong therapeutic rapport with the youth. Clinicians highlighted challenges regarding their mental health knowledge base, professional skills, and limited possibilities for additional training and access to adapted assessment tools, while all three groups listed the importance of building a trusting connection with youth's healthcare provider.

2.1 Mental health knowledge, tools, and professional development (barrier)

The first subtheme, discussed by clinicians, relates in large part to limited mental health training available for those working with youth with physical disabilities, which is a unique group with specific challenges. Some clinicians noted that they did not feel very competent working with dual diagnoses, which was a barrier to providing adequate services within their program.

I think that people are not comfortable [screening for mental health problems] yet because they haven't had to do it. I think we need to sit together and discuss it and ask them what would be helpful. I think that it would be useful to all sit and role play. So, everyone has a chance to ask the questions and formulate it in a way that they feel comfortable with because they're not, for me anyways, they're not written in the most user-friendly way. 100T (clinician, rehabilitation program)

Clinicians expressed uncertainty about asking the right questions and broaching sensitive topics with youth they had concerns about. They requested more guidance and support for working with youth that have emerging mental health problems. One clinician commented: "*I feel very, very inadequate with patients that have mental health issues. Um. Yeah, just to not know like quite how to approach things sometimes or, you know, the right things to say, feels a little bit difficult… or what to say, what to avoid saying. Yeah, that's a bit difficult."* 205T (clinician, rehabilitation program). Another clinician went as far as paying for peer mentoring out of pocket to debrief challenging cases with co-occurring diagnoses to better service their program. Clinicians also noted a lack of adapted mental health assessments suited for youth with physical disabilities. To illustrate, one acknowledged that*: "For the psychology assessments, I'm always having to adapt what I'm doing because of impairments. And so, it's hard to find tests. It's hard to find adaptations and there's certainly no norms. "* 100T (clinician, rehabilitation program)

2.2 Therapeutic rapport between clinician and youth (facilitator actual)

The second subtheme focuses on clinicians' ability to connect with youth and work with them on sensitive topics. This came up as a facilitator present in many of the sites and was clearly expressed across all three stakeholder groups. For youth, it allowed them to share openly and express their concerns when they felt they could be honest with their clinician. They could explore challenging situations while feeling supported and heard by someone outside of their family unit.

It's easy and I'm able to tell them, I'm able to be honest with them all the time. (…) It's easier to talk to the professionals more than my family. It's 'cause they react easily. 101Y (youth, school)

The importance of such a connection was also raised by parents: *"And I hope that this will continue for a long time because there are bonds of trust that are established, and all that, the clinicians know her story, if you will. "* 304P (parent, rehabilitation transition program; translated)

Parents were reticent to have their child change care providers once a good contact was established and hoped they could continue the follow-up long-term, as the efforts to find clinicians suited to their needs and create new bonds to work through delicate situations are substantial.

3. Links and partnerships with key players

The third theme encompasses the team coordinating with family and external institutions such as specialized mental health programs and community organizations offering mental health support to attend to youths' needs. All groups hoped for more direct pathways to external resources, with clinicians providing specific ideas about how that could be done. Parents in particular raised the challenges and benefits of working closely with the team to ensure mental health services were obtained.

3.1 Improved pathways to access mental health services across programs and organizations (facilitator ideal)

The first subtheme highlights the links between institutions and with community organizations which are crucial for providing complementary services to address all aspects of care. Clinicians and parents both had specific ideas about how care pathways could be easier and more direct for youth to navigate.

We asked our boss to make the link with the hospital because we say that we are a big [umbrella organization], why don't we have as easy access to mental health *services? There was a meeting with a person to try and set up a certain corridor, so we would have access to consultations with psychiatrists fairly quickly. (…) But we are working to have a corridor because, despite being a large institution, we still work in silos, and it is hard to have support from hospitals outside of our center.* 403T (clinician, adult rehabilitation program; translated)

In addition to having specific mental health professionals working with the team to provide direct services and act as specialized consultants for their colleagues, some participants suggested that it would be ideal to have a key worker appointed to coordinate different aspects of care and external referrals. *"Whether it's at the level of support, whether it's a nurse or another professional, someone who would be a key worker, a social worker who would direct you, who would immediately say okay, I will register you here, here, here. That would help."* 205P (parent, rehabilitation transition program; translated)

A desire for quicker and simpler pathways to coordinate with and access specialized care outside of their rehabilitation program was prominent, moving towards eventual collaboration between parties for efficient and comprehensive service provision.

3.2 Family involvement and advocacy (facilitator actual)

The final subtheme pertains to family as advocates for mental health, supporting their child to ensure they receive the services they need and acting as coordinator to manage their care. The parent caregivers reported dealing with the many aspects of their child's care and expressed some frustration and lack of support throughout the process. They felt largely unequipped despite wanting to advocate for their child's needs and felt at a loss for where to turn. Overall, parents played a big role in coordinating services, albeit unofficially and without adequate information and support. However, over time they often managed to find ways to ensure that the youth accessed care as needs arose and acted as facilitators in this process.

The rehab person at [the site] called me when he was released [from hospital] and asked me for discharge notes and stuff like that, which I didn't have because they never gave me anything because they just sort of discharged him over Christmas, spur of the moment type of thing. And so I didn't really get much and they said what they can do at school, but I'm like, you guys never did anything anyways, but that was besides the point. 101P (parent, school)

I was rowing alone for 12 years. Going to physio, to occupational therapy, everywhere, but in the private sector, then trying to get help (…), I always had to be the driving force in seeking resources. 304P (parent, rehabilitation transition program; translated)

Parents wished for better coordination between internal, external institutions and community programs. They desired a more direct connection with clinicians to facilitate interactions regarding information about available services that could benefit their child and how to navigate access. Youth also mentioned the importance of having their family members involved. One noted that his mother oversaw everything regarding his care and likely knew the next steps (while he did not). Some clinicians expressed a desire to work more closely with families as this would ensure that all stakeholders were on the same page and working towards common goals together.

Discussion

This study provides initial insights into mental health services in the context of physical rehabilitation, amplifying the voices of youth with physical disabilities, their family members, and clinicians. The narrative accounts illustrate key stakeholder challenges and unmet needs despite youth being followed in a rehabilitation program. They also highlight current supports available and ideas for overcoming barriers and improving services. While there were some variations and nuances, the experiences and ideas raised by the three stakeholder groups and across rehabilitation sites largely overlapped. The main exception was in cases where teams had direct access to a psychologist and/or psychiatrist within their staff, which greatly facilitated access to mental health support.

Rehabilitation services for youth with co-occurring physical disabilities and mental health problems in this study focused mostly on physical aspects of their disability as per their program mandates, which did not always correspond to the youth's presenting needs. Indeed, dealing with emerging anxiety or depression, for example, is quite common in this population as determined by a first scoping review on the topic (1). The review highlighted many mental health care access issues for youth with physical disabilities, citing some studies that found less than a quarter of youth who required it actually had access (1). This obstacle also extends to youth in general who are seeking access to mental health care (29, 30, 31).

Available services in rehabilitation programs for youth with childhood-onset physical disabilities experiencing mental health problems may be insufficient in terms of quantity and consistency (theme 1). These findings complement a chart review study conducted at the same clinical sites which highlighted that in 43% of cases, rehabilitation goals or interventions addressing youths' co-occurring mental health needs were not found (10). This could be partially explained by the results of the present study citing a lack of available clinical resources for mental health (theme 1) or insufficient clinician knowledge and tools to best target this specialized aspect of care in their physical rehabilitation treatment (theme 2). One potential solution might be to embed a mental health specialist (or team) directly within the rehabilitation setting, thereby bypassing the need for referrals to external resources (32). Clinicians also expressed a desire to focus on building capacity (such as practicing scenarios via role playing) to develop confidence and expertise in delivering mental health care, which is concurrent with one of the twelve key principles for organization of services for this population described in our team's scoping review (2), namely staff training in mental health. Interprofessional work was another key principle raised by the review (2) which echoes participants' thoughts as to the importance of being part of an interdisciplinary team that complements each other. Having a key worker was yet another principle (2) that also emerged in this study, which could help with navigating resources and pathways for optimal care. When turning to external entities offering mental health services, difficulties establishing links could also impact a physical rehabilitation team's efficiency in addressing youths' mental health needs more globally. Creating ties and strengthening partnerships with multi-sector services and community resources, focusing on improving corridors of access and working more closely with families all came up in this study as promising ways to ensure comprehensive services (theme 3). Participants hoped to have better pathways to refer or seek specialized consultation, working towards the principle of collaboration across institutions (2). Additionally, information, support and training workshops for youth and family members about available community resources as well as the importance of family involvement are all key principles in the organization of services (2) and have been supported in other studies (13, 33).

Access to more comprehensive, specialized mental health care in rehabilitation is needed to address emerging problems early and minimize negative impacts (1). Clinical guidelines and national strategy documents are increasingly advocating for a biopsychosocial approach to comprehensive care delivery, and new ways to integrate mental health services are being proposed (32). Recommendations to improve transition to adult care for youth with complex health care needs are also starting to emerge and can help guide service reorganization (34).

Limitations

Participants were recruited from five different sites across one major city, which brings diverse contexts to the forefront (having different resources and supports in place) but may limit the generalizability of findings to other geographical areas. Variations in service delivery could have impacted the perspectives obtained, however we reported on patterns observed across the data set to mitigate this effect. An effort was made to recruit participants in linked triads (one youth with one of their family members and one of their clinicians) but only had 4 (approximately half the sample). Family members were the most difficult group to access, with only 4 parents agreeing to participate. Despite the relatively small sample size, combining the 3 groups possibly provides a more complete picture. While the sample was heterogeneous in terms of participants (which included service providers and receivers, with clinicians representing various professions and youth having different diagnoses), it is the first study to overview this topic for a better understanding of the needs, barriers, and facilitators from different angles. There may be perspectives that were not represented in the recruited sample as well as a selection bias since recruitment involved clinicians identifying eligible participants, however as they know them well, they were well-placed to identify suitable candidates. The research team could have ensured further dependability by having an individual not involved in the study validate the coding process and analysis, though measures such as frequent team discussions to build on multiple versions of the coding framework facilitated rigorous analysis.

Conclusion and future directions

Findings suggest that certain areas related to mental health services can be improved. Clinicians and policymakers at the level of the organization can further appreciate the importance of addressing mental health in rehabilitation settings and ensure that teams are equipped to facilitate increased accessibility to mental health care. This can be done via training opportunities and peer and organizational support in addition to establishing links with external partners to address gaps in service integration. Organizations can also ensure adequate staffing and create pathways within their institutions and with external partners to deliver well-coordinated mental health services. Future research can focus on best approaches for providing care while taking into consideration clinical contexts and working closely with families. It may also look at managers' perspectives for a better understanding of institutional factors and considerations to instigate change at the organizational level.

Key Messages

- Clinicians would benefit from greater institutional support and resources (such as training and peer mentoring) to address mental health needs for youth with physical disabilities.
- Families involved in care can work collaboratively with the rehabilitation team and help navigate available resources in the community.
- Rehabilitation organizations can consider restructuring services to establish corridors for mental health consultations and referrals, and appointing key workers to facilitate all parties working together in synergy.

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Chapter 8: Bridging Manuscripts 3 (interviews with youth, family members and clinicians) and 4 (focus groups with managers)

The 22 individual interviews brought to light several barriers, facilitators, and ideas for improved care as described by youth, family members and clinicians based on their experiences. However, some of the points addressed higher-level implications at the institutional level relating to organizational structures. These aspects would benefit from additional insights from the perspectives of managers.

It is important to look at different ecological levels when seeking to better understand current practices and services across several sites with the goal of planning knowledge translation interventions to promote organizational change (Anaby et al., 2022). Incorporating managers' voices is crucial to understanding the phenomena within the local context across different sites. One qualitative implementation study on knowledge translation programs for participation-based practices in inclusive education explored the perspectives of seven occupational therapists via focus groups and thirty-nine occupational therapy managers through a survey (Waisman-Nitzan, Ivzori, & Anaby, 2023). A content analysis resulted in ten themes addressing the micro, meso, and macro levels, though macro-level themes involved managers only, highlighting the importance of including this group as relevant stakeholders. Similarly, managers' perspectives can be added to findings from Study 3 to better understand the clinical contexts of the five participating sites which can lead to the proposal of solutions for more efficient, accessible, and comprehensive rehabilitation care. Managers from the five sites contributed information pertaining to the internal structures and processes of their programs as well as considerations relating to collaborating with other institutions (see Appendix 6).

For the fourth study, clinical or program managers were recruited to ensure that there was at least one representative for each included organization. Two focus groups (one in English and one in French) were proposed to facilitate expression in participants' preferred language. Having solely managers take part in the focus groups (versus including clinicians, family members and/or youth) limited the potential for power dynamics to negatively affect participant expression.

Therefore, to address Objective 4: to gain insights on service delivery and organizational contexts at the institution level, two focus groups with managers were undertaken. In the next chapter (Chapter 9), the focus group methods are described and the key themes that emerged from the data are presented to shed light on the current state of mental health services in physical rehabilitation settings from managers' perspectives.

Chapter 9: Manuscript 4, Manager perspectives on services addressing mental health needs of youth in physical rehabilitation: A focus group study

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Abstract

Background: Mental health is becoming a priority in Canadian healthcare, but models for organizing services in physical rehabilitation centers to meet the growing needs youth with chronic physical disabilities and co-occurring mental health problems are scarce. Initial research in this area revealed barriers youth, families and rehabilitation specialists faced when accessing or providing mental health services. We aimed to complement recent findings by adding the perspectives of managers on challenges, strengths and opportunities for mental health service delivery and integration in physical rehabilitation for youth with physical disabilities at the organizational level. Methods: Two semi-structured focus groups were conducted with a total of 9 managers employed across five organizations offering rehabilitation services in a large Canadian city. Data were analyzed using inductive and deductive thematic analysis. Results: Barriers and facilitators expressed by managers fell into three categories: (1) available clinical resources for mental health (access to mental health specialists within internal team, and internal organizational structures and mandates); (2) clinician workforce capacity (internal mental health knowledge and professional development for staff in physical rehabilitation, and external mental health professionals' knowledge in physical disability); and (3) links and partnerships with key players (working in silos, external organizational structures and procedures, and actions to improve pathways to access mental health services across external programs and organizations). Conclusion/implications: Managers' insights can guide the development of policies and advocate for change at the level of the organization to support the trajectory of mental health service delivery within physical rehabilitation. This can be done by building capacity on mental health knowledge and skills of their

teams and establishing collaborative partnerships and procedures within and outside of their organization.

Keywords: physical disability, mental health, co-occurrence, rehabilitation services, focus group, managers

Body

Introduction

The importance of prioritizing mental health care is gaining unprecedented attention in Canada and beyond (1, 2). This prompts a critical examination of how services are currently being delivered in specific contexts and for different groups. As such, little is known about how mental health services are organized in physical rehabilitation centers, where the needs of youth receiving services for chronic physical disabilities can be significant, and models for organizing services in physical rehabilitation centers to meet the growing needs youth with chronic physical disabilities and co-occurring mental health problems are scarce (3). A recent scoping review conducted by our team revealed only 2 service delivery models for this population, though twelve key principles pertaining to collaboration and coordination, training and support, and delivery of care were identified across published studies (3). Indeed, the mental health problems documented for many youths in this group are substantial and warrant attention, especially considering the potential long-term impacts on overall health and wellbeing (4). Youth aged 15 to 24 years old are particularly vulnerable as this is when mental health problems tend to emerge, with most mental illnesses and symptoms beginning to develop before the mid-twenties (5). It also coincides with the transition to adulthood which can bring about additional stressors (6). Recent research has consistently highlighted the various mental health challenges faced by these youth, emphasizing the need for early, tailored support for best long-term outcomes (7, 8).

Youth who are already followed by a multidisciplinary team are seemingly well placed to receive holistic care tailored to their diverse needs (9). Unfortunately, previous studies point to a concerning gap where, despite the needs, in many cases mental health co-occurrences are not adequately addressed within the trajectory of physical rehabilitation (8, 10). To illustrate, chart reviews of 60 rehabilitation charts highlighted that despite youths' emerging needs, no mental health assessments were found, and mental health goals or interventions were present in less than half (43%) of charts (10). Subsequently, a qualitative study of 22 youth, parents and clinicians revealed a range of barriers such as little access to mental health specialists within the rehabilitation team and few available tools and professional development opportunities for clinicians, limiting organizational structures and mandates, and challenges with continuity of care during the transition to adult services (8). Indeed, the targeted age range complexifies delivery of services as youth must also transition from pediatric to adult care settings during this timeframe, causing further disruptions (11, 12). These disparities raise questions about the current state of mental health services for youth with physical disabilities and underscore the importance of identifying the barriers and possibilities for improvement as the healthcare system faces pressures to adapt. Managers can play a pivotal role in shaping the practices and procedures of their clinical programs. Aware of and uniquely positioned between the institutional and clinical realities, they can advocate for organizational change to benefit the clients they serve. Previous studies have demonstrated the impact of managerial perspectives on making decisions that shape healthcare practices (13, 14), but not for this population. The experiences and insights of these key decision-makers can shed light on the complex landscape of mental health service delivery and integration for youth with physical disabilities as they navigate their emerging co-occurrence.

As part of a larger study seeking to better understand current practices and services targeting mental health for youth in physical rehabilitation, this paper aims to complement and extend beyond the experiences of youth/family/clinicians across 5 organizations providing rehabilitation services in Canada to include managers at the level of the organization. The aim of the study was to understand the perspectives of managers regarding the challenges, supports and opportunities for mental health service delivery and integration in physical rehabilitation programs for youth with physical disabilities at the institutional level.

Methods

To complement previous findings on current practices and services targeting mental health for youth in physical rehabilitation across 5 rehabilitation centers, a descriptive qualitative research design was chosen to elicit managers’ perspectives on the present state of physical rehabilitation services (15, 16). This approach is useful for obtaining knowledge on practical challenges such as understanding current clinical realities through stakeholder perspectives, while staying close to participants’ words and identifying patterns within this context. Focus group methodology was chosen for this exploratory study because it stimulates discussion on commonalities and differences across settings while encouraging participants to listen to others, elaborate on specific ideas and reflect on their perspectives (17).

Specifically, the research team developed a focus group guide to elicit an in-depth reflective discussion about the organizational context. Discussions amongst the research team to ensure that the questions would not be leading, and review of the questions by a clinical coordinator prior to use helped limit potential bias. Discussion topics included exploring team compositions, program mandates, collaborations between programs and institutions, needs and areas for improvement as well as barriers and supports within the organization. Examples of focus group questions are presented in [Appendix 7] Supplementary File 1.

Recruitment process

Targeted managers (program managers or clinical coordinators) represented five recruitment sites (under 2 umbrella organizations) consisting of rehabilitation centers providing services for youth with physical disabilities in a large Canadian city. The sites were diverse in terms of language (English or French services; both official languages), programs available, constitution of their healthcare team, age range and population served, and were the same recruitment sites for our previous study and as such are described in greater detail elsewhere (8).

Managers were recruited for one of two focus groups (one of which was in English and the other in French) to provide different perspectives on the care provided (and structured) by their programs/organizations. Eligible participants spoke fluent English and/or French and had at least one year of managerial experience in programs for this population to ensure that they had gained a certain expertise and were familiar with their organization’s procedures. They were approached by their local research coordinator who introduced the study and sought permission to be contacted by the research team for further information if interested. At least one manager from each site was purposefully selected to ensure representation of perspectives from all studied contexts.

Ethics approval was obtained from the Research Ethics Board of the *Centre de recherche interdisciplinaire en Réadaptation du Montréal métropolitain* (CRIR; MP-50-2022-1348). All participants provided written informed consent.

Data collection

Data collection occurred between June and July 2023. Virtual focus groups of approximately one hour were video and audio recorded and transcribed verbatim using a secured online platform (Microsoft TEAMS) and reviewed by the primary author (A1), promoting dependability (18). Online meetings have become common post-COVID-19 and have several benefits such as facilitating recruitment, as managers were accustomed to the platform and could have the meeting from their office (19). The focus group were both conducted by A1, a female, bilingual PhD candidate and occupational therapist with qualitative research experience, but no managerial experience or lived experience of disability, who is currently studying rehabilitation service organization. Most participants had not previously met or communicated with A1 prior to introducing them to the study (reviewing the study goals and consent form together), while one had provided feedback on an earlier part of a prior study. Notes were taken by hand during and after the meetings to create summaries complementing the transcripts.

Data analysis

Sample descriptive statistics were calculated with Microsoft Excel. Following Braun and Clarke's six steps for thematic analysis (20), data familiarization of the transcripts preceded modifying an initial coding list and framework based on a previous study by our team after interviewing youth, parents, and clinicians receiving/providing services in the 5 studied sites (8). It was generated using ATLAS.ti software (version 22.0.5.0, Berlin, Germany) by A1. The initial framework was used as a starting point given that the recruitment sites were the same, however targeted participants differed (in this case managers instead of clinicians, youth, and family members). Therefore, the framework was adapted accordingly in subsequent iterations. The first focus group was coded by applying inductive and deductive coding and then discussed with A3 to achieve consensus. The updated framework was then applied to the second focus group, and codes were discussed with both senior researchers (A2 and A3) with experience in qualitative analysis, resulting in additional changes and refinement. In total, five iterations were built on, with the addition of 12 new codes, to encompass the final (English) coding framework to be reapplied to both focus groups (see [Appendix 8] Supplementary File 2). The coded data were then reviewed to identify themes and subthemes representing the challenges, supports, and ideas observed across participants in the two groups. The team concluded that the data fit within the three main themes from our previous research study, though some subthemes differed and were developed accordingly (8). External input on the themes was sought by a consultation committee member (clinical coordinator at one of the recruitment sites who was not a participant in the study). Consensus agreement across the team and detailed notes in addition to the detailed semi-structured focus group guide contributed to the credibility of findings, and findings can be traced back to raw data attached to coded participant IDs, ensuring confirmability (18). Quotes used to illustrate the results were translated to English (if applicable) and back translated by a research assistant independent of the study to ensure fidelity to the essence of the quote.

Results

The focus groups averaged a duration of 59 minutes (range 57-61 minutes). There were nine managers (with backgrounds in clinical rehabilitation) present from 9 different programs across 5 sites (see Table 1 for details). Most (n=7, 78%) of the managers were female, and they had an average of 9.8 years of experience working in their managerial role (range of 3-17 years).

Table 1. Participant demographics

Focus group	#	Sex	Title	Program	Pediatric or adult services	Site
#1 (in French)	1	F	Clinical coordinator	Transition program within a rehabilitation center	Pediatric/ transition age	1
	2	M	Interim program manager	Stroke and non-traumatic brain injuries, return to work programs	Adult	2
	3	M	Program manager	Adapted education and training program for young adults with disabilities / Transition program within a rehabilitation center	Pediatric/ transition age	1
#2 (in English)	4	F	Program manager	Rehabilitation specialized schools and services for assistive technology and communication	Pediatric/ transition age	3
	5	F	Clinical coordinator	Motor disabilities program for youth and young adults	Pediatric/ transition age	4
	6	F	Program manager	Rheumatology, neuromusculoskeletal, chronic pain programs	Adult	5
	7	F	Clinical coordinator	Neurology program	Adult	5
	8	F	Clinical coordinator	Neuromusculoskeletal program	Adult	5
	9	F	Program manager	Return to work, driving rehabilitation, assistive technology, traumatic brain injuries programs	Adult	5

Themes

The managers discussed several considerations that were framed as either barriers or facilitators, namely (1) available clinical resources for mental health; (2) clinician workforce capacity; and (3) links and partnerships with key players. Themes and subthemes are expanded on below (see Table 2), and additional participant quotes are available in [Appendix 9] Supplementary File 3.

Table 2: Focus group themes and subthemes

1. Available clinical resources for mental health	**2. Clinician workforce capacity**	**3. Links and partnerships with key players**
1a. (B, F) Access to mental health specialists within internal team	2a. (B, F) Internal mental health knowledge and professional development	3a. (B) Working in silos
1b. (B) Internal organizational structures and mandates	2b. (B) External mental health professionals' knowledge in physical disability	3b. (B) External organizational structures and procedures
		3c. (F) Actions to improve pathways to access mental health services across external programs and organizations

B = barrier; F = facilitator

Theme 1: Available clinical resources for mental health

Subtheme 1a. Access to mental health specialists within internal team

According to managers, limited staff availability posed a significant challenge in addressing increasing mental health needs for their clientele. They reported that many of the clients in their programs had challenges (such as anxiety) that were evident, whether they were diagnosed or emerging.

So that is a major issue because the same positions are available, we don't have people sitting in these chairs and like, OK, for now, we have, on the team, we have two positions in social services. The two positions are not filled. (…) We do our best and we reach out to other programs for access to social workers. And but it's difficult to manage and that's a problem within the province, like recruiting and having all the positions filled. -24M

One solution to cope with staffing issues raised by the managers was relying on mental health professionals from other teams within the institution. One manager was confident that this approach would greatly improve access to the few professionals working in the institution, as counting on a large increase in staff available to be hired that would meet the growing demands was not realistic.

I think that if we helped each other by program, by umbrella organization, we would be able to cover the waitlists for psychologists. –13M (translated)

Subtheme 1b. Internal organizational structures and mandates

There were few structures or procedures in place, if any, to help address mental health aspects among their clients. As one manager noted: '*There's not really any procedures or politics to address that issue. The team evaluates. If there are, we will refer to partners, but we won't be involved with that aspect*.' -23M

Program mandates within the organizational structure clearly focused on physical disability diagnoses and their implications, which limited the capacity to adequately address mental health concerns within their clientele. It was very clear to all managers that the focus of their program was on the physical aspects: '*But we are really, we have a mandate of physical health*.' -11M *(translated)*

However, the clinical reality made it so that roles and expectations were not always as clear-cut, which made for some complex decisions to be made.

It's a bit beyond our mandate sometimes too, like our psychologist is very open to working with the clients and she would probably work longer with them if she felt… because technically our mandate was for the rest, to work on things that are related to mental health that are related still with their physical impairments, (…) but then she's questioning, should I continue or not because that's not technically our mandate and we have long wait lists and the time that's allocated in the physical disability program is this amount of time and this amount of resources. And so I think even for the therapists themselves, it's hard because they feel conflicted between what they should do clinically, but also what they need to do within the institution. -22M

According to managers, clinicians felt caught between wanting to provide longer term support and being limited by their organization and needing to provide support to others. However, if the client was not able to access mental health services in a timely manner in parallel, teams were inclined to make exceptions to the rule and try to support them as best as they could.

Theme 2: Clinician workforce capacity

Subtheme 2a. Internal mental health knowledge and professional development

While there are some professionals hired as part of the psychosocial team that have more in-depth mental health knowledge (such as social workers and psychologists) to address aspects of coping with their diagnosis, managers raised the issue that some of the rehabilitation specialists in their teams were much less comfortable addressing co-occurrences. Their skillset was generally limited as they were less accustomed to identifying and addressing emerging mental health problems in the context of their work with youth who have physical disabilities.

But the idea is the same, to say that we offer services where the bulk is in physical disability. And we have support for the mental health side because it's not our specialty. -12M (translated)

Also, the mental health team seems to think that because they have a physical disability, the mental health aspect should be treated by our team, but our team doesn't feel they have the expertise to deal with the mental health part of the diagnosis. So there's a sort of, I find the clients were stuck in between the two departments. -21M

Roles seemed to not be well defined when it came to mental health, as questions arose as to who was better positioned to take it on. Many rehabilitation specialists have had limited training in this domain, though it was starting to become more of a priority within the organizations, as one manager mentioned: '*We've done a lot of training for the staff recently on suicide. Many of them have been trained on detecting suicide risk, the screening tools and how to go about that after.' -21M*

They also compensated for the limited knowledge in mental health by fostering interdisciplinary collaboration and working closely as a team through frequent team meetings and case discussions. This came up as a facilitator ensuring a collective approach to addressing mental health complexities.

What helps a lot is that we have the team discussions and that we are like a multidisciplinary team. (…) They don't diagnose anything or, we might not say the right terminology of what the patient is telling or showing us, but we explain it as much as possible to the team. (…) So this is what makes our teams very, very strong in looking at, *other than the physical disabilities, what are the other factors… it could be family, it could be a work, it could be, yeah, um, social whatever. And so discussions are made to present these difficulties and having the support from the other professionals. -24M*

Subtheme 2b. External mental health professionals' knowledge in physical disability

The physical rehabilitation managers noted challenges when attempting to refer clients to external mental health services (i.e., offered outside the organization). Some managers highlighted that they and their teams were often faced with resistance, in part stemming from a lack of understanding or willingness to accommodate, or simply not knowing how to address the co-occurrence from the mental health professionals.

Well, it really works both ways. And when we met with the mental health team, we could see that they didn't know us that well either, so they don't know what we're doing. (…) So I think that it would be helpful if they were aware of certain things so that we could work really, really close, you know, in a real collaboration. -26M

So it's psychologists that are not all suited to work with our clientele either. -11M (translated)

Limited awareness and expertise were brought up where external mental health staff would not always consider how a physical disability could impact care. The managers felt that both sides would benefit from knowing more about how the other worked.

Theme 3: Links and partnerships with key players

Subtheme 3a. Working in silos

Navigating external mental health services proved challenging due to confusion about how to access different programs and services and overall lack of clear pathways to link between the two areas. Even accessing an initial contact person was difficult, as organizations are set up in separate silos which impose more work for those wanting to collaborate between them.

When the person does not have a mental health team, but has a need, it becomes much more challenging to find a team or resource that will be able to support them. So, to add, to be less in silos, to gather, but I think that it will have to go more by partnerships and collaborations rather than integration of a sole offer of service. -12M (translated)

Overall, there was a clear divide between the physical and mental health services as distinct entities, down to the budgets that fund them. This made collaboration efforts less likely.

The whole organization of services at the ministry level, I mean, there's some budgets for mental health and budgets for physical rehab, so if they're not talking to each other and they're not like, planning for a mixed diagnosis population, it'll never trickle down to reorganizing the services at our level. Because we're all caught up with our budgets and performance and…. So something has to be done at the ministry level for that aspect. -23M

Subtheme 3b. External organizational structures and procedures

The requirement of having a diagnosis of mental illness to access external services was brought up as a significant barrier which delayed the possibility of receiving necessary care due to long waits for psychiatric evaluation and diagnosis by a psychiatrist or mental health professional. It was suggested that presenting with the relevant symptoms should be enough to access services. Additionally, waitlists for many of the programs specialized in mental health also contributed to delays that could extend for over 1.5 years (as was specified in one case example where the youth is still waiting to be followed by a psychologist externally), as the demand exceeded the available resources. There were sometimes limitations in terms of physical accessibility. These structural obstacles hindered timely access to essential mental health support.

And we've tried very hard to make links with our mental health partners. But often our clients don't qualify for the services, so especially when there's like a significant motor impairment, then they don't qualify for the mental health services because let's say the place is inaccessible (…) so for sure when there's a comorbid situation of a significant physical disability, there's a lot less services out there for us to even partner with and refer to. -21M

The absence of streamlined processes made it difficult for youth with physical disabilities to be referred to mental health programs or services and access the support they need in a timely and efficient manner. Managers noted wanting a roadmap to better understand where to orient youth and how to navigate available services via well-defined corridors. On top of that, there was little consistency of external mental health services, and it was noted that they often lacked the capacity to meet the needs of this clientele.

So, that's it, partnership and once we have it, sometimes it works well, but it changes a lot. And I also know that there is a lack of staff in mental health, that's a reality. -11M (translated)

Subtheme 3c. Actions to improve pathways to access mental health services across external programs and organizations

Preliminary inter-institutional meetings (between rehabilitation and MH organizations) were arranged by some of the teams at 2 different sites and demonstrate a proactive first step to exchange information and form direct connections with external contacts who could help guide the referral process or make mental health consultants available to collaborate on the case with.

We've had a meeting recently with the Centre d'Excellence, that's something that, they've been providing us with quite interesting information that we didn't really know prior to that. So we haven't really experienced that pathway yet, but I'm definitely keeping these contact people. If another situation like those can present, at least we're gonna know who to talk to and perhaps maybe get some help more quickly so that we can share the information with the partner and hopefully transfer the client to the right resource prior to having them come back once they're ready, to continue with the physical rehab. -25M

At (our center), it was our initiative because it was in one of my teams that there was a lot of challenge getting mental health support from our [umbrella organization] and we didn't know exactly what they were doing. So we asked them to come and present to us their services. With the goal of eventually being able to work a little bit more closely together and being able to get support from their team and make sure that the client would have like a more fluid, you know, transition of services. -26M

A few sites were quite proud of the work they were doing and wanted to share their models with other programs, such as the Social Circus program promoting social participation of transition-age youth with physical disabilities (21). The exchanging of information about effective practices, innovations, and models of service delivery with other teams would help foster collaboration and improve overall pathways and efficiency of services.

There are other teams that want to reproduce a model of our program that would be not exactly the same, (…) but from the point of view that we have modalities that really work well. It would be interesting at some point to exchange ideas with them. -13M (translated)

Discussion

This study provides insight complementing what was raised by youth, parents, and clinicians regarding mental health services in the context of physical rehabilitation in our previous research (8), in this case as described by program managers and clinical coordinators. Challenges, needs and current supports and facilitators for overcoming barriers and improving services are discussed in the context of their (internal) programs and in collaboration with (external) partners, contributing another layer of information.

Healthcare systems are largely guided by a biomedical model which focuses on supplying diagnoses and curing disease, often in the short-term, rather than considering long term management and the broader psychosocial contexts (9, 22). Service delivery in rehabilitation settings for youth with physical and other comorbid disabilities is complex as physical and mental health implications are intertwined and impact each other (23). The emphasis on exclusively physical aspects at the level of the organization despite an increase in overall mental health needs may therefore hinder the provision of long-term follow-up and comprehensive support addressing the client as a whole, as illustrated by Theme 1 (available clinical resources for mental health). Having limited access to mental health specialists and resorting to ‘borrowing’ professionals from other departments reflects the strain on internal resources and the increasing demand for mental health support within physical rehabilitation settings.

However, it is not always a question of organizational resources, as managers pointed out that there were positions for social workers and psychologists that were unfilled. This leads us to question why certain professionals working in the realm of mental health are not drawn to work in physical rehabilitation settings (24). It is plausible that mental health specialists may not feel competent or may have limited knowledge in providing services for those with physical disability, as illustrated in Theme 2 (clinician workforce capacity). A systematic review showed that mental health staff overall had inadequate training and knowledge impacting their ability to work efficiently with individuals with intellectual disability (25). Further studies focusing on perspectives of mental health specialists are needed to examine this assumption regarding working with youth with physical disabilities.

Many rehabilitation specialists are equally inexperienced in addressing co-occurring disabilities or have had limited training in mental health, from their university studies and professional programs (such as for physical therapists), to continuing education (8, 26). Unfortunately, there are very few trainings available relating to physical disability and mental health (27-29). Professional development opportunities that are relevant for this specific population are scarce and would therefore be a valuable avenue to develop, as supported by the key principle of staff training revealed in a recent scoping review (3). Clinician workforce capacity emerged as a growing area needing attention within institution, as highlighted by both managers, and clinicians in our previous study

(8), but managers talked about its relevance for external mental health teams as well (Theme 2).

Several challenges arose when discussing referrals to mental health teams as services generally fell into silos that were not well connected (Theme 3: links and partnerships with key players). As mental healthcare is separated into a distinct area, there may be an incomplete picture of clients' global needs and ambiguity over which service is responsible for which part of the care. Roles were not always well-defined, and it was often unclear where to draw the line as symptoms emerged, or to what extent the physical rehabilitation team should address presenting mental health difficulties, particularly if they could not access other supports in a timely manner. Indeed, it was difficult for teams to find appropriate external services for youth due to unclear or limiting admission criteria and the lack of procedures in place to facilitate referrals. This may be in part due to associated costs and required resources for the external programs, and limited communication between the two regarding ways to work together in parallel. Even if some youths were eventually linked to mental health teams, both services may end up managing some of the same aspects (in a fragmented way) while on the other hand, leaving large gaps in care. These elements are all crucial to consider when developing efficient service delivery models, and echo what was concluded in a recent scoping review, where the key principle of collaborations across institutions was prominent (3). Resistance is perhaps present in both directions, and a cultural shift in how healthcare organizations work is needed, including allowing more time for meetings to discuss and liaise between different institutions and programs (22). Initial actions taken by managers to foster partnerships and exchange information between the two sectors are promising and demonstrate leadership and advocacy as they strive to provide the best care for their clients (3).

The three main themes arising from the focus groups with managers also came up as important from the perspectives of youth, parents, and clinicians in our previous research with youth, parents, and clinicians (8). Present findings complement ideas pertaining to accessing mental health professionals, the need for additional training, the impacts of organizational structures and mandates, and the importance of improving pathways to access mental health services. These elements also arise in other studies on organizing services and implementing efficient service delivery models for youth with disabilities (9, 30, 31). A major change in organizational policies and structures allowing flexibility in provision of care to facilitate referrals (with less strict admission criteria and direct pathways) and mental health service delivery within the institution, supported by joint funding would be envisioned for entities to work together towards mutual goals for youth wellbeing. Leadership at the public policy level is therefore needed to request more overlap in funding and programming, and improve sharing of information, service coordination and integration for youth with physical disabilities and co-occurring mental health problems across sectors. Digital health innovations to facilitate the referral (and self-referral) process that allow clinicians to communicate about the status of referrals may also be an important consideration in this context (32, 33).

Limitations

Though our data represents a relatively small sample of managers from five sites (having different resources and supports in place) in one city (potentially limiting generalizability), it provides an initial and important contribution to an under-researched topic. Additional focus groups including different sites and contexts could have allowed more participants to share their ideas and possibly more varied perspectives. It would also be important to include managers working in mental health institutions to add their perspectives to the discussion. Though the research team built on a previous framework that was validated at an earlier stage which contributed to similar themes arising, additional measures such as inductive analysis, frequent team discussions throughout multiple versions of the coding framework contributed to the rigor and helped to provide additional insights on the issue.

Conclusion and implications

Managers highlighted several considerations which can be addressed through building capacity on mental health knowledge and skills of their teams and establishing collaborative partnerships and procedures within and outside of their organization. Findings can guide the development of policies and advocate for change at the level of the organization to support the trajectory of mental health service delivery within physical rehabilitation.

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Chapter 10: Comprehensive Discussion

Summary of Findings Resulting from the Studies

The overall objective of this thesis was to contribute to a better understanding of current interdisciplinary rehabilitation practices and services for youth with childhood-onset physical disabilities who experience mental health problems. Until recently, there was scarce evidence to indicate even the prevalence of mental health problems among youths with physical disabilities, not to mention their significant healthcare needs and limitations in services available to them.

Several gaps, challenges, supports and suggestions pertaining to the overarching objective above were highlighted across four manuscripts. The scoping review revealed that only two models of organization of services for the targeted population are available in the published literature, though the twelve key principles identified can be used to guide service organization for this group and inform the development of future service delivery models that are collaborative, supportive, and holistic (Objective 1). The chart reviews from across five sites confirmed that many mental health problems were present among youth with physical disabilities, yet associated goals and interventions (such as those pertaining to emotional management) were addressed in only 57% of charts, and not all youth had received or been referred to pertinent mental health services (Objective 2). The interviews highlighted the practice needs and workforce capacity challenges of rehabilitation specialists, and navigation and access issues faced by youth needing mental health services and their clinicians, as well as their families' involvement and advocacy (Objective 3). Finally, the focus groups with managers added another layer of insights at the organizational level and solidified the necessity to train staff to be more well-rounded and to partner with external organizations to optimize available resources (Objective 4).

The three studies following the scoping review contribute to a deeper understanding of current local rehabilitation practices and services and provide complementary results. While there is increased awareness regarding the problems and initial steps are being taken to address them at the five different sites, there is still much to be done across multiple levels to drastically improve rehabilitation practices and access to services for youth with physical disabilities and co-occurring mental health problems.

Recommendations and future directions derived from the studies' findings include providing better links between rehabilitation teams and external mental health providers and increasing youth and their families' awareness of existing supports within and external to the organization providing rehabilitation services. As not all rehabilitation staff will have the knowledge and experience required to address a variety of mental health problems that may arise within their caseload, it is also recommended that personnel with expertise in mental health are accessible to provide guidance as needed, and that specific training be made available. Some suggestions can be implemented more easily than others, such as certain key principles presented in the scoping review that would require a re-allocation of existing resources rather than creation of new positions requiring additional funding (e.g., attributing a key worker role to one of the staff). Suggestions for ideal care listed in the interviews (e.g., to improve pathways to access mental health services across programs and organizations) may prove to be more complex to attain but are worth addressing nonetheless as changes are necessary on multiple levels. Integrated findings are summarized below.

Training in Mental Health for Rehabilitation Professionals

Provision of mental health training for physical rehabilitation professionals is one of the key recommendations stemming from the thesis results. It was a concern that came up in both the **interviews** with clinicians and in the **focus groups** with managers within the theme of "workforce capacity". Clinicians voiced having little expertise pertaining to co-occurring disorders and expressed that they did not always feel competent in addressing mental health problems that presented among youth they followed. Managers described how some of their staff did not have the required skillset to manage all the complex clinical cases they followed. This also emerged in the **scoping review** via the category of "training and support" and one of the key principles to guide service organization (i.e., staff training) which encouraged workshops to be made available for clinicians so they would feel well prepared to work with clients that had mental health problems. This may shed light on the findings from the **chart reviews**, where 43% of the reviewed charts did not have goals or interventions targeting mental health aspects despite having identified a mental health problem. Rehabilitation professionals can therefore be provided with a variety of training opportunities to build workforce capacity in different aspects of mental health screening, assessment, and service delivery.

As highlighted in a systematic review on pathways for youth mental health services, primary care providers must be adequately trained to detect mental health problems, provide support and treatment, coordinate with different healthcare entities, and refer elsewhere as needed (MacDonald, Fainman-Adelman, Anderson & Iyer, 2018). Unfortunately, many rehabilitation specialists have limited mental health training because of their professional backgrounds. For example, physical therapists have little to no course content specifically on mental health during their university studies. A scoping review of 135 studies found that physical therapists' clinical practice had a strong focus on physical health and function with limited attention to mental illness, and training variations across different countries influenced the opportunities they had to develop skills to address mental health beyond the physical factors (Heywood et al., 2022). Occupational therapists have a longer history working with people that have various mental health problems, as these were indeed at the root of the developing profession during World War I (Sedgwick, Cockburn & Trentham, 2007). Though occupational therapy students do have mental health courses in their curriculum, they do not necessarily continue to work in that field, gain experience and develop competencies. A recent cross-sectional survey (n=52) and interview (n=6) mixed-methods study found that only 65% of educators felt that occupational therapists were well prepared during their education to become qualified mental health professionals (Nissen, Ikiugu, Barash, Kathol & Oorlog, 2023). Some occupational therapists undertake more in-depth post-graduate mental health training, such as pursuing a psychotherapy license (Marshall et al., 2022), though this is far from the majority. Occupational therapists can provide a unique contribution to mental health from an occupational perspective, however the development of strategies to increase professional resilience can encourage more advocacy for their role in addressing mental health no matter which setting they work in (Ashby, Ryan, Gray & James, 2013). Overall, it is important for all rehabilitation specialists to have a good basic knowledge of mental health and how it manifests in different populations. Indeed, it is plausible that there is a need for more interprofessional curricula incorporating co-occurrences of mental and physical health problems to increase awareness for the students (such as including more case studies that involve both) as courses have traditionally also been organized, and taught, in distinct silos. It would therefore be helpful to integrate content related to mental health in university curricula when teaching courses related to physical disabilities and training future clinicians.

Across the five sites studied in this thesis project, two professions (social work and psychology) provided the bulk of mental health services within rehabilitation, however they presented with their own set of challenges. Most psychologists working with this specialized population lack formalized training in pediatric rehabilitation psychology, and training pathways must be improved to build their capacity working with children and youth with physical disabilities (Kaufman, Lahey & Slomine, 2017). This was echoed by the psychologist **interviewed** in Study 3. There has been some emphasis on more formal training at the postdoctoral level to build well-rounded rehabilitation psychologists that have the competencies to work with youth that have co-occurring health problems, though greater uptake is needed (Stiers et al., 2015).

Perhaps the responsibility of addressing mental health needs is to be shared by all rehabilitation team members, while each remaining within their scope of practice, in a truly multidisciplinary manner (Scratch et al., 2020). Post-professional continuing education for rehabilitation professionals should therefore be considered to make this feasible. The thesis findings uncover the need for pertinent training to be (created and) made available to rehabilitation staff to increase their mental health knowledge base and resulting competence. A survey of 153 healthcare professionals who worked with persons with intellectual or developmental disabilities found that the most influential experiences on their career choices involved pre- and post-professional disability training, which increased their sense of competence and willingness to work with clients presenting with complex, co-occurring cases (McCann, Smith, Urbano, Dykens, & Hodapp, 2023). Increased self-efficacy due to specialized training and interactions with individuals having co-occurring disabilities was noted, supporting the claim that such trainings should be made available to rehabilitation professionals which can encourage them to work with this population (Smith et al., 2020). There is already progress in this direction, as some clinicians expressed in the **interviews** that they had undergone training to screen for suicide risk among their caseloads. This was reiterated in the **focus groups** with managers. Other similar workshops addressing complementary aspects would have value in being rolled out across staff.

Specific training needs

A systematic review (n=13 articles) looking at healthcare services for individuals with intellectual disabilities found that health professionals lacked the required knowledge and skills to support physical and mental health needs in general and aimed to identify what was missing (Hemm, Dagnan, & Meyer, 2015). Perceived training needs included general communication strategies, additional mental health knowledge and profession-specific needs, leading to the authors suggesting the production of a core training package to be used across professions that contained profession-specific elements (Hemm et al., 2015). A scoping review of 16 studies also looked at specific disability training needs (including types and amounts) across different healthcare professions (e.g., general medicine physicians, clinical psychologists, nurses) who worked with individuals that had intellectual or developmental disabilities (e.g., Down’s syndrome, cerebral palsy). Lack of knowledge was the biggest theme, and a major barrier to more disability-specific training was in fact related to the absence of relevant curricula (Smith, McCann, Dykens & Hodapp, 2020). This ties into the **scoping review**'s second category of key principles on "training and support" and a component in one of the included models about supporting the rehabilitation team in providing comprehensive care (Scratch et al., 2020). Available resources made up another theme whereby healthcare professionals reported a lack of knowledge concerning existing resources to support families and additional continuing education to increase their skillset, therefore not knowing how to access any supports and information that did exist (Smith et al., 2020).

The need for appropriate tools to screen for and assess mental health problems

Some clinicians brought up, during the **interviews,** a challenge that they were facing with regards to screenings and assessments for identifying mental health problems. The dearth of specific tools targeting mental health adapted to this population was also raised in the scoping review by Lal and colleagues (2022), and no assessments targeting mental health were found in the **chart reviews** across the five sites. While it is possible that specific assessments done by psychologists or other professionals were undertaken but simply not found during the chart review search (as some documents can be stored in office charts that are not integrated within the multidisciplinary rehabilitation charts), typically the results should be documented and accessible to the team. Follow-up should be adapted to youths' holistic needs and goals within the rehabilitation context, which implies that in addition to having appropriately trained professionals, access to adequate assessment tools is necessary. Whether screening for mental health problems is part of their program mandate and standard procedures is an important consideration, followed by whether they have access to the tools to do so (if they even exist to begin with). As noted by some of the clinicians in the **interviews** (including the psychologist), adapted screening and evaluation tools are not readily available and would need to be adjusted to the population to consider different limitations and to establish new norms for this group in order to be clinically useful.

Training of mental health professionals on physical disability aspects

Training mental health professionals to be proficient in working with those who have physical disabilities should also be considered. This was brought up by managers in the **focus groups** and some clinicians via the **interviews** who had experienced barriers when trying to refer youth to external mental health services. The resistance they were met with was likely in part due to the mental health team having insufficient knowledge on physical disability aspects of care to support the potential new clients. Similarly, a scoping review (n=27 articles) on the attitudes and training of psychiatrists and other mental health professionals working with individuals that had co-occurring intellectual disability and psychiatric disorders emphasized the need to improve their knowledge, competence and attitudes pertaining to these comorbidities via specific disability training and practice opportunities (Werner & Stawski, 2012). The findings and many of the recommendations stemming from the scoping review (e.g., the types of training proposed) can likely be transposed to those with physical disabilities and mental health problems. However, these assertions would need to be verified from the mental health professionals' perspective.

Improving Integrated Services within Physical Rehabilitation

Integrating mental health care services within physical rehabilitation settings came up across the studies of this thesis from different angles. Our **scoping review** highlighted a service integration model that detailed how to incorporate mental health professionals into a rehabilitation hospital setting in two phases (Scratch et al., 2020). In addition, the scoping review highlighted several key principles for ‘delivery of care’ supporting integration such as interprofessional work to address needs holistically and conducting psychosocial evaluations internally which links to previous research (Lal et al., 2020) where ‘value for comprehensive care’ emerged in the content analysis. The **chart reviews** indicated that mental health services were received in-house in 24 of the charts (40%), while there were 14 youth (23%) that had not been referred elsewhere and still had unmet mental health needs. A main theme throughout the **interviews** pertained to the ‘available clinical resources’ within the physical rehabilitation setting such as the access to mental health professionals and the organizational structures and mandates in place that impacted the ability to provide integrated mental health care. This was raised by clinicians, youth, and parents. Similarly, the **focus groups** with managers also resulted in a theme pertaining to ‘available clinical resources for mental health’ which emphasized the resources and structures in place (or that needed to be established) to address mental health needs.

Several benefits stem from addressing mental health problems directly within rehabilitation settings, assuming the presence of adequate professional and material resources to make it possible. Indeed, screening and addressing some preliminary mental health symptoms within the physical rehabilitation context would target a pressing need for early intervention that could greatly reduce negative impacts of mental health problems among youth with physical disabilities who are at risk (Scratch et al., 2020). Clinicians working in pediatric rehabilitation environments for the most part already know their clients well by virtue of having worked with them for a large part of their life. In addition to saving time not having to become familiar with medical histories of new clients as is the case when referred to a new team, there is the added benefit that clinicians have likely developed a strong therapeutic alliance with the youth over time. The importance and power of a strong therapeutic rapport in mental health care and pediatric service delivery on health outcomes is non-negligible (King, 2017; Kornhaber, Walsh, Duff & Walker, 2016).

Multidisciplinary teams working in complementarity

Working with different rehabilitation professionals that have a range of clinical backgrounds is beneficial as team members can discuss complex cases in meetings and combine their insights and complementary expertise to guide complex treatment plans. This echoes one of the key principles coming from the **scoping review** (interprofessional work) as well as strengths listed by the clinicians in the **interviews** and managers in the **focus groups** regarding their teams (under the subtheme of ‘access to mental health professionals’). Results coincide with a recent study which found that factors facilitating optimal care delivery for children with special healthcare needs included having a coordinated interdisciplinary team that could provide psychosocial support as needed (Ayoub, Rava, Lewis Hunter, & Kuo, 2022). The combination of skills and professional knowledge across multiple disciplines working towards common clinical goals has proven beneficial across different populations in terms of improved patient outcomes, enhanced program efficiency, and increased overall staff morale, resulting in a better work environment (Haworth & O’Leary, 2022).

To have optimal organization and delivery of holistic rehabilitation care, the way in which job descriptions are written and programs are structured needs to be carefully looked at. Indeed, specific clinical mandates potentially constrain the types of services and interventions that rehabilitation professionals can provide within their teams, even if they have the skills to do more (alluding to the key principle of accessible and flexible care described in the **scoping review**).

The need for support for complex mental health cases

When working through complex clinical cases, the importance of support from team members is crucial. This came up in the **interviews**, with examples such as having regular multidisciplinary team meetings to discuss challenging cases and having access to expert consultants when necessary to guide the provision of care. One clinician also shared that they had paid for peer supervision outside of their organization to obtain the necessary support. Managing complex cases with mental health components also came up in the **scoping review** via one of the two models, the biopsychosocial service integration approach elaborated by Scratch and colleagues (2020), which emphasized a stepwise approach to ensure that rehabilitation clinicians were well supported by mental health experts to address mental health needs within their setting. The effectiveness of multidisciplinary collaboration in rehabilitation is enhanced through good communication and empathic understanding of different roles and realities, just like in a therapeutic relationship. An article on the topic explored barriers and facilitators to empathic teamwork and suggested ways in which rehabilitation students could perfect their communication skills (e.g., practice active listening) to be best prepared for their future professional roles working within a multidisciplinary team (Koch, Gitchel & Higgins, 2009).

Breaking Organizational Silos and Establishing Inter-Institutional Partnerships

In addition to improving the offer of service within physical rehabilitation settings, increasing collaboration with organizations specializing in mental health care would be beneficial to ensure that all needs are met. ‘Collaboration across institutions’ came up as a key principle from the **scoping review**, and the Client Network Consultation model that was described also supported interagency collaboration (Van Dongen, Sabbe & Glazemakers, 2018). Additionally, the **chart reviews** found that 30 charts had documented mental health services provided externally (50%) in addition to 18 referrals to other sites (30%) that were pending. However, there is an overall sense of frustration and confusion with regards to navigating referrals in addition to communication barriers expressed by stakeholders across thesis studies. Youth and their families often felt like they were on their own and ill-equipped to navigate the system and understand how to have their evolving needs met. Indeed, the **interview** participants discussed the need for improved pathways to access mental health services across programs and organizations via the theme of ‘links and partnerships with key players’. The **focus groups** also highlighted some concrete actions to improve those pathways and counter the silos (which came up as an important subtheme), reiterated below. Unfortunately, a variety of inter-institutional barriers can complicate establishing partnerships, such as distinct electronic information systems that limit communication of information as staff must rely on paper-based summaries and extensive intake interviews rather than full client health records being available (Hamdani et al., 2014). Research studies that explore how technology can be used to facilitate access to youth mental health services and that leverage digital health technologies to streamline pathways to mental health care, empower youth and families in the help-seeking process, and facilitate communication between service providers are in progress and warrant further attention (Lal, 2021; Lal, Starcevic & Fuhrer, 2020).

Processes and resources to enable collaboration across institutions

The importance of having positions filled with competent staff who can be available for team meetings and to coordinate individualized intervention plans with external partners (as well as provide some in-house services) are needed to implement holistic rehabilitation interventions that meet the wide-ranging needs of youth with physical disabilities and co-occurring mental health problems. Having a specific contact at the partnering site and a better understanding of how to navigate referrals (e.g., what information is needed, what are the inclusion and exclusion criteria) is crucial to create links between programs. Managers in the **focus groups** discussed concrete actions such as initiating meetings to better understand the mental health programs' functioning and identifying contacts for future guidance and support. Clinicians mentioned that it would be helpful to have a roadmap or diagram to facilitate navigation once they had a better understanding of the possible offers of service from various partners. Youth and family members also felt unclear about the referral process to other programs and wished for more transparent communication between stakeholders and overall to be more involved in the process. The notion of 'family involvement' came up in both the **scoping review** (as a key principle) and in the **interviews** (as a subtheme pertaining to 'family involvement and advocacy') and highlights the importance of including family members as an integral part of the multidisciplinary team as experts on their child's needs.

These considerations are especially important during this timeframe as youth are transitioning to adult care and losing many of their established connections. Indeed, the **interviews** brought to light aspects pertaining to the ‘continuity of services during the transition to adult care’ across youth, parent, and clinician participants. Flexible processes such as undertaking gradual transitions (starting early and with a less strict age limit) to ensure that clients are well connected to all indicated services, as proposed in the literature, would be ideal to reduce the strain on youth and their families during this delicate time (Nguyen et al., 2023).

Managers in the **focus groups** suggested that the mental health clinicians also had barriers and limitations with regards to including youth with physical disabilities in their care partially due to lack of information of what following a youth who had a physical disability, in addition to the mental health problem, would entail. Therefore, more effective communication systems across service levels and programs should be established to clarify certain elements and determine how to best work in collaboration. Several meetings that have already taken place with the mental health sector to become acquainted with those teams, their overall functioning, and how to navigate their services, at the initiative of clinicians and managers, have provided some hope to establish better links. Once stronger partnerships are in place, collaboration across different settings can foster a comprehensive approach to mental wellness by sharing valuable resources and knowledge, thereby leveraging collective expertise to address the evolving needs of youth with physical disabilities.

Strengths and Limitations

This thesis provides new knowledge in an understudied area on rehabilitation services and practices pertaining to mental health concerns in a specific local context and has several strengths. The findings represent a collective, multidisciplinary perspective including stakeholders from different backgrounds (youth, parents, five types of rehabilitation professionals and managers) across five sites serving both the English and French communities in Greater Montreal. The non-categorical approach to care taken here can positively impact the organization of services, health professional education and research by including a wider variety of participants in studies and training well-rounded professionals who have the necessary skills to work with more complex cases to ensure that all youth healthcare needs can be met (Miller, Gardiner & Rosenbaum, 2023). Results have been presented at several scientific conferences (see Appendix 10).

The themes and suggestions that emerged across the studies can be relevant to other (pediatric and/or adult) rehabilitation sites yet should be considered with caution. Transferability of findings to other groups may be supported by having looked at different levels of service provision across several sites, rather than solely individual level aspects. However, the heterogeneity of sites can also be a limitation as many factors are linked directly to the barriers and facilitators within the specific settings, though they were selected as they provided services to the same population with the intent to identify some commonalities across sites. Clearly, there is a risk that findings only be applicable to the targeted rehabilitation sites (that are not necessarily representative) and in relation to the specific population of youth with physical disabilities since different regions may have differing policies and resources that subsequently impact the barriers and supports in providing integrated care. In this case, the aim was not for statistical generalization, but rather to begin to understand general themes related to delivery of coordinated care that may be important to consider.

While many types of physical disabilities (affecting mobility) were included in this study, we did not specifically record the severity of these disabilities (except in part in study 3, by excluding those with major cognitive problems that would impact the ability to participate in an interview). A broader range of disabilities including those with more complex physical disabilities, as well as those with less obvious diagnoses such as developmental coordination disorder (DCD) could be included in future studies. Doing so may help shed light on whether severity of disability has an impact on mental health and on access to services, as this variable is inconsistently reported in available studies (Lal et al., 2022).

Another main limitation impacting the presented work is that the perceptions of mental health professionals working in mental health settings (e.g., specialized psychiatric hospitals where youth may be referred to) were not explored. Their perspectives on how they can work with youth that have physical disabilities (including their perceived competence and training needs) would be important to understand the full picture and enable effective partnership creation. Few models of organization of services or studies describing inter-institutional collaboration applicable to this population were available in the published literature, though it is possible that some information can be found in the grey literature which was not explored in the context of this thesis. Additionally, models for collaborative care in mental health could also be highly relevant (e.g., Reist et al., 2022), though they are yet to be evaluated for a population of youth with physical disabilities. Moreover, many groups are likely doing important and relevant work in different clinical sites across the province, country, and world, but the knowledge and know-how is not (easily) accessible.

Specific challenges inherent to the types of data collection chosen for the studies were also present. Difficulties related to conducting chart reviews, particularly when looking across diverse clinical sites, include the selection of charts (e.g., undefined criteria, different systems or codes used, low availability of staff), accessing the physical charts (e.g., having a designated spot on-site in multiple locations), illegibility, and the fact that they are not organized in a standard way (Hess, 2004). Even languages of documentation can vary (e.g., some in French and others in English in Study 2), even within a same treating team or program. Additionally, it is hard to capture certain practices and activities such as team meetings in a clinical chart. Data extraction is complex as for the most part, variables of interest are not binary (yes, no), so one must also establish how much text to extract. As for the interviews, the initial intention was to employ a matched sampling method involving youth-family member-clinician triads, but it was finally not feasible as we recruited less family members than anticipated which may limit the richness and scope of the findings. Challenges associated with focus groups include potential difficulty in gathering a representative sample, and the fact that participants may be influenced by what others say and choose not to respond with their thoughts, especially when they differ from what was shared by other participants (Kitzinger, 2006).

With regards to integrating aspects of patient-oriented research, it was difficult to recruit stakeholder partners who were available throughout the project in a consistent manner. Several consultants contributed feedback at different points in time, but it would have been ideal to have them involved more significantly, for example, in joint meetings to discuss together, and regularly over the course of the project. Those who agreed to participate ultimately had little time to offer. They had the potential to bring valuable input with regards to the needs of youth and their families, the clinical realities faced, and wishes for integrated rehabilitation services, but in the end, consultation was minimal despite engagement efforts.

Overall insights generated by this thesis cannot be considered as explicit guidelines or recommendations, though further research can build on these findings to create guidelines (as described in more detail below).

Implications for Clinical Practice and Policy

The findings from the four studies highlight rehabilitation practices and service delivery activities, and other rehabilitation sites can draw on them when seeking to improve service delivery for youth with co-occurring disabilities. Understanding the mental health and related needs of youth with physical disabilities and their access to, and use of, mental health services is extremely important for identification and early intervention to prevent progression to more severe problems. Such knowledge lends further support to the development of training to address youth-specific service delivery, integrated rehabilitation service approaches to improve internal processes and resources, and established links leading to inter-institutional partnerships that can comprehensively address the mental health and well-being of young people with physical disabilities.

Some of the initial insights gathered across studies implicitly rely on clinicians for their implementation, which raises the question of whether and how tasks such as conducting assessments, developing holistic treatment plans, and navigating external resources can be manageably integrated into their existing workload, or if these would require additional funding and resources. Challenges in accessing comprehensive mental health care highlight a crisis in the healthcare system despite previous investments and reforms. Deeper issues include the healthcare worker shortage with high turnover and burnout rates, exacerbated by difficult working conditions and systemic inefficiencies (Willard-Grace et al., 2019). Progress therefore requires a reimagining of healthcare delivery, informed by collective experiences of stakeholders.

The development of policies and structures suggests the involvement of organizational leadership. Leadership at the mid-management level across partnering organizations is crucial in committing staff, resources, and training time to the improvement of mental health services, influencing changes to organizational and clinical practices. ‘Leadership’ emerged as a key principle in the **scoping review** within the category of ‘collaboration and coordination’, as champions are needed to advocate for major changes across sectors. Triangulation of results from multiple levels can provide insights into how organizational changes can be introduced in complex systems of care (Da Ros, Pennucci, & De Rosis, 2024).

Policy initiatives such as the United Nation’s Convention on the Rights of Persons with Disabilities (CRPD), which aims to “ensure that persons with disabilities have the right to the highest attainable standard of health without discrimination”, can influence the resources made available at a national and provincial level, such as which trainings are offered (CRPD, 2006, p.18). This thesis sets the stage for the development of guidelines for the organization and integration of mental health services within physical rehabilitation practice. This can be done by deriving a list of recommendations from the results of the four studies to have validated by experts in both physical rehabilitation and mental health, which can then be taken to the policy level to inform generalized organizational change.

Future Studies

As a next step, the development and evaluation of guidelines for the provision of mental health services in physical rehabilitation can be done through an eDelphi approach (Donohoe, Stellefson & Tennant, 2012). Specifically, experts' opinion to propose and evaluate guidelines stemming from the results of the knowledge synthesis (Study 1) and studies on current rehabilitation practices (Studies 2, 3, 4) can be sought which can in turn inform the effective and efficient organization of services for youth with co-occurrence of physical and mental health problems. Results from the four studies in this thesis can form the initial items for the Delphi survey, equivalent to the idea generation step (Khodyakov et al., 2020; Restall, Diaz & Wittmeier, 2020). A Delphi study would serve to determine the prioritization of guidelines presented to key stakeholders to help inform policy changes for the organization of mental health services within rehabilitation care.

Future directions include determining specific clinician training needs, approaching job descriptions and program mandates with more flexibility, and emphasizing building workforce capacity for both mental health and physical rehabilitation specialists across disciplines. Evaluation of models of service delivery such as the Biopsychosocial, Collaborative, Agency-Based Service Integration Approach (Scratch et al., 2020) would also be pertinent. Additionally, developing and evaluating novel ways of improving access to mental health services for youth such as integrating technology are warranted (Lal, 2021; Lal et al., 2023). Incorporating measures of parent mental health could be relevant for future studies as family-centered care and family involvement (as highlighted by a key principle in the **scoping review**) is crucial, however their caregiver role is often emotionally draining and may influence youth mental health (Li et al., 2024). Finally, while there was representation at the micro (clinicians, youth, family members) and meso levels (managers at the level of the organization) across the presented studies, barriers and facilitators at the macro level were not investigated in this thesis and would require future studies involving stakeholders at the ministry level who are involved in healthcare system reform.

Chapter 11: Concluding Remarks

While mental health needs are often present among youth with physical disabilities, our findings suggest that services to address them were not always available, with several barriers and challenges noted. Managers, clinicians, and families are already taking initial steps to address certain barriers, differing across the five studied sites to adapt to their unique contexts. A reorganization of services for more efficient care is possible, but considering resource constraints, processes that make the most of the available (human and material) resources are needed. Luckily, multidisciplinary rehabilitation teams encompass a great diversity in expertise and perspectives, and when bolstered by additional training and support as well as a revision of clinical mandates, and in collaboration with partnerships established with existing organizations specialized in mental health, better healthcare for all youth can be achieved.

This thesis brought to light new knowledge and insights pertaining to an important area in which evidence is scarce. Results from the four studies enhance our overall understanding about current multidisciplinary rehabilitation practices and services and can inform policymakers, managers, rehabilitation clinicians, and researchers on future directions for research and on ways to improve the organization and delivery of mental health services for youth with physical disabilities. Multiple avenues to target service coordination and integration for co-occurring physical and mental health problems are suggested. Further studies are needed to include novel models and approaches to care and additional perspectives from all pertinent stakeholders including mental health professionals and higher-level managers and health ministers to continue advocating for change to better support youth with co-occurring physical and mental health needs.

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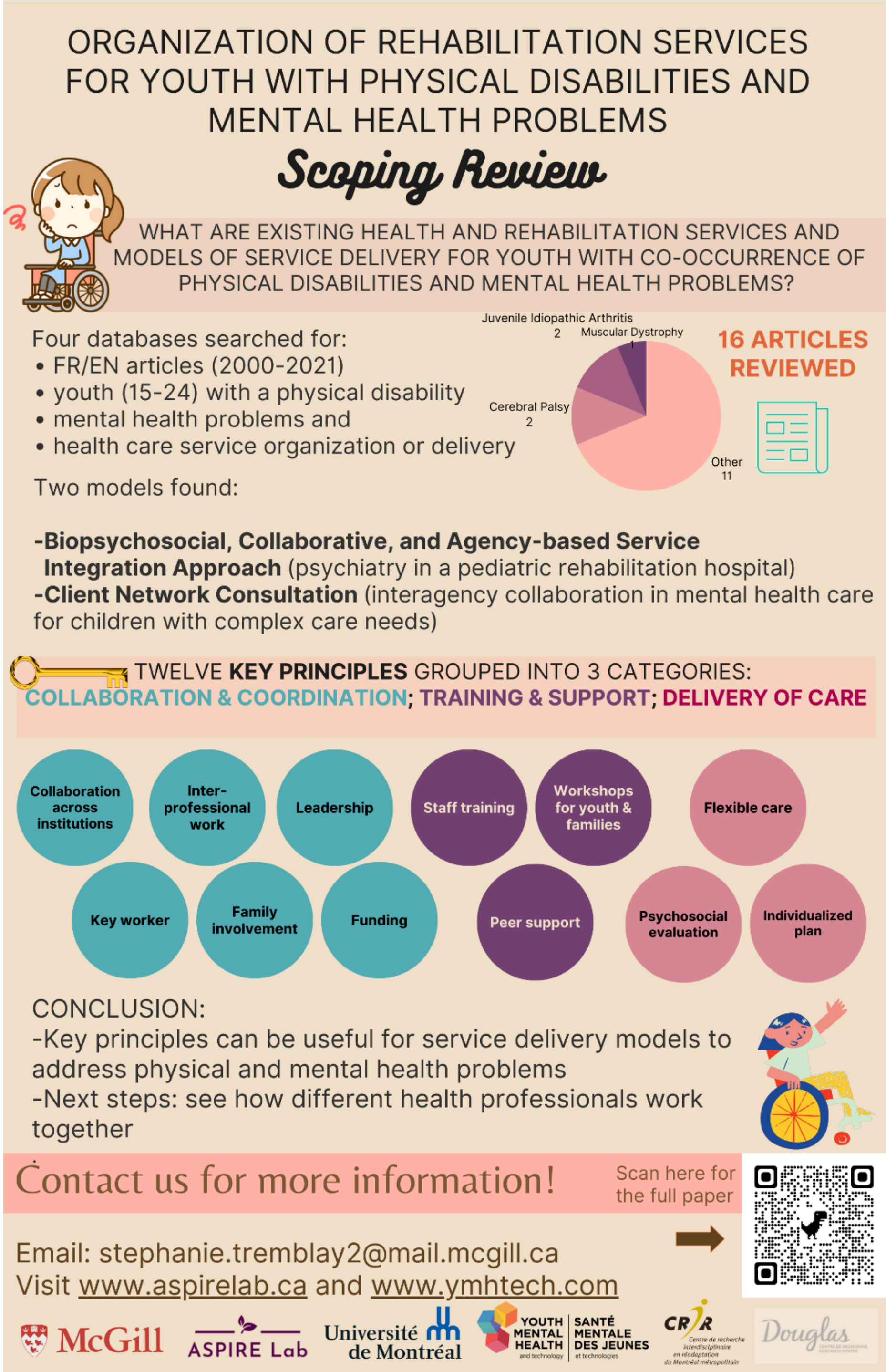
Appendices

Appendix 1: Scoping Review Infographic



ORGANIZATION OF REHABILITATION SERVICES FOR YOUTH WITH PHYSICAL DISABILITIES AND MENTAL HEALTH PROBLEMS

Scoping Review

WHAT ARE EXISTING HEALTH AND REHABILITATION SERVICES AND MODELS OF SERVICE DELIVERY FOR YOUTH WITH CO-OCCURRENCE OF PHYSICAL DISABILITIES AND MENTAL HEALTH PROBLEMS?

16 ARTICLES REVIEWED

Four databases searched for:
- FR/EN articles (2000-2021)
- youth (15-24) with a physical disability
- mental health problems and
- health care service organization or delivery

Two models found:

-**Biopsychosocial, Collaborative, and Agency-based Service Integration Approach** (psychiatry in a pediatric rehabilitation hospital)
-**Client Network Consultation** (interagency collaboration in mental health care for children with complex care needs)

TWELVE **KEY PRINCIPLES** GROUPED INTO 3 CATEGORIES:
COLLABORATION & COORDINATION; **TRAINING & SUPPORT**; **DELIVERY OF CARE**

Collaboration across institutions
Inter-professional work
Leadership
Staff training
Workshops for youth & families
Flexible care
Key worker
Family involvement
Funding
Peer support
Psychosocial evaluation
Individualized plan

CONCLUSION:
-Key principles can be useful for service delivery models to address physical and mental health problems
-Next steps: see how different health professionals work together

Contact us for more information!

Scan here for the full paper

Email: stephanie.tremblay2@mail.mcgill.ca
Visit www.aspirelab.ca and www.ymhtech.com

Appendix 2: Interview Guide for Youth

Version 2, English, Approved by Ethics Committee on October 6th, 2021
(A similar guide was approved for use with family members)

Attendees: the interviewer (PhD student) and the youth will be attending
Location: the interview will take place virtually via Microsoft TEAMS
Time: approximately one hour

Instructions: I will ask you open-ended questions about services you have received, and this discussion will be recorded and later transcribed. Let me know if you would like to take a break at any time, and we will stop.

Preamble: Please take a moment to think about your rehabilitation. I will ask you questions about how things went and your ideas for how things could be different!

1. To start, please tell me a bit about why you come to this rehabilitation center.
   Prompts:
   a. What was the initial reason for coming for rehabilitation services?
   b. How is your care overall?
2. Please tell me about the evaluation process.
   Prompts:
   a. Do you remember any assessments or questions that were asked about your mental health? Please elaborate.
   b. Do you feel that your therapists were worried about your mental health? Why or why not?
3. Now let's talk about mental health care more broadly.
   Prompts:
   a. Were there any challenges to talking about or taking into account your mental health during your rehabilitation sessions? Please elaborate.
   b. What about solutions and supports? Please elaborate.
   c. Were any new therapists involved in your care to help with your mental health? (ex. Psychologist, occupational therapist, social worker)
   d. Do you have any ideas about how care could be different to address all your needs?

Appendix 3: Chart-Stimulated Recall Interview Guide for Clinicians

Version 2, English, Approved by Ethics Committee on October 6th, 2021

Attendees: the interviewer (PhD student) and the service provider will be attending
Location: the interview will take place virtually via Microsoft TEAMS
Time: approximately one hour

Instructions: A clinical chart is used to help guide recall about the details of one of your clients' cases. I will ask open-ended questions, and this session will be recorded and later transcribed. Referring to your chart is permitted. You can also let me know if you would like to take a break at any moment.

Preamble: Thank you for being willing to share the chart of this client. I have reviewed it and would like to further discuss it with you to learn more about your practice. Please take a moment to think about this specific client, and I will ask you questions related to strategies, processes and procedures presented in the chart. In addition, we will discuss your practice in general and the organization of services in your institution:

4. To start, please tell me a bit about this client.
   Prompts:

   a. What was the reason for initially seeking rehabilitation services?

5. Please tell me about the evaluation process.
   Prompts:

   a. What assessments were done? Were assessments related to mental health used? If so, can you name them for me?

   b. Based on the results, what are your overall clinical impressions?

   c. What other information may have been relevant in relation to their mental health?

6. Describe a situation with the client where you may have suspected emerging mental health problems.
   Prompts:

   a. What type of mental health problems have emerged?

   b. What actions or strategies did you take to address some of the mental health problems?

c. Were there any challenges or barriers to delivering mental health services? If so, please elaborate.

d. What about existing supports and solutions that worked? What did not work?

7. Now let's talk about mental health care more broadly.
Prompts:

e. Have any other professionals been involved to offer mental health services to the client? If not, are there any that you think should?

f. Do any service providers in your organization screen for mental health problems?

g. Are cases of youth with co-occurring problems discussed with colleagues in team rounds?

h. Are they referred in-house or externally to a psychologist, occupational therapist, or other health professional with psychiatric expertise?

i. What structures are in place for identification of mental illness (specialized staff, specific psychiatric training)?

j. What should an ideal situation for comprehensive mental health care in a physical rehabilitation setting look like (ex. Wait lists, allocation of resources)?

8. Finally, I would like to know more about your ease in delivering mental health services.
Prompts:

a. What is your perceived level of competency in targeting mental health with your clients?

b. What are your needs in order to be better equipped to deliver mental health services in the future (in terms of supports, additional training, etc.)?

Appendix 4: Final Coding Framework from Interviews Manuscript

Supplementary File 1 from Interviews Manuscript

Codes V5	Subcodes
1 General	1.1 Interview questions 1.2 Demographics 1.3 Logistics 1.4 Research project implications and results
2 Physical Diagnosis (PD)	2.1 PD Diagnosis & Symptoms 2.2 PD Impacts on function 2.3 Self-perception with PD
3 Physical Rehabilitation Services	3.1 Types of physical rehabilitation received 3.2 Overall satisfaction with physical rehabilitation 3.3 Consistency of physical rehabilitation service
4 Mental Health (MH) Diagnosis	4.1 MH Diagnosis & Symptoms 4.1.1 Avoiding Disclosure MH 4.2 MH impacts on Function 4.2.1 Frustration, Difficulty Managing MH 4.3 MH and PD Co-occurrence 4.3.1 Complexity of Cases
5 Mental health care pathways	5.1 Why accessed MH services 5.2 How accessed MH services- Pathway, Referral 5.2.1 Linear pathway, easy referral 5.2.2. Circular, winding, difficult pathway or referral 5.2.3 Source of Referral- Clinician or Teams 5.2.4 Source of referral- Family 5.2.5 Source of referral- Youth 5.3 Rapidity and Consistency of MH Service Access 5.3.1 Fast access 5.3.2 Slow access, waitlists 5.3.3 Consistent MH services access 5.3.4 Inconsistent or limited MH services access
6 Mental Health care delivery	6.1 MH Evaluations and screening 6.2 MH interventions and strategies 6.2.1 MH Medications 6.2.2 Limited Length or Number of Sessions 6.2.3 Frustrations with MH Services 6.2.4 Structure of MH Sessions 6.2.5 MH Peer support groups 6.3 Clinicians or programs delivering MH services: 6.3.1 Internal MH clinicians involved

	6.3.1.1 Psychologist, neuropsychologist 6.3.1.2 Social Worker 6.3.1.3 Psychoeducator, vocational, special care counsellor 6.3.1.4 Psychiatrist 6.3.1.5 Nurse 6.3.1.6 OT 6.3.1.7 Key Worker 6.3.1.8 Interprofessional Teamwork 6.3.2 Inter-institutional MH services 6.3.2.1 CLSC 6.3.2.2 Specialized Hospital, Psychiatrist 6.3.2.3 Private MH Services, Psychologist 6.3.2.3.1 Cost for Private MH Services 6.3.2.4 School 6.3.2.5 Family doctor 6.3.2.6 MH consultant 6.3.2.7 Inter-Institutional Collaborations 6.3.3 MH community organizations 6.3.4 Family Involvement 6.4 Advocacy for MH care, Taking Initiative 6.5 Overall satisfaction with MH rehabilitation 6.6 Therapeutic Rapport 6.7 Ideal scenario of MH care
7 Transition to adult care	7.1 Transition follow up 7.1.1 Transition follow up established 7.1.2 Transition follow up unclear, lack of information 7.1.3 Loss of services in transition
8 Clinician Workforce Capacity	8.1 Clinicians- organization MH structures and procedures 8.1.1 Integration of MH within Organization 8.1.2 Communication with other professionals 8.2 Organization resources, staffing 8.3 Clinicians- MH knowledge and skills 8.3.1 competency delivering MH services 8.3.2 MH training 8.3.3 MH support (peer, supervision) 8.3.4 adapting MH assessments

Appendix 5: Additional Participant Quotes to Support Themes and Subthemes from Interviews Manuscript

Supplementary File 2 from Interviews Manuscript

Theme	**Subtheme**	**Quote 1**	**Quote 2**
Available clinical resources for mental health	**Access to mental health specialists within team**	We have a psychologist. Well, I don't know if she's back yet, to be honest, she was on leave for a long time. We have a psychologist in the team (...), though not a ton of resources, so it's a very, very long wait list. But that's especially for motor impairment related stress, anxiety and depression. -101T (clinician, rehabilitation transition program)	Before, we had a psychologist that was there full-time. But now the resources have diminished. Now I think 2 and a half days but more programs, so definitely we would also like having more psychologists at our center, but resources are limited, and also with us it's short-term follow-up as well, and linked with the diagnosis so when it's too big to handle, well then we have to refer elsewhere. -304T (clinician, adult rehabilitation center; translated)
	Impact of organizational structures and mandates	More concentrated on helping me walk better, in fact. They didn't take [my mental health] to heart. Even if I had a psychologist. Like, my number one was not my mental health. It's more physical. -209Y (youth, rehabilitation transition program; translated)	Our interventions are also in line with the diagnosis. So for example, a case where a client who has a musculoskeletal condition, who would have anorexia. But it's not, I can't work on the anorexia component because it's not related to the diagnosis, so that's why, that's when the social worker would help me to see where we could refer her so she can have follow up regarding that. So that's why sometimes we are a bit limited because we cannot work on a certain component because it's not related to the diagnosis. *-304T (clinician, adult rehabilitation center; translated)*
	Continuity of services during transition to adult care	But now, now when I need to see a physio, apparently, it has to be my doctor that sends a referral. My doctor must prescribe it to me. She has to declare that I need a physio before I can go, even if I need it, because I tried, I	Yes, but I'll soon have to, in a few months, have to change because of my age. I don't know when. ST: OK. Has there been anything put in place to sort of start that process or not yet?

		went [to the adult rehabilitation center] where I get my wheelchair fixed and (…) they can't take care of me. ST: Yeah, it's more complicated. 208Y: Yes. -208Y (youth, adult rehabilitation center; translated)	100Y: I think so, I think so. Um, (…) I thought [the pediatric rehabilitation center] was for everyone. But turns out it's for kids only. I think they started the, like they signed me up, but it's gonna be in a couple of months to even get a chance to actually go there. So [the pediatric rehab center]'s with me until I make the transfer. *-100Y (youth, pediatric rehabilitation program)*
Clinician workforce capacity	**Mental health knowledge, tools and professional development**	I think that you know, there are so many trainings that we can do that at a certain point, we have to decide. My colleagues are much more competent than me, so I feel very comfortable referring to them, and they are there for that. -403T (clinician, adult rehabilitation center; translated)	It's true that a, a training that would maybe be more specific, it would be pertinent for the whole team. *-304T (clinician, adult rehabilitation center; translated)*
	Therapeutic rapport between clinician and youth	Yeah, sure, you can connect with someone, but then it potentially stops. Then a couple of months later, you're gonna have to do it with someone else, and you have to see how they react to you… some are just colder or some that are better at listening, like 100T. So then, you know, we're moving around. It's a little annoying. -100Y (youth, pediatric rehabilitation center)	And my therapist is one of the people who is doing it for the passion of it, you know? (...) I think that's why I had this connection with her. -403Y (youth, adult rehabilitation center)
Links and partnerships with key players	**Improved pathways to access mental health services across programs and organizations**	It's navigating for us also each time it happens, it's figuring out you know, navigating the system a bit, who is the right person to refer to. It's extra complicated when it's a client who is deaf because there aren't a lot of interpretation	In an ideal situation, I would say having access to services more rapidly would be helpful, but that would be great in all situations. And then services within the community as well, like, there seems to be a big barrier to receiving services in the community. It seems like the

		services and that can make things a lot more complicated which you don't want when someone is feeling suicidal. *-100T (clinician, pediatric rehabilitation program)*	need for those services are so big and the weight is so big that people kind of, I think, get discouraged and even, even privately as well. It sounds like it's been harder and harder to find a private psychologist even if you have the means to do that. -205T (clinician, pediatric rehabilitation center)
	Family involvement and advocacy	You need to have the parent know what's going on and aware of what's up. You know. You have to. It's, it's a must. The parents not aware of what's going on and you know they're, they're, they're talking to the kids because the kid is of age, it makes no sense. Because where do we go from there? Not where do they go? Where do we go from there? (…) Yeah, well the communication not there 'cause they communicate with her, you know… if she's not feeling a way, she'll tell the team, the team will talk to her and obviously with her. You know what I mean? But it's what we could do together as a team. That's what, that's the whole meaning of a team is that a bunch of people come together. Find the right points and achieve the goal the same way. -103P (parent, pediatric rehabilitation center)	You know, it's resources like that, the other day I told her I should speak to the social worker, see if there wasn't a resource so that 205y could communicate with someone when she has difficulties sharing with me. -205P (parent, pediatric rehabilitation center; translated)

Appendix 6: Focus Group Guide

Version 2, English, Approved by Ethics Committee on October 6th, 2021

Attendees include the interviewer (PhD student) and managers/clinical coordinators
Location: the focus group will take place virtually via Microsoft TEAMS
Time: July 2024, 1 hour

How it will work: Open-ended questions about services will be asked, and discussion amongst yourselves is encouraged. It will be recorded and transcribed. If you want a break at any point, please let me know.

Preamble: Please take a moment to think about the provision of rehabilitation services and programs in your organization and how they may (or may not) provide integrated physical and mental health care. To start, please tell me a bit about your rehabilitation programs that service youth and young adults (aged 15-24) with co-occurring physical disabilities and mental health problems at your institution. *Prompts:*

What are the organizational structures and internal policies in place to address mental health? How about resource allocation?

What healthcare professionals as part of your team contribute to the provision of mental health care?

What are some facilitators or strengths relating to integration of mental health care within your physical rehabilitation center?

Are there any barriers or weaknesses when providing services to this population? If so, please specify.

Now let's talk about mental health care more broadly. *Prompts:*

In terms of client needs, has the importance of addressing mental health changed over the past few years?

Do you have any ideas about how care could be better integrated to address all needs? What opportunities support this?

Let's now reflect on factors outside of the organization. *Prompts:*

What factors external to the organization affect the organization and delivery of services? Please elaborate.

What other institutions (in Montreal, across the province or elsewhere) provide integrated care that serve as inspiration for your institution?

Appendix 7: Examples of Questions from Focus Group Guide

Supplementary File 1 from Focus Group Manuscript

1. What are the organizational structures and internal policies in place to address mental health within your physical rehabilitation center or program, if any?

2. Are there any barriers when providing services to this population? If so, please specify.

3. Do you have any ideas about how care could be better integrated to address all needs, including mental health? What opportunities support this?

4. What factors external to the program affect the organization and delivery of services, if any?

Appendix 8: Final Coding Framework from Focus Groups

Supplementary File 2 from the focus group manuscript

Codes FGV5	Subcodes
1 General	1.1 Focus group questions 1.2 Demographics 1.3 Logistics 1.4 Research project implications and results
2 Physical Diagnosis (PD)	2.1 PD Diagnosis & symptoms 2.2 PD Impacts on function
3 Physical Rehabilitation Services	3.1 Types of physical rehabilitation provided 3.2 Access to PD program
4 Mental Health (MH) Diagnosis	4.1 MH Diagnosis & symptoms 4.1.1 Avoiding disclosure MH 4.1.2 Needing MH diagnosis (or criteria) for services 4.2 MH impacts on Function 4.3 MH and PD Co-occurrence 4.3.1 Complexity of cases 4.3.2 Augmenting need for MH care in PD
5 Mental health care pathways	5.1 Why access MH services 5.2 How access MH services- Pathway, referral, navigation 5.2.1 Linear pathway being established 5.2.2. Confusing, winding, difficult pathway or referral 5.3 Slow access, waitlists 5.4 Inconsistent or limited external MH services access
6 Mental Health care delivery	6.1 MH Evaluations and screening 6.2 MH interventions and strategies 6.2.1 MH Medications 6.2.2 Limited Length or number of sessions 6.2.3 Limited time to develop new MH interventions, programming 6.3 Clinicians or programs delivering MH services: 6.3.1 Internal MH clinicians involved 6.3.1.1 Psychologist, neuropsychologist 6.3.1.2 Social Worker 6.3.1.3 Psychoeducator, vocational, special care counsellor 6.3.1.4 Psychiatrist 6.3.1.5 Nurse 6.3.1.6 OT 6.3.1.7 Key Worker

	6.3.1.8 Interprofessional teamwork 6.3.2 Inter-institutional MH services 6.3.2.1 CLSC 6.3.2.2 Specialized Hospital, psychiatrist 6.3.2.3 Private MH Services, psychologist 6.3.2.3.1 Cost for private MH services 6.3.2.4 School 6.3.2.5 Family doctor 6.3.2.6 MH consultant 6.3.2.7 Inter-Institutional MH collaborations (current) 6.3.3 MH community organizations and resources 6.3.4 Family Involvement 6.3.4.1 Family MH 6.4 Advocacy for MH care, taking Initiative 6.5 Ideal scenario of MH care
7 Transition to adult care	7.1 Transition follow up (changing teams) 7.1.1 Differences in pediatric and adult services
8 Clinician Workforce Capacity	8.1 Rehabilitation Clinicians- MH knowledge and skills 8.1.1 MH training 8.1.2 MH support (peer supervision, mentoring) 8.2 MH clinicians limited PD knowledge and skills
9 Organization structures and resources	9.1 Organization MH structures and procedures (internal) 9.1.1 Integration of MH within organization (desired) 9.1.2 Organization mandates regarding MH (focus on PD) 9.1.2.1 Suspend PD services until MH is stabilized 9.1.3 Divide between MH and PD programs, silos 9.1.4 Co-occurrence disqualifies service access 9.2 Organization resources, staffing (internal) 9.2.1 Borrowing MH professionals from other teams 9.3 Ministry budgets and funding 9.4 Establishing partnerships with other (external) organizations 9.4.1 Exchanging information, models, interventions with others 9.5 Organization resources, staffing (external) 9.6 Best practices and programs (not) published in literature

Appendix 9: Additional Participant Quotes to Support Focus Group Themes

Supplementary File 3 from the focus group manuscript

Theme	Subtheme	Quote 1	Quote 2
1. Available clinical resources for mental health	**1a. Access to mental health specialists within internal team**	But anxiety is something that is present in almost all of our clients (…). But now, we talk about it more, but we don't really have the resources. Maybe that's the challenge? -11M (translated)	And when the team doesn't have a psychologist also, or a social worker, we can always ask for a consult from another team. If we, you know, let's say the client says something that would benefit from being screened a little bit more in depth, so we can refer to someone from another team. -26M
	1b. Internal organizational structures and mandates	But it remains that the main reason (for referral to our program) must be the physical disability itself. -12M (translated)	So to pass from one team to another with the shortest delay possible, that to me is an obstacle, because then we end up on our part keeping the client and maintaining services and we have the social worker or the psychologist involved to make sure that we fill in the gaps because we feel that the client is at risk and we don't want the client to stay without any services while the client's waiting, although we know that it's still not within our mandate. So we end up just filling the gaps. -25M
2. Clinician workforce capacity	**2a. Internal mental health knowledge and professional development**	We find that the need for these types of services is augmenting and our skill set is not that big since we're used to working with individuals with physical disabilities and not so much on the mental health side. -21M	But we're not specialized in mental health, so we will go find partners. -11M (translated)
	2b. External mental health professionals' knowledge in	I don't know how much the mental health teams or staff know the impact of their physical disability on their clients. -24M	And finally the (other program) does not have the psychology resources so they say yeah, we would like to but we don't have those resources.

	physical disability		-11M (translated)
3. Links and partnerships with key players	**3a. Working in silos**	I believe that the system manages too much by the way it is organized, not by the people working within it, but by how it is. It is too much in silos. I think that there is a lot of room for partnerships. -13M (translated)	OK, we need the help. We need to work together and like yes, a perfect team that would do both and/or the collaboration between both teams because they're very sectorized, like this is mental health and this is physical disability. -24M
	3b. External organizational structures and procedures	I think that there should be better corridors of service between the two. (…) It's really hard for us to know where to orient the client, so I find that it needs a better trajectory, or like a visual to help us. -21M	I think the fact that you need a diagnosis to access certain services continues to be a problem depending on what it is. So sometimes just getting the diagnosis, there's such long waiting lists that if they're presenting all the symptoms or, I don't know, it's not my area of expertise. But (…), like somebody with a depression or personality disorder or whatever, it would be great that they could get services for that without waiting to be diagnosed by someone for that first for example. -21M
	3c. Actions to improve pathways to access mental health services across external programs and organizations	We organized two different ones, so one with GASMA (the centralized referral center for mental health services), it was to look at the exclusion criteria and what programs they had to offer because we were a bit confused about where to orient our services. -21M	I think there must be so many things that are not in the literature. Case in point. If I do a Google search on our program, there is not much research that was done however there is a lot of work that's been done [by our team to develop novel comprehensive programs]. -13M (translated)

Appendix 10: Knowledge Translation and Results Dissemination at Conferences

Tremblay, S., Lal, S., Ferro, M. & Anaby, D. (2024). Services for youth with co-occurrence of physical disability and mental health problems: A qualitative study. Abstract submitted to be presented as a scientific paper at the 78th AACPDM Annual Meeting, 2024 October 23-26, Quebec City, Canada.

Tremblay, S., Lal, S., Ferro, M. & Anaby, D. (2024). Mental health practices in physical rehabilitation: A chart review study for youth with physical disabilities. Poster presented at the 36th EACD Annual Meeting, 2024 May 29- June 1, Bruges, Belgium.

Tremblay, S., Lal, S., Ferro, M. & Anaby, D. (2024). Mental health practices in physical rehabilitation: A chart review study for youth with physical disabilities. Poster (virtual) presented at the Child & Adolescent Mental Health Conference, 2024 March 18-20, Gold Coast, Australia.

Tremblay, S., Lal, S., Xiang, L., Ferro, M. & Anaby, D. (2022). Models and principles to guide the organization of physical and mental health services for youth: A scoping review. Poster presented at the 34th EACD Annual Meeting, 2022 May 18-21, Barcelona, Spain. Abstract published in *Developmental Medicine and Child Neurology, 64*, S3, 267.

Tremblay, S., Lal S., Xiang L., Ferro M. & Anaby, D. (2022). Services for youth with co-occurring physical and mental health problems. Poster presented at the CAOT Conference; 2022 May 6; Whistler, BC.

Lal, S., **Tremblay, S.,** Starcevic, D., Mauger-Lavigne, M. & Anaby, D. (2020). Mental Health of Young People with Childhood-Onset Physical Disabilities: A Scoping Review. Paper presented at the EACD Virtual Conference; 2020 November 28; Poznań, Poland. Abstract published in *Developmental Medicine & Child Neurology, 62, S4, 6.*

Lal, S., **Tremblay, S.,** Starcevic, D., Mauger-Lavigne, M. & Anaby, D. (2020). Mental Health of Youth with Childhood-Onset of Physical Disabilities. Poster presented at the CAOT Virtual Conference; 2020 May 9; Saskatoon, SK.