Development of the Child Community Health Inclusion Index: Measure of Community Inclusion of Children with Disabilities in Community Facilities

Paul Yejong Yoo, B.Sc.(Hons.), M.Sc.A.
School of Physical and Occupational Therapy
Faculty of Medicine and Health Sciences
McGill University, Montreal
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Abstract

Background: Participation and inclusion of children with disabilities in the community is a fundamental human right affirmed by the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Rights of the Child (CRC). The CRPD calls for the full and effective participation and inclusion of individuals with disabilities in society. Participation is important in the development of a child's social and academic skills, sense of competence and identity, with key benefits to physical and mental health. Despite these benefits, children with disabilities face restrictions in participation in comparison to typically developing children. These restrictions have been linked to environmental factors such as physical (e.g. built environment, accessibility), social (e.g. peer support), attitudinal (e.g. perceptions of disability and recreation), and institutional (e.g. policies, availability of adapted programs) factors that can act as facilitators or barriers to participation.

Measuring aspects of the environment that influence a child's inclusion is crucial to inform health promotion interventions for marginalized populations such as children with disabilities. A clear understanding of contextual factors linked to community inclusion and health can support the development of public health strategies, health and social policies, and community-based rehabilitation and educational programs.

Currently, there are no comprehensive measures of community inclusion for children with disabilities addressing the different environmental aspects. The Community Health Inclusion Index (CHII) is a measure of contextual factors as barriers and facilitators in the community that affect participation for individuals with disabilities. Although it is a comprehensive index of community inclusion for persons with disabilities, it includes a limited number of items related specifically to the inclusion of children with disabilities and their families. The community activities and participation roles of children with disabilities differ from those of adults with disabilities. The lack of a proper measure may limit the identification of gaps and the development of context-based, systems-level interventions that aim to improve inclusion and promote participation through changes in the environmental factors.

Objectives: The overarching objective of this doctoral thesis was to develop an index to measure the context-based factors that aim to promote the inclusion and participation of children with disabilities in the communities where they live. This objective included adapting the pre-existing CHII to the Canadian pediatric population, newly named the Child Community Health Inclusion Index (CHILD-CHII). The specific objectives were: (i) to systematically review the research evidence on context-based, systems-level interventions that aim to increase participation of children with disabilities in the community; (ii) to develop the content and test the feasibility of a community health inclusion measurement tool that identifies and assesses the barriers and facilitators in different community-level facilities and environments that affect the participation of children with disabilities living in Canada.

Methods: For the first specific objective, a structured literature review was conducted using a systematic review methodology. The knowledge was synthesized using the Family of Participation-related Constructs Framework (fPRC) and the Community Wellbeing Framework (CWF) (**Manuscript 1**, “The Effect of Context-based Interventions at the Systems-level on Participation of Children with Disabilities: A Systematic Review”). For the second specific objective, we conducted a structured review of existing measures, guidelines, and checklists related to inclusion of children with disabilities in the community at large (including the measures identified in the systematic review of **Manuscript 1**) to generate potential items for the content development of the CHILD-CHII. An extensive expert panel consultation was used to select, refine, adapt and merge items identified into the original CHII (**Manuscript 2**, “Content development of the child community health inclusion index: An evaluation tool for measuring inclusion of children with disabilities in the community”). Following the initial development of the content we adopted a modified e-Delphi technique to validate and clarify items by stakeholders through two rounds of review (**Manuscript 3**, “Content validation of the Child Community Health Inclusion Index: An evaluation tool for measuring health inclusion of children with disabilities in the community”). After content validation and adaptation, we tested the feasibility of the tool through community-based stakeholder evaluators (**Manuscript 4**, “Application of the Child Community Health Inclusion Index- an evaluation tool for measuring health inclusion of children with disabilities in the community: A feasibility study”).

Results: In **Manuscript 1**, 11 articles were included for knowledge synthesis. Four studies were level I, II, and III evidence, based on the Centre for Evidence-Based Medicine hierarchy. All four showed that context-based interventions had a positive effect on participation and participation-related outcomes. All 11 studies had intervention properties that were coded to at least one domain on the Community Wellbeing Framework. The heterogeneity of outcome measures and scarcity of higher-level evidence on context-based interventions made knowledge synthesis difficult. These findings highlighted the need for a single measurement tool that assesses environment factors related to the participation of children with disabilities.

A comprehensive overview of existing measures and items that could contribute to this measurement led to the content development of the CHILD-CHII measurement tool, in **Manuscript 2**. The literature review identified 199 items from 12 instruments and best practice guidelines. Expert consensus contributed to the generation of a comprehensive list of 189 most relevant items related to the inclusion of children with disabilities in the community. Expert suggestions were considered to refine and reduce the item list to 106 items. These items were validated in **Manuscript 3** where 48 participants completed the first round of the Delphi technique and 38 completed the second. Participants were presented 106 items, of which 101 items were rated important with high consensus and were retained. Seventeen items were modified for clarity and presented in the second round. In the second round, all 17 modified items were deemed clearer, and all items were deemed very relevant. In **Manuscript 4**, the validated content of the CHILD-CHII measurement tool was tested for feasibility. Of the 12 purposefully sampled participants, 92% indicated that the tool was ‘long’ or ‘much too long’; 66% indicated that the tool was clear; 58% indicated that the tool was ‘valuable’ or ‘very valuable’. No consensus on a difficulty indicator was reached. The comments provided by the participants were helpful in dissecting the rationale for the ratings and identifying the modifications needed to enhance feasibility of the tool. The evaluators’ knowledge and familiarity surrounding inclusion and accessibility and their access to information played a key role in making the tool more feasible to use. The perceived value of the tool can be a strong facilitator for its use.

Conclusion: Community inclusion is an essential outcome to consider and promote when it comes to providing opportunities for participation in the community and enhancing the health of children with disabilities. Furthermore, it is a fundamental human right upheld by the United Nations’ CRPD. Normative frameworks like the ICF, CRPD and CWF exist to ensure the

inclusion of children with disabilities in all aspects of life, including community life. One way of achieving this outcome is by understanding the important elements that should be considered and should be present in the different settings and spaces where children participate, such as health facilities, schools, leisure spaces, and community facilities in the child's neighbourhood. The CHILD-CHII is a measurement tool that comprehensively identifies and assesses the barriers and facilitators in community facilities and environments that can impact the participation of children with disabilities. It was developed, validated, and tested for feasibility with extensive input from stakeholders who will be directly using or who will be impacted by the use of the tool. The CHILD-CHII is a measurement tool that is well-aligned with the aforementioned frameworks. The appropriate and effective measurement of community inclusion using the CHILD-CHII can be used to estimate community inclusion of facilities for children with disabilities and its health impacts, and to inform organizations and facilities regarding the inclusion of their facilities and programs. It can be used to identify areas that can be targeted for interventions with aims to increase inclusion of children with disabilities. Furthermore, the tool can be used as an outcome measure for future studies to explore context-based, systems-level interventions targeting facilities and communities, enabling new avenues for research with inclusion as the outcome. The CHILD-CHII serves to help program managers, health care providers, educators and decision-makers assess the inclusion of a certain community setting to develop context-based, systems-wide strategies to promote inclusion of children with disabilities in the community.

Résumé

Contexte : La participation et l'inclusion des enfants handicapés dans la communauté sont des droits humains fondamentaux proclamés par la Convention relative aux droits des personnes handicapées (CDPH) des Nations Unies et la Convention relative aux droits de l'enfant (CDE). La CDPH appelle à la participation et à l'inclusion intégrales et effectives des personnes handicapées dans la société. La participation est importante pour le développement des aptitudes sociales et scolaires, du sentiment de compétence et de l'identité d'un enfant, et a des avantages clés pour la santé physique et mentale. Malgré ces avantages, les enfants handicapés sont confrontés à des restrictions de participation par rapport aux enfants au développement normal. Ces restrictions ont été liées à des facteurs environnementaux tels que des facteurs physiques (par exemple, l'environnement bâti, l'accessibilité), sociaux (par exemple, le soutien des pairs), attitudinaux (par exemple, les perceptions du handicap et des loisirs) et institutionnels (par exemple, les politiques, la disponibilité de programmes adaptés) qui peuvent agir comme des facilitateurs ou des obstacles à la participation.

Il est essentiel de mesurer les aspects environnementaux qui influencent l'inclusion d'un enfant afin d'informer les interventions de promotion de la santé auprès des populations marginalisées telles que les enfants handicapés. Une compréhension claire des facteurs contextuels liés à l'inclusion dans la communauté et à la santé peut soutenir le développement de stratégies de santé publique, de politiques sanitaires et sociales, et de programmes de réadaptation et d'éducation communautaires.

À l'heure actuelle, il n'existe pas de mesures complètes pour l'inclusion des enfants handicapés dans la communauté qui tiennent compte des différents aspects environnementaux. *Community Health Inclusion Index (CHII)* est une mesure des facteurs contextuels comme les obstacles et les facilitateurs dans la communauté qui affectent la participation des personnes handicapées. Bien qu'il s'agisse d'un index exhaustif de l'inclusion des personnes handicapées dans la communauté, il comprend un nombre limité d'éléments liés spécifiquement à l'inclusion des enfants handicapés et de leurs familles. Les activités communautaires ainsi que les rôles de participation des enfants handicapés diffèrent de ceux des adultes handicapés. L'absence d'une mesure appropriée peut limiter l'identification des lacunes et le développement d'interventions contextuelles en matière des systèmes qui visent à améliorer l'inclusion et à promouvoir la participation à l'aide de changements des facteurs environnementaux.

Objectifs : L'objectif principal de cette thèse de doctorat était de développer un index pour mesurer les facteurs contextuels qui visent à promouvoir l'inclusion et la participation des enfants handicapés dans les communautés où ils vivent. Cet objectif comprenait l'adaptation de l'index préexistant CHII, nouvellement nommé *Child Community Health Inclusion Index (CHILD-CHII),* à la population pédiatrique canadienne. Les objectifs spécifiques étaient les suivants : (i) examiner systématiquement les données de recherche sur les interventions contextuelles au niveau des systèmes qui visent à accroître la participation des enfants handicapés dans la communauté ; (ii) développer le contenu et évaluer la faisabilité d'un outil de mesure de l'inclusion en santé communautaire qui identifie et évalue les obstacles et les facilitateurs dans différents établissements et environnements au niveau communautaire qui affectent la participation des enfants handicapés vivant au Canada.

Méthodes : Pour le premier objectif spécifique, une analyse documentaire structurée a été réalisée en utilisant une méthodologie d'examen systématique. Les connaissances ont été synthétisées à l'aide du *Family of Participation-related Constructs Framework (fPRC)* et du *Community Wellbeing Framework (CWF)* (**Manuscrit 1**, *The Effect of Context-based Interventions at the Systems-level on Participation of Children with Disabilities: A Systematic Review*). Pour le deuxième objectif spécifique, nous avons effectué une revue structurée des mesures, directives et listes de contrôle existantes liées à l'inclusion des enfants handicapés dans la communauté en général (y compris les mesures identifiées dans la revue systématique du **Manuscrit 1**) afin de produire des éléments potentiels pour le développement du contenu du CHILD-CHII. La consultation approfondie d'un panel d'experts a été utilisée pour sélectionner, affiner, adapter et fusionner les éléments identifiés dans le CHII original (**Manuscrit 2**, *Content development of the Child Community Health Inclusion Index: An evaluation tool for measuring inclusion of children with disabilities in the community*). Après le développement initial du contenu, nous avons adopté une technique *e-Delphi* modifiée pour faire valider et clarifier les éléments par des parties prenantes à travers deux cycles de révision (**Manuscrit 3**, *Content validation of the child community health inclusion index: a modified e-Delphi study*). À la suite

de la validation et de l’adaptation du contenu, nous avons testé la faisabilité de l’outil par le biais d’évaluateurs de parties prenantes basés dans la communauté (**Manuscrit 4**, *Application of the Child Community Health Inclusion Index- an evaluation tool for measuring health inclusion of children with disabilities in the community: A feasibility study*).

Résultats : Dans le **Manuscrit 1**, 11 articles ont été inclus dans la synthèse des connaissances. Quatre études étaient de niveau I, II et III, selon la hiérarchie du *Centre for Evidence-Based Medicine*. Les quatre études ont montré que les interventions fondées sur le contexte avaient un effet positif sur la participation et les résultats liés à la participation. Les 11 études avaient toutes des caractéristiques d’intervention qui étaient codées à au moins un domaine du cadre de bien-être communautaire. L’hétérogénéité des mesures liée aux résultats et la rareté de données probantes de haut niveau sur les interventions basées sur le contexte ont rendu la synthèse des connaissances difficile. Ces résultats ont mis en évidence la nécessité de disposer d’un outil de mesure unique permettant d’évaluer les facteurs environnementaux liés à la participation des enfants handicapés. Un aperçu complet des mesures existantes et des éléments qui pourraient contribuer à cette mesure a conduit à l’élaboration du contenu de l’outil de mesure CHILD-CHII, dans le **Manuscrit 2**. L’examen de la littérature a permis d’identifier 199 éléments provenant de 12 instruments et de lignes directrices sur les meilleures pratiques. Le consensus des experts a contribué à l’élaboration d’une liste complète des 189 éléments les plus pertinents liés à l’inclusion des enfants handicapés dans la communauté. Les suggestions des experts ont été prises en compte pour affiner et réduire la liste à 106 éléments. Ces éléments ont été validés dans le **Manuscrit 3** où 48 participants ont complété la première étape de la technique Delphi et 38 ont complété la seconde étape. Nous avons présenté 106 éléments aux participants, dont 101 ont été jugés importants avec un consensus élevé et ont donc été retenus. Dix-sept éléments ont été modifiés pour plus de clarté et présentés durant la deuxième étape. Pendant la deuxième étape, les 17 éléments modifiés ont été jugés plus clairs et tous les éléments ont été jugés très pertinents. Dans le **Manuscrit 4**, le contenu validé de l’outil de mesure CHILD-CHII a été testé pour sa faisabilité. Sur les 12 participants échantillonnés à dessein, 92 % ont indiqué que l’outil était « long » ou « beaucoup trop long » ; 66 % ont indiqué que l’outil était clair ; 58 % ont indiqué que l’outil était « utile » ou « très utile ». Aucun consensus sur un indicateur de difficulté n’a été atteint. Les commentaires fournis par les participants ont été utiles pour analyser la

justification des notes et identifier les modifications nécessaires à faire pour améliorer la faisabilité de l'outil. Les connaissances et la familiarité des évaluateurs en matière d'inclusion et d'accessibilité ainsi que leur accès à l'information ont joué un rôle clé pour rendre l'outil plus facile à utiliser. La valeur perçue de l'outil peut être un puissant facilitateur de son utilisation.

Conclusion : L'inclusion dans la communauté est un résultat essentiel à considérer et à promouvoir lorsqu'il s'agit d'offrir des possibilités de participation dans la communauté et d'améliorer la santé des enfants handicapés. En outre, il s'agit d'un droit humain fondamental soutenu par la CDPH des Nations Unies. Des cadres normatifs tels que la CIF, la CDPH et la FCF existent pour garantir l'inclusion des enfants handicapés dans tous les aspects de la vie, y compris la vie en communauté. Une façon d'atteindre ce résultat est de comprendre les éléments importants qui doivent être pris en compte et qui doivent être présents dans les différents cadres et espaces où les enfants participent, tels que les établissements de santé, les écoles, les espaces de loisirs et les installations communautaires dans le quartier de l'enfant. Le CHILD-CHII est un outil de mesure qui identifie et évalue de manière exhaustive les obstacles et les facilitateurs dans les installations et les environnements communautaires qui peuvent avoir un impact sur la participation des enfants handicapés. Cet outil a été développé, validé et testé pour sa faisabilité avec la participation active des parties prenantes qui l'utiliseront directement ou qui seront affectées par son utilisation. Le CHILD-CHII est un outil de mesure qui est bien aligné avec les cadres susmentionnés. La mesure appropriée et efficace de l'inclusion communautaire à l'aide du CHILD-CHII peut être utilisée pour estimer l'inclusion communautaire des installations pour enfants handicapés et ses impacts sur la santé, et pour informer les organisations et les installations sur le niveau d'inclusion de leurs installations et programmes. Il peut être utilisé pour identifier les zones qui peuvent être ciblées pour des interventions visant à augmenter l'inclusion des enfants handicapés. En outre, l'outil peut être utilisé comme une mesure des résultats pour de futures études visant à explorer les interventions contextuelles au niveau des systèmes ciblant les établissements et les communautés, permettant ainsi de nouvelles voies de recherche avec l'inclusion comme résultat. Le CHILD-CHII sert à aider les gestionnaires de programmes, les prestataires de soins de santé, les éducateurs et les décideurs à évaluer le niveau d'inclusion d'un certain cadre communautaire afin de développer des stratégies contextuelles et systémiques pour promouvoir l'inclusion des enfants handicapés dans la communauté.

Dedications

I dedicate this thesis to my loving family. To my father, Jaisun Yoo (유재선), my mother, SooJeong Oh (오수정), and my sister, Ann Yoo (유예현); for their support and sacrifice that have allowed me to live, love, and learn.

My father left his life in South Korea with his established degrees and positions and endeavoured to study a different profession in a completely foreign language. This was all to provide for his family and to give them a better life. He then ventured to pursue another academic degree, this time, for his own love and interest. My earliest memories of my father are of him studying at night as I fell asleep beside him in bed, and of him in the same position as I awoke the next morning. This, I have come to understand, was a necessity as he had to work during the day to make ends meet. His life-long desire and strive to learn, now I see, has instilled within me a continuous desire to learn. Thank you for inspiring me.

My mother is the closest thing to genuine love that I have encountered in life. The love she has for her children is so full and intense. Despite the hours she spent working during the day, she always found the time to ensure that her family was well fed and properly taken care of. Most mornings and evenings she would place her hand on my head and pray as I lay half-asleep. Her faith and unrelenting love for her family despite all circumstances have instilled within me the dedication and persistence to pursue what I love, for those whom I love. Thank you for loving me.

My sister is my oldest and truest life companion. Throughout the entirety of my life, she has never ceased to be in my corner. Thank you for trusting in me.

Immanuel. God with us.

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"So we see that they were not able to enter, because of their unbelief." -Hebrews 3:19 NIV
First and foremost, I thank God for His guidance and grace that has allowed me to pursue my PhD. From His delicate sensitivity to my smallest needs and prayers, to His grandeur and providence beyond my imagination. To God be the glory.

My desire and goal in my professional/academic life has been to help ameliorate the lives of children with disabilities, in any way that I can. This desire stems from my experiences working at Camp Merrywood, a camp for children with physical disabilities. Campers and fellow staff who have inspired me with their resolve, resilience, and love for life, thank you all.

I want to express my greatest and sincerest gratitude to my supervisor, Dr. Keiko Shikako, who has paved a path for me in achieving my goal. Beyond the endless support and guidance that you've provided as my supervisor from the beginning to the end of my research, I thank you for your honesty and compassion as a mentor in life. Beyond the many achievements you've garnered just in the span of my thesis, I am most inspired by your genuine desire to make a lasting change in the lives of children with disabilities. I will never forget what you told me when I knocked on your door to congratulate you for receiving tenure- these things are secondary to the real impact and change we can make in the lives of those for whom we are doing the things that we do. You inspire me to be better every day while remembering why we do the things that we do. I cannot thank you enough for all that you've given me and taught me, in both my professional and personal growth.

I echo this deep gratitude to my co-supervisor, Dr. Annette Majnemer, who I first approached right before I started my master's degree in Occupational Therapy. Thank you for making the time to meet with me at that time, amidst the bustle of grant application season, and listening to my young desire to be involved in research aiming to ameliorate the lives of children with disabilities. You have shown me the same attentiveness and consideration as your PhD student. I am truly grateful for your continuous support and direction. Although I came to know Dr. Keiko Shikako as an Occupational Therapy student, thank you for introducing me to her in the realm of research. This encounter led to the pursuit of my PhD and the completion of this thesis. Furthermore, the grant application that was being completed during our first meeting ended up supporting my PhD training, for this I am again truly grateful. It's incredible how the world works sometimes.

I wish to thank my supervisory committee, Dr. Robert Wilton (McMaster University) and Dr. Sara Ahmed (McGill University) for their feedback in the design and conduct of my research, and for their time in revising my manuscripts and this thesis. Thank you both for your expertise and suggestions at each phase of this thesis.

I want to acknowledge and thank Dr. Yochai Eisenberg (University of Illinois at Chicago) who is the author and principal investigator of the original Community Health Inclusion Index (CHII). Thank you for your support and expertise in the initial stages of the adaptation process. Thank you for your openness and willingness to explore the development of a child version of the CHII.

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Preface

i. Statement of originality

This thesis consists of original content that presents the process of developing the Child Community Health Inclusion Index, a measurement tool to assess the inclusion of children with disabilities in the community. This tool was adapted from the Community Health Inclusion Index (Eisenberg et al., 2015). While utilizing a similar format for the tool and framework, novel elements have been generated and included in the newly adapted and developed tool addressing the specific needs of children with disabilities and their families. The tool itself was also developed with full consideration of the Canadian context, including the creation of the tool in English and French, the official languages of Canada.

The initiative of developing this tool stemmed from a systematic review on the effects of context-based interventions on the participation of children with disabilities that was conducted by the author of this thesis (Chapter 3). Existing knowledge was synthesized using the Family of Participation-related Constructs and Community Wellbeing Framework. The systematic review revealed the need for a measurement tool that considered the environmental context of the child. For the initial development of the content of the tool, items were generated from existing measures, guidelines, and best practice recommendations relating to universal accessibility and inclusion. The generated items then underwent multiple levels of refinement with the input of an expert panel to create the content of the tool, as presented in Chapter 5. In Chapter 7 the generated content was validated through a modified Delphi technique with diverse stakeholders. The two rounds of content validation and clarification of the items resulted in a completed item list and the general format of the tool. The completed tool was then tested to estimate its feasibility in community applications by evaluators in different sectors of the community. The feasibility testing is presented in Chapter 9.

The original scholarship of this thesis aimed to contribute to the knowledge and measurement of the contextual factors contributing to the community inclusion of children with disabilities. The thesis consists of the development of a tool that assesses community-based facilities in the health, education, government, and community organization sectors. The development process of the tool can inform future methodological development of context-based outcome measures. The tool development process describes a comprehensive review of international and national frameworks and guidelines for the item selection, and the use of expert consensus to adjust for relevance and utility. The tool itself can have implications for the assessment of clinical interventions, creation of programs and services, and policymaking for children with disabilities. The contributions of this thesis stemming from the realm of Rehabilitation Science has the potential for the expansion of knowledge from research to clinical practice, and further to society. It aims to offer avenues for knowledge translation from research to policy. Another contribution of this thesis is in relation to stakeholder engagement in research, providing opportunities for a diverse group of stakeholders to share their knowledge and engage in the entire research process, from conception of research questions to study development, analysis, and knowledge mobilization.

ii. Contribution of authors

This thesis is presented in manuscript format and includes four manuscripts. All four manuscripts have already been submitted for publication (two published, two under revision as of submission date). Paul Yejong Yoo, the doctoral candidate and author of this thesis is the main contributor and first author in all four manuscripts presented in this thesis with extensive review, editing, and feedback from his supervisor, Dr. Keiko Shikako and co-supervisor, Dr. Annette Majnemer.

The conception of research objectives, study design, and methodology for each manuscript were undertaken by the doctoral candidate in collaboration with his supervisor and co-supervisor, with input from the supervisory committee members Dr. Sara Ahmed, and Dr. Robert Wilton. Data collection, statistical analysis, and full write-up of the manuscript, submission of the manuscript, and revision/modification following peer review for journals were conducted by the doctoral candidate with direct supervision of Dr. Keiko Shikako and Dr. Annette Majnemer. The supervisory committee provided review and feedback on each manuscript and approved the thesis submission.

Additional collaborating authors of each manuscript contributed to different aspects of the research process for that study. Specifically:

For **Manuscript 1**, Dr. Ebele Mogo, assisted in the initial screening of title & abstracts, full manuscript screening, data extraction, and review of the manuscript. Dr. Janet McCabe, Ms.

Melanie Bergthorson, Miss Rose Elekanachi, Dr. Roberta Cardoso, and Dr. Mehrnoosh Movahed assisted in the full manuscript screening, data extraction, and review of the manuscript.
For **Manuscript 2**, Miss Laury-Anne Bolduc, Miss Karen Chen, Miss Erin Lamb, and Miss Tanisha Panjwani assisted in the data collection, data analysis, and write-up of the manuscript.

iii. Thesis organization and overview

This thesis is manuscript-based with four manuscripts and has been constructed as per the McGill Graduate and Postdoctoral Studies guidelines on thesis preparation. All four manuscripts have been submitted for publication in peer-reviewed journals, as indicated in the beginning of each chapter. For published articles the pre-print version was used. Following the guidelines, the four manuscripts were incorporated into this thesis with additional chapters linking each manuscript and an overarching Background, Discussion, and Conclusion section. A brief outline is as follows.

Chapter 1 provides a background and literature review regarding concepts of participation and inclusion, rights-based approach to understanding the intersection between participation and community inclusion, environmental determinants of participation and community inclusion, measurement of community inclusion and its challenges, and the use of a foundational framework for measuring community inclusion.

Chapter 2 presents the rationale and objectives of this thesis.

Chapter 3 presents **Manuscript 1** titled “The Effect of Context-based Interventions at the Systems-level on Participation of Children with Disabilities: A Systematic Review”. This systematic review synthesized the existing knowledge and evidence on the effects of context-based interventions on participation of children with disabilities.

Chapter 4 presents the conceptual links between **Manuscript 1** and **Manuscript 2**.

Chapter 5 presents **Manuscript 2** titled “Content development of the Child Community Health Inclusion Index: An evaluation tool for measuring inclusion of children with disabilities in the community”. This study initiated the adaptation of the Community Health Inclusion Index to develop the Child Community Health Inclusion Index. This was done through item generation using existing measures, guidelines and resources, then item refinement with expert input.

Chapter 6 presents the conceptual links between **Manuscript 2** and **Manuscript 3**.

Chapter 7 presents **Manuscript 3** titled “Content validation of the child community health inclusion index: a modified e-Delphi study”. This study validated the content developed in **Manuscript 2** through a modified e-Delphi technique with various stakeholders involved in childhood disability, inclusion, and universal accessibility.

Chapter 8 presents the conceptual links between **Manuscript 3** and **Manuscript 4**.

Chapter 9 presents **Manuscript 4** titled “Application of the Child Community Health Inclusion Index- an evaluation tool for measuring health inclusion of children with disabilities in the community: A feasibility study”. This study was a feasibility study to estimate the feasibility of applying the Child Community Health Inclusion Index on community facilities by stakeholder evaluators. Evaluators rated feasibility as four indicators: Length, Difficulty, Clarity, and Value while providing comments related to each indicator.

Chapter 10 is a summary of the findings of the four manuscripts, an overarching discussion of the findings and their relation to the thesis, and the implication of said findings on future practice and research.

The corresponding figures, tables, and references for each of the manuscripts are contained within each manuscript. For the remaining chapters (1, 2, 4, 6, 8, 10), the figures are presented at the end of the chapter and the references are presented at the end of the thesis.

Ethics approvals for each study are detailed in the corresponding manuscripts.

Chapter 1: Background

1.1 Participation

The International Classification of Functioning, Disability, and Health (ICF) by the World Health Organization (WHO) defines participation as a person's involvement in life situations, which includes activities of self-care, mobility, socialization, education, recreation, and community life (WHO, 2001). As outlined in the ICF, participation is an essential factor in determining an individual's level of functioning and health (WHO, 2001). Although the WHO first introduced the concept of participation through the ICF in 2001 and therefore legitimized its importance in health and functioning, there has been diverse interpretations of what constitutes participation (Granlund, 2013). Furthermore, it has been a challenge to measure participation, given its complexity and the multitude of personal and environmental factors that influence it. Consequently, there have been diverse methods used to measure participation (Adair et al., 2015). In 2017, the Family of Participation-Related Constructs (fPRC) framework was developed with hopes to clarify the definition of participation and harmonize the use of participation as a concept and construct in the literature (Imms et al., 2017). The fPRC framework conceptualizes participation as both attendance (being there) and involvement (experience of participation) in an activity. Attendance is seen as the "frequency of attending, and/or the range or diversity of activities" attending (Imms et al., 2017); while involvement includes elements of engagement, motivation, persistence, social connection, and level of affect (Imms et al., 2016).

1.2 Community inclusion

The community inclusion movement for people with disabilities is predicated on the assumption that all individuals have the right to be fully participating citizens of their communities (Wolf-Branigin et al., 2001). Minnow defined inclusion as living among, doing things with, and deciding together with people without disabilities (Minow, 1990). Hall's qualitative meta-analysis defined inclusion as six themes: being accepted as an individual with personal characteristics that are accepted by others; relationships including friendships and interactions with others; involvement in activities with access to these activities and community amenities; living accommodations including physical location and transportation; employment including social opportunities and training; and supports including information about services, resources for utilization, and community support (Hall, 2009). These themes are important in describing community inclusion as essentially the interaction with others in the community and the access to community facilities (McConkey, 2007). People with disabilities have the right to equal access to the community and its resources- for this equal access, they require varying types, durations, and frequencies of supports (Minow, 1990). The provision of these supports to ensure the same levels of participation and decisional power in the community is what constitutes community inclusion (Soresi et al., 2011).

1.3 Participation and inclusion as a right

According to the United Nations, participation in the community, being able to play, and being treated as equal is a human right for all people, further affirmed for those with disabilities. The guiding principles of the Convention on the Rights of Persons with Disabilities (CRPD) calls for full and effective participation and inclusion in society. Persons with disabilities, including children, should be included in communities where they live. Possible ways of achieving inclusion are through the availability of accessible physical environments, and equal access to public transportation, information and communications technology, and other facilities and services available to the public (UN, 2006).

Inclusion for people with disabilities has been a theme in disability policy, practice, and research for approximately 50 years (Neely-Barnes & Elswick, 2016). The disability rights movement has led to improvements for individuals with disabilities by advocating for physical accessibility, access to education and jobs, access to information and services, community inclusion, and developing a collective consciousness of inclusion (McCarthy, 2003).

Canada ratified the CRPD in 2006, attesting to the country's commitment to implement and use the Convention on its policy and program development nation-wide. To achieve these aspirations of a society that provides equal opportunities for children with disabilities, we must create concrete opportunities for full citizenship (Wolf-Branigin et al., 2001). Such opportunities may require the provision of both individual supports and community-wide adaptations at the same time and according to the different abilities and needs (Minow, 1990; Soresi et al., 2011).

1.4 Participation in children with disabilities

Scientific evidence highlights the importance of participation for children in various occupational areas such as self-care, education, and leisure within different environments (Humphry & Wakeford, 2006). Participation has been found to be vital for a child's development of social and academic skills along with their sense of competence and identity (Cairney et al., 2010). Participation has also been shown to have key benefits to the physical and mental health and wellbeing of children with disabilities (King et al., 2003). Participation in physical activity helps with motor-skill development while improving cardiovascular fitness and decreasing rates of obesity (Beauvais, 2001). Participation in extracurricular activities benefits emotional wellbeing, life satisfaction, and social relationships with peers (King et al., 2003). Participation also promotes wellbeing for both the children with disabilities and their families (Shikako-Thomas et al., 2014).

Despite the benefits and importance of participation, children with disabilities experience participation restrictions when compared to typically developing peers (Bedell et al., 2013; Law et al., 2011). Children with disabilities have been found to participate less frequently, in a decreased variety of activities, with lower levels of active involvement (Bedell et al., 2013; Ullenhag et al., 2014). This pattern may be due to both child-specific and context-related factors. Child-specific factors as described in the WHO ICF include the child's functional abilities, interests, preferences, and self-esteem, which are intrinsic factors that can facilitate or hinder participation (King et al., 2003; Shikako-Thomas et al., 2008).

1.5 Environmental determinants of participation and community inclusion

Contextual factors, such as the environment in which the child and their family live, can affect participation (Shikako-Thomas et al., 2008; Anaby et al., 2014). There are different aspects of the environment that can act as a facilitator or barrier to participation: physical (e.g. built environment, accessibility), social (e.g. peer support), attitudinal (e.g. perceptions of disability and recreation), and institutional (e.g. policies, availability of adapted programs) (Law et al., 2007). Each domain must promote inclusion and be inclusive for individuals with disabilities to be a facilitator in participation; lack thereof may become a barrier to participation. Inclusion in the community by overcoming these barriers, is a key element to achieving health and is a necessary component of full participation. Environmental factors can serve to either bring together diverse people from various backgrounds, or they can perpetuate exclusion and discrimination, reinforce, and sustain inequities, and induce feelings of inadequacy and failure on the part of marginalized individuals.

Community inclusion encompasses inclusion in terms of the physical environment, social and attitudinal environment, and the institutional environment. When viewing community inclusion within a person-environment fit model of disability as Soresi and colleagues have done, an emphasis is placed on the role played by the contextual factors in successful human functioning, in the types, intensity and duration of supports, on active community participation (Soresi et al., 2011). Supports are defined as resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning (Thompson et al., 2009). These supports, or lack thereof, can present themselves in the different environmental domains.

1.5.1 Physical environment

The physical environment can act as a barrier or facilitator to inclusion of children with disabilities and their participation within the community. Individuals with disabilities encounter a variety of hazards and obstacles that inhibit their participation in the community activities (Sherman & Sherman, 2013). The physical environment comprises the built environment, access to equipment in the community, and the geographic location of community facilities. Everyday access to the built environment is a fundamental human right for complete inclusion of people with disabilities into the community (Sherman & Sherman, 2013). The built environment is defined as "the human-made space in which people live, work, and re-create on a day-to-day basis" (p. 28; Roof & Oleru, 2008). For example, it includes the presence and conditions of sidewalks like curb cuts for wheelchairs, designated tactile patterns for intersections (Rimmer et al., 2004), the maintenance and accessibility of public spaces and facilities like the existence of ramps and push button doors, and width of doorways to accommodate wheelchairs (Imrie & Kumar, 1998; Renalds et al., 2010). The built environment has the capacity to impede and/or prevent mobility for people with disabilities while restricting their access to specific places (Golledge, 1993). Access to equipment and their utilization is also a component of the physical environment. This includes adaptations made to existing equipment for use by those with disabilities. This would include, for example, water chairs included in pools to aid in transfers, Velcro straps to allow a better grip on fitness equipment, height of the front desk (Rimmer et al., 2004), colour contrasts and tactile references and other equipment in a community facility to enhance access by those using wheelchairs (Imrie & Kumar, 1998). Lastly, the geographic location of community facilities is also an important component of the physical environment that can influence community inclusion. This includes the geographic location of parks and recreational and healthcare facilities; public transport that allows easy access to these facilities, and their proximity to one another and to where people live (Pearce et al., 2006). Sherman suggests that perhaps no other barrier inhibits community inclusion more than the lack of accessible and available transportation (Sherman & Sherman, 2013). Changing the physical environment to remove its architectural barriers to facilitate access and bringing people with and without disabilities together in that setting, could allow for all individuals to interact positively and have meaningful social and leisure experiences within the community (Schleien et al., 1996). For individuals with disabilities, especially children with disabilities, the safety, accessibility, and inclusion of the physical environment should be considered. This includes built features like ramps, elevators, and automatic doors that make the building accessible to wheelchairs and strollers; instructions and directions that are easy to understand with the use of child-friendly language (e.g. Braille, visual aids, pictures, and large text); equipment that have different sensory elements to include tactile input, lights, music and sound. It should be noted that physical accommodation and physical proximity alone do not sufficiently produce positive interactions and inclusion in the community (Schleien et al., 1996).

1.5.2 Social and attitudinal environment

In terms of community inclusion, the social environment can be understood to include social networks, roles, relationships, and interactions within the community (Simplican et al., 2015). The opportunity to form and strengthen relationships with family, friends, acquaintances in the community are major indicators of social inclusion (Hall, 2009). Reciprocal interpersonal relationships provide companionship and resource support (Ware et al., 2007). Family members provide a great deal of support and make up a major portion of the social environment (Pawson et al., 2005). Family members and friends provide a network of support that facilitates community inclusion (Hall, 2009). For children, having parental support and participating in activities with their siblings strongly encourage participation, adding to their enjoyment and confidence (Askarai et al., 2015). Engaging in activities with friends with and without disabilities also augments enjoyment and the creation of role models (Eldeniz & Cay, 2020). Additionally, interactions and exchanges with community members are essential to increasing inclusion in the community (Hall, 2009). The support provided by community staff are also important in providing social opportunities (McConkey, 2007) as staff who understand the specific needs and abilities of children with disabilities can help facilitate participation (Askarai et al., 2015). Concomitant with these social networks and relationships within the social environment are the attitudinal environment, or the attitudes of members of the community. Negative community-based attitudes toward individuals with disabilities can impede community inclusion (Abbott & McConkey, 2006). For children, these negative attitudes can be in the form of stigma around disability, the preconceived notion of their inability to participate and overt bullying (Anaby et al., 2013). These negative attitudes limit the opportunities for the child and restrict their participation. However, positive attitudes by members of the community that are grounded in beliefs and values surrounding their abilities and advocacy for their independence and maximizing opportunities, all act as facilitators to their participation (Anaby et al., 2013). The portrayal of disability in the media can also positively or negatively influence the perceptions of a child's abilities and the attitudes toward children with disabilities (Kamenetsky et al., 2016). The attitudes at the community level influence the individual attitudes of its members (Bigby et al., 2012), which further affects the relationships between the child with disabilities, family members, acquaintances and staff (Power, 2008).

1.6 Rights-based approach to understand the intersect of participation and community inclusion

Human rights legislation affirms the principles of equality, non-discrimination, participation, and inclusion for all, regardless of class, nationality, sex, ethnicity, religion, or any other status (UN, 2017). The purpose of the CRPD is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity (UN, 2006). The CRPD includes: a right to access buildings, schools, programmes and public transport, a right to live independently and to be included in the community, a right to personal mobility, freedom of expression and opinion, and access to information, the right to have privacy protected, a right to participate in political life and a right to participate in cultural life, recreation, leisure, and sport (UN, 2006). The CRPD explicitly describes the prime importance of inclusion in that all persons with disabilities should be able to participate fully in all aspects of life (UN, 2006).

With the increasing interest and consideration of the social model of disability governing public policy and healthcare in recent years, focus on determinants of participation have also shifted from the child to also consider the environment of the child (Harpur, 2012). The medical model lays focus on the clinical diagnosis, viewing the individual with the disability as the issue at hand to be cured or treated (Kaplan, 1999). Although elements of the medical model are important, like characteristics of a certain condition or disease, its pathophysiology and prognosis, this model tries to 'improve' or 'fix' a person's intrinsic physical or mental state while disregarding other important issues such as the removal of environmental barriers or providing support to enable the person to exercise other rights (Harpur, 2012). With the social model of disability, focus has shifted from a child's impairment that makes them 'disabled' to the way in which society is structured, the environment causing the impairment to become disabling (Oliver, 2013). Hence, with the social disability model, considerations and efforts should be made to render the environment more inclusive (Harpur, 2012).

The essential characteristics to a rights-based approach to health include access to quality services, to built environments where these services are provided, and to institutions that can promote health, including community facilities (Shikako-Thomas & Shevell, 2018). A rights-based approach together with the social model of disability, can collectively support the elaboration of programs and policies that support the participation of children with disabilities in the community, by ultimately creating communities that affirm these human rights and are fully inclusive of children with disabilities. The intersect between community inclusion and participation can exist in that community inclusion are environmental factors that facilitate and ensure an individual's right to full participation in the community, in line with human rights underscored by the United Nations Convention. Full participation in the community would include each of the rights of the CRPD mentioned above such as access to community facilities, services, and public transport; freedom of independence, expression, and opinion; and being authentically included in the community. The creation of structures and processes that allow the implementation and monitoring of the rights of the convention itself is essential and is called for by the CRPD (UN, 2016). Community inclusion as an outcome is comprised of factors in the environment that secure an individual's right to full participation in the community. Its measurement can be a process through which the implementation of the rights outlined in the CRPD can be monitored.

1.7 Measurement of community inclusion and its challenges

Measurement is the act or process that allows description and comparison of results over time. The usefulness of measurements in clinical research and in the decision-making process depends on the extent to which one can rely on the data to represent accurate and meaningful indicators of behaviors, attributes, or phenomena (Gadotti et al., 2006). The measurement of community inclusion can be applied to evaluate the current state of a given community and/or an individual within a community (De Vet et al., 2011) and can also be used as an outcome measure to track the impact of a context-based intervention on community inclusion of individuals with disabilities (De Vet et al., 2011). The analysis of community inclusion as an outcome can be used to inform policy, clinical practice, and program development (Fox, 2005). Health promotion initiatives, policies, and built environments that make the community more inclusive can facilitate participation opportunities for children (Anaby et al., 2014). Public health policies and community programs should foster community inclusion; and ultimately aim to promote health with consideration of human rights (Shikako-Thomas & Shevell, 2018). Measurement of community inclusion can identify what interventions and strategies already exist, what can be improved, and what can be changed. It can help set priorities and shed light on areas that can otherwise be overlooked- like the need for spaces that are both accessible and child-friendly. We need to understand and appreciate community inclusion as an outcome, in order to implement and evaluate policies and programs that promote community inclusion and identify ways of measuring and monitoring the implementation of said policies and programs.

Multiple measures that aim to capture different aspects of community inclusion exist in the literature. Many of these measures strive to measure a single dimension rather than encompass the multidimensional nature of community inclusion. The challenge lies in comprehensively measuring the different aspects of community inclusion. Existing measures assess specific domains of the environment that have an impact on the individual such as the physical environment or social environment. A review by Coombs and colleagues (2013) aggregated ten different measures of social inclusion, including measures focused on social aspects of the environment and the community (e.g. Social and Community Opportunities

Profiles, Social Inclusion Measure) (Coombs et al., 2013). These measures addressed social inclusion domains of employment, education and relationships.

Some measures also exist to quantify the physical accessibility of built environments (e.g. Measure of Accessibility to Urban infrastructures for Adults with Physical disabilities, Measure of Environmental Accessibility) (Gamache et al., 2018; Gamache et al., 2012); or considers the geographic location of a reference point in relation to the distance between the reference point to other areas of activity (Cumulative Opportunities Measure) (Kelobonye et al., 2020).

The development of measures that comprehensively capture inclusion of children with disabilities in the community is still lacking (Odom et al., 2011). There are a number of tools that measure inclusion of children in their environment using the individual as the unit of measure, rather than the facility/environment level (Lero, 2010), meaning that items address the child's ability to participate in their community and are responded to by the individual: the child and/or the parent. Although this is a crucial perspective and source of information, it may only reveal part of the picture. Applying measurement at the facility-level addresses characteristics of the facility and its provisions that contribute to (i.e. facilitate or hinder) the inclusion of children with disabilities. Furthermore, despite the existing body of literature on inclusion, there is not one gold standard measure that encompasses all the environmental aspects of inclusion with substantial and sound psychometric testing to ensure its validity and reliability (Neely-Barnes & Elswick, 2016).

1.8 The ICF as a foundational framework for measuring community inclusion

A theoretical framework is essential in providing structure to a measure (Neely-Barnes & Elswick, 2016). The ICF framework (Figure 1) provides a conceptual basis for the definition and measurement of health and disability which was conceived within a person-environment interaction paradigm (Buntinx & Schalock, 2010). It underscores the importance of environmental factors in determining health and functioning (WHO, 2001). In the ICF, environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives (WHO, 2001). They are considered external to the individual but interact with health conditions to produce disability outcomes at all levels (i.e. body structure and function, activities and participation in society) (Whiteneck et al., 2004). Furthermore, in 2007, the Child and Youth version of the ICF (ICF-CY) was introduced by the WHO which underscored the unique needs of childhood disability and health. The Child and Youth version was then merged with the original ICF in 2012.

Community inclusion is a key component of participation which considers the environmental context that enables it. It is vital for health and wellbeing (Whiteneck et al., 2004). The 'Environmental Factors' domain of the ICF includes 'Products and Technology' (e1), 'Natural Environment and Human-made Changes to Environment' (e2), 'Support and Relationships' (e3), 'Attitudes' (e4), and 'Services, Systems and Policies' (e5) (WHO, 2001). The subdomains of the Environmental Factors domain encompass the elements that influence community inclusion and enable individuals to participate in age-appropriate life roles of their choosing. Through the scope of the ICF, community inclusion is seen as a multidimensional construct. Community inclusion encompasses physical and social aspects of health that influences the person situated in an environment. It is a construct that is composed of variables that are both observable and non-observable. For example, the 'Natural Environment and Human-made Changes to Environment' ICF subdomain of community inclusion can be observable in the way that the height or angle of a ramp for wheelchair access to a community facility is observable and measurable (WHO, 2001). On the other hand, the 'Attitudes' subdomain would be non-observable, which is not tangible but still an essential component of community inclusion, in the form of attitudes towards an individual by members of the community, peers and family members that can influence the individual's social behavior (WHO, 2001). Community inclusion as a construct is multi-faceted and holistic, therefore it cannot be limited to one dimension of measurement.

1.9 The Community Health Inclusion Index

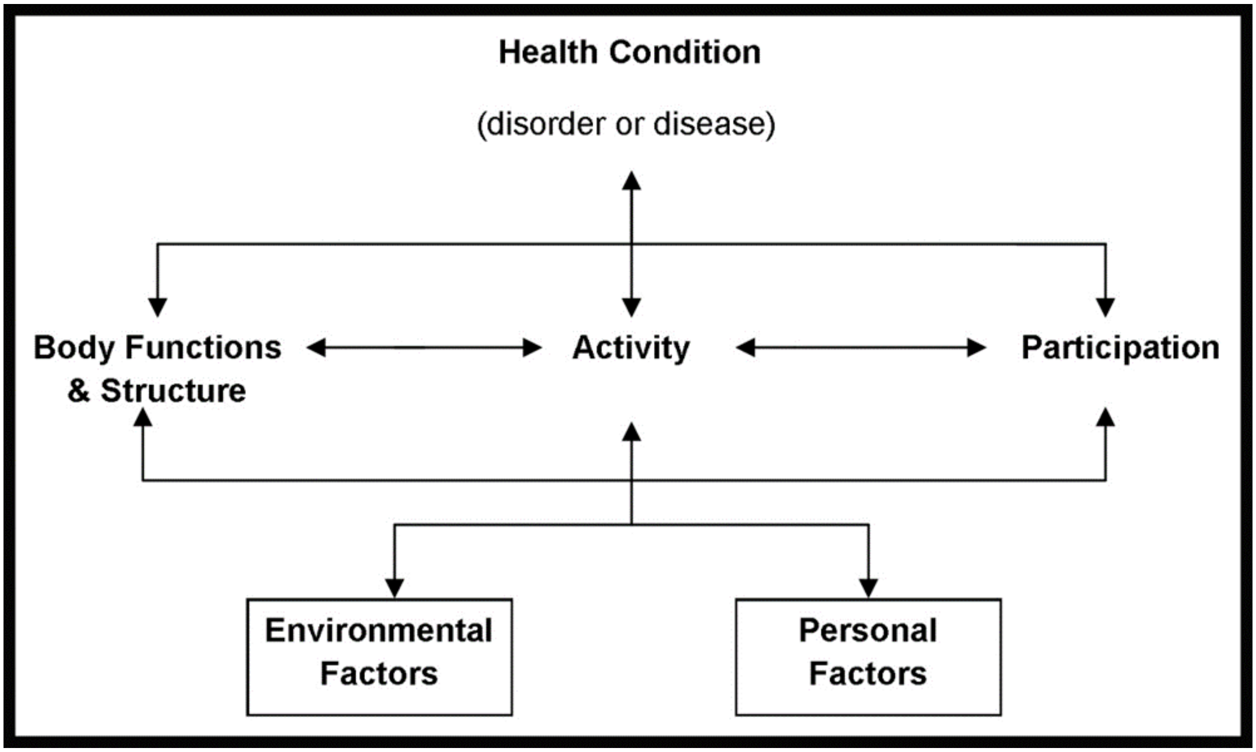
The Community Health Inclusion Index (CHII) was developed by Eisenberg and colleagues (2015) in the United States to comprehensively assess the scope and depth of factors that influence participation in local communities that collectively foster healthy, active living among people with disabilities (Eisenberg et al., 2015). The structure of the CHII closely resembles the ICF framework and items of the CHII address the subdomains of the 'Environmental Factors' domain of the ICF. Using the environment, programs, policies, and locations as the units of measure, the CHII takes into account five different inclusion domains: Built Environment, Equipment, Programs/Services, Staff, and Policies; within four different sectors of the community: School, Health Care, Work Sites, and Community Institutions/Organization. The items of the inclusion domains are not limited to one aspect of the environment but address the different aspects of the environment mentioned above. Hence, the measure comprehensively assesses the inclusion of individuals with disabilities in all sectors of their community.

Additionally, the CHII was developed through a rigorous process. The content of the CHII was developed in three phases: literature review, focus groups, and expert panel review. A comprehensive list of items related to barriers and facilitators to healthy, active living were identified in the literature. Existing measures considered highly influential and used in public health practice were also identified. Subsequently, focus groups were conducted in the United States. The focus groups entailed a discussion of the facilitators and barriers to community health inclusion structured around five domains: Built Environment, Equipment, Programs/Services, Staff, and Policies. These domains have been established as being associated with community health inclusion (Rimmer et al., 2004). Experts with experience working with people with disabilities then reviewed the items from the literature review and the focus groups. The CHII then underwent cognitive response testing to determine its feasibility. Further field testing was also conducted to estimate its reliability, to include internal consistency and inter-rater agreement. For the CHII, all evaluator-reported items in the measure had acceptable internal consistency with Cronbach's alpha over 0.700 (Cortina, 1993; Eisenberg et al., 2015); Inter-rater reliability was calculated to be between 0.61-1.00 which ranged from substantial to almost complete agreement (McHugh, 2012; Eisenberg et al., 2015).

The CHII is an index that an individual completes through an evaluation of the facility; the index consists of multiple items that provide an ordinal score (Eisenberg et al., 2015). The CHII is an index that is completed through both an assessment of the facility by an evaluator, and through interviews with facility staff. This captures the multiple characteristics of community inclusion outlined above, providing both quantitative data measured by the evaluator and qualitative data reported by the facility's staff. This measure holistically and comprehensively assesses community inclusion of individuals with disabilities. However, it is limited in addressing the specific needs of children with disabilities.

Figures

Figure 1- International Classification of Functioning, Disability and Health Framework



Chapter 2: Rationale and Objectives

2.1 Rationale

Community inclusion and participation is a principal right for all people, including children with disabilities, as affirmed by the United Nations' CRPD. An inclusive community is one where all individuals can participate fully in their life roles. Contextual factors can facilitate or limit a child's participation. However, knowledge of the impact of interventions at the systems-level is limited. Measuring aspects of the environment that may influence a child's inclusion and health is crucial to better understanding the impact of contextual factors on a child. Elucidation of these enablers and barriers to participation can further inform the development of context-based interventions to enhance community inclusion and participation of children with disabilities. A comprehensive index can generate the information necessary to evaluate the current state of a community's level of inclusion (De Vet et al., 2011). It can also be used as an outcome measure to monitor changes over time following an intervention (De Vet et al., 2011). In addition, measuring community inclusion as an outcome can be utilized in research to estimate the effectiveness or efficacy of interventions. The results and analysis of these outcome measures in research can be used to inform policy and clinical practice (Fox, 2005).

The usefulness of measurements in research and in practice depends on the extent to which one can rely on the data as accurate and meaningful indicator of the behavior, attribute, or phenomena of interest (Portney & Watkins, 2009). The CHII aims to measure the community inclusion of individuals with disabilities. Currently, there are no comprehensive measures of community inclusion for children with disabilities addressing their unique environmental requirements. As mentioned, the CHII takes into account the barriers and facilitators in the community that affect participation for individuals with disabilities but includes a limited number of items related to the inclusion of children with disabilities and their families. This is an important discrepancy to note as the activities and participation roles of children with disabilities differ from those of adults with disabilities (WHO, 2008).

The development of a measure that comprehensively assesses the inclusion of children with disabilities at the community level, encompassing multiple domains of the environment in the Canadian context can help add to the existing body of literature on inclusion, providing special attention to that of children with disabilities. The Canadian context considers the different contexts of weather, political structures, and service provision. The development of a comprehensive measure may contribute to implementation efforts and measurement of systems-level strategies that aim to improve inclusion through changes in the environment, not the child.

2.2 Objectives of this thesis

2.2.1 Overarching primary objective

The primary objective of this doctoral project was to develop a measurement tool that assesses community-based contextual factors that can promote the inclusion of children with disabilities in the communities where they live. The main goal was to identify environmental factors across community-based facilities (e.g. schools, rehabilitation centres, community organizations, etc.) that are deemed important for the inclusion of children with disabilities in their community. The development of a comprehensive measurement tool that assesses the community inclusion of children with disabilities through stakeholder involvement can optimize the use of the tool. Furthermore, it can highlight the potential of systems-level changes, programs, and policies; and further inform their development.

2.2.2 Specific objectives

To address the primary objective, the specific objectives included:

1) To systematically review the research evidence on context-based interventions that aim to increase participation of children with disabilities in the community.

2) To develop the content and test the feasibility of a community health inclusion measurement tool that identifies and assesses the barriers and facilitators in different community level facilities and environments that affect the participation of children with disabilities living in Canada.

The pre-existing CHII will be adapted to the Canadian pediatric population, newly named the Child Community Health Inclusion Index (CHILD-CHII).

2.2.3 Study design and methods

For the first specific objective, a structured literature review was conducted using a systematic review methodology. The knowledge was synthesized using the Family of Participation-related Constructs framework (fPRC) and the Community Wellbeing Framework (CWF) (**Manuscript 1**).

Following the first specific objective, the results of the systematic review were used to guide the initiation of the second specific objective. The content of the CHILD-CHII was developed first as item generation through a literature review of existing measures, guidelines, and checklists related to inclusion (including the measures identified in the systematic review of **Manuscript 1**); then through multiple iterations of item refinement with expert panel consultation (**Manuscript 2)**. Following the initial development of the content, the measurement tool was then validated through a modified e-Delphi technique where the items were validated and clarified by stakeholders through two rounds of review (**Manuscript 3**). The validated content and measurement tool was then tested for feasibility through the application of the measure on community facilities by stakeholder evaluators (**Manuscript 4**). Detailed descriptions of the design and methods for each study are provided in each manuscript.

Chapter 3: Manuscript 1

The Effect of Context-based Interventions at the Systems-level on Participation of Children with Disabilities: A Systematic Review

Paul Yejong Yoo, MSc., OT
PhD Candidate
School of Physical and Occupational Therapy, McGill University
3500 Blvd Decarie, Rm. 433
Montreal, Quebec, Canada
H4A3J5
paul.yoo@mail.mcgill.ca

Ebele R. I. Mogo, DrPH
Research Associate
MRC Epidemiology Unit, University of Cambridge School of Clinical Medicine
Cambridge, England

Janet McCabe, RN, PhD
Associate Dean, Nursing
Faculty of Health Sciences, Ontario Tech University
Oshawa, Canada

Melanie Bergthorson, OT
Occupational Therapist
Lethbridge-Layton-Mackay Rehabilitation Centre
Montreal, Canada

Rose Elekanachi
PhD Student
School of Physical and Occupational Therapy, McGill University

Montreal, Canada

Roberta Cardoso, RN, PhD
Research Associate
McGill University Health Centre, McGill University
Montreal, Canada

Mehrnoosh Movahed, PhD
Research Associate
School of Physical and Occupational Therapy, McGill University
Montreal, Canada

Annette Majnemer, OT, PhD, FCAHS
Vice-Dean, Education
Faculty of Medicine and Health Sciences, McGill University
Montreal, Canada

Keiko Shikako-Thomas, PhD, OT
Associate Professor
School of Physical and Occupational Therapy, McGill University
Montreal, Canada

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Abstract

Aims: To synthesize evidence on the impact of context-based interventions on the participation of children with disabilities in the community.

Methods: A systematic review was conducted using the American Academy for Cerebral Palsy and Developmental Medicine Guidelines for systematic reviews. Seven databases were searched; articles included were on children with developmental disabilities under the age of 19 years, describing systems-level, context-based interventions aimed to improve participation and Participation-related outcomes of the Family of Participation-related Constructs framework. Intervention characteristics were coded using the Community Wellbeing Framework (CWF).

Results: Eleven articles were included for knowledge synthesis. Four studies were level I, II, and III based on the Centre for Evidence-Based Medicine hierarchy. All four showed that context-based interventions had a positive effect on participation and participation-related outcomes. All 11 studies had intervention properties that were coded to at least one domain on the CWF.

Conclusion: There is a scarcity of high-quality studies that focus on context-based interventions at the systems-level, as opposed to the individual-level. Albeit low-level quality, existing evidence emphasized the importance of creating opportunities and spaces of play, mobility, socialization, and development of partnerships to change the system and promote participation.

Keywords

Children with disabilities, Context-based, Participation, Intervention, Systems-level, Policy

Introduction

The International Classification of Functioning, Disability, and Health (ICF) by the World Health Organization (WHO) defines participation as a person's involvement in life situations (WHO, 2007). Full and effective participation in the community is a human right for every child as stated in the United Nations' Convention on the Rights of the Child (CRC) (UN, 1989) and the Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006). To be able to participate, individuals with disabilities need access to facilities and services provided to the public at large (UN, 2006). Participation and inclusion in the community are both integral parts of a collective perception of community wellbeing (CBOC, 2018). Participation of children with disabilities in leisure activities promotes inclusion in the community, can minimize physical deconditioning, contributes to cardiovascular health, and enhances overall psychosocial wellbeing and life satisfaction (Cairney et al., 2010; Murphy & Carbone, 2008; Shikako-Thomas et al., 2014; Yazicioglu et al., 2012). Despite the benefits and importance of participation, children with disabilities face participation restrictions in comparison to that of typically developing children (Bedell et al., 2013; Law et al., 2011). These restrictions can be linked to factors related to both the child and the environment (Shikako-Thomas et al., 2014). Interventions aimed at improving participation of children with disabilities should address both intrinsic and environmental factors that negatively affect participation.

Most rehabilitation interventions described in the literature that aim to enhance participation as an outcome are individualistic in nature (Adair et al., 2015; Clutterbuck et al., 2020; Reedman et al., 2019). The interventions are mostly designed and catered to address activity competence for the single child and are not aimed at a broader collective or public health level (Imms, 2008; Lammi & Law, 2003; Novak et al., 2013). Although some interventions do target contextual factors of the environment to facilitate the participation of the child (Anaby et al., 2018; Law et al., 2015), they are still individualized to modulate the immediate environment of that child (e.g. offering information about the child's disability to the instructor so as to adapt the activity). They are generally not aimed at larger environmental changes (e.g. institutional, structural, or policy based). To date there are no research reviews describing and evaluating the impact of context-based interventions at the systems-level. For the purpose of this review, context-based interventions include interventions that are implemented at the systems level, that target the community and/or group of participants as a whole rather than interventions offered individually (1:1) to children with disabilities. These interventions can present themselves as curriculum changes, policies, health initiatives, community programs, and services provided and/or implemented at the community level, aiming to promote participation of children with disabilities.

To address this gap in literature, the objective of this systematic review was to synthesize existing evidence on the effect of context-based interventions at the systems-level, as described above, on the participation of children with disabilities using the Family of Participation-related Constructs (fPRC) framework, and to analyze these context-based interventions and their properties of community inclusion using the Community Wellbeing Framework (CWF).

Methods

A systematic review was conducted to address the following question: What are the comparative effects of systems-level context-based interventions on the participation levels of children with developmental disabilities compared to no interventions? A secondary aim was to identify the main characteristics of these interventions in relation to community wellbeing. The review was registered on PROSPERO (CRD42021270457).

Search Strategy

A comprehensive search was conducted on August 17, 2021 in the following databases: CINAHL, EMBASE, Medline, PsycINFO, PubMed, and further searches in ProQuest Dissertations & Theses Global, and Social Work Abstracts. The detailed search strategy for Medline can be found in Appendix 1. Key terms included: child, developmental disabilities, community, context, initiatives, campaign, program. Searches were limited to peer-reviewed publications in the English language and further limited to articles that were published from the year 2008 and onward. The timeframe reflects a contemporary window of relevancy, following the publication of the ICF-CY framework by the WHO in 2007 (WHO, 2007). Conference abstracts were not included, as they are not indexed in Medline. Figure 1 illustrates the review flow chart. The references for included studies were also scanned for additional relevant studies.

Study Selection

Inclusion/exclusion criteria is found in Table 1. For inclusion, studies needed to investigate a context-based intervention for the population of children with acquired or congenital developmental disabilities (e.g. cerebral palsy, autism spectrum disorders) that directly impacted child development. Studies that were excluded were those that: i) addressed interventions specific to chronic health conditions such as diabetes and/or obesity, and ii) exclusively included individuals over the age of 19 years because these individuals are deemed as more autonomous and are typically supported by adult services (Canada, 2017). Studies that investigated the effects of interventions that were context-based and/community-based were included: interventions that targeted the community as a whole, or the context of a group of individuals of interest; additionally, interventions that were at the systems-level like policy, health initiatives, and programs were included. Studies that reported on changes to the environment (e.g. task modifications, adaptations) for the individual child were excluded. Randomized control trials and non-randomized studies of intervention were included. Outcomes related to Participation and Activity were included because the ICF does not clearly distinguish between the activity and participation domain which had led to varied interpretation of the concept in literature with varied approaches to their measurement (Imms et al., 2016). In an attempt to ensure that pertinent studies on relating to participation were not missed, studies that captured any element(s) of Activity and Participation domains were included.

Study Screening

A random sample of 10% of the titles and abstracts were independently screened by two reviewers applying the selection criteria to test clarity of the criteria and a 90% agreement was reached in this initial screening. The remaining titles and abstracts were screened by the two reviewers. A third reviewer was consulted to resolve conflicts. A subsequent pilot screening was done for 10% of the included titles and abstracts for the full-text screening. After 90% agreement was reached, full-text screening was independently conducted for the 200 included articles from the initial screen and 11 articles went on to data extraction as presented in figure 1.

Data Extraction

Data extraction was performed using a customized data extraction form developed for this review. Extracted data included participant characteristics, details of the intervention to include system-level characteristics, the measurement of activity/participation and/or other outcomes, effect of the intervention on the outcomes. The data extraction form was piloted using 2 of the 11 articles retained from the full-text screening. Ninety percent agreement on content of the data extracted was reached between the first author and the five secondary reviewers. After the pilot testing, and further clarification of each variable of the data extraction tool, data extraction was completed on the remaining 9 articles by five pairs of reviewers with the first author being a member of each pair. Any discrepancies between reviewers were reconciled by a third reviewer, as needed.

Knowledge Synthesis

Data extracted from the included articles were synthesized by applying two different frameworks to present the knowledge. The Community Wellbeing Framework (CWF) created by the Community Board of Canada and its components were used to categorize the studies based on the characteristics of their interventions (CBOC, 2018). The CWF is an evidence-based framework that was developed to support an holistic consideration of program and policy design to promote community wellbeing (CBOC, 2018). The CWF provides a community approach to examining intervention features that contribute to wellbeing (CBOC, 2018). The framework is made up of five domains: *social, cultural, environmental, economic, and political*; and 18 indicators across the 5 domains, that determine the presence of community wellbeing (CBOC, 2018) (Refer to Supplementary Table 1). Interventions in this review were coded in terms of the indicators and domains targeted.

The studies were also synthesized based on the outcomes that they measured, applying the Family of Participation-related Constructs (fPRC) framework (Adair et al., 2018; Imms et al., 2017). Stemming from the Participation domain of the ICF and its relationship with the other domains, the fPRC framework was developed to provide a clear understanding of participation and to promote consistency in its use as an outcome (Imms et al., 2017). The fPRC describes participation in terms of attendance (being there) and involvement (level of engagement) (Imms et al., 2017). Using the fPRC definitions, we included articles measuring outcomes related to different elements of participation: *Attendance* – measured as frequency of attending and/or range of diversity of activities, and *Involvement* – experience of participation while attending including elements of engagement, motivation, persistence, social connection, and affect - were collectively coded as *Participation* (Adair et al., 2018; Imms et al., 2017). Articles describing outcomes related to Participation such as *Preferences* (interests or valued activities), *Sense of Self* (factors related to confidence, satisfaction, self-esteem), and/or *Activity Competence* (ability to execute activity according to expected standard) were coded as *Participation-related* (Adair et al., 2018; Imms et al., 2017). A study could be assigned multiple codes aligned with multiple outcomes of interest.

Quality Assessment

Quality assessment was performed following the guidelines of the AACPDM methodology for systematic reviews of treatment interventions (Darrah et al., 2008), in assessing the quality or conduct of each study. The quality assessment was only performed on studies with levels of evidence I, II, and III- based on the hierarchy developed by the Centre for Evidence Based Medicine (Medicine, 2009) as per the AACPDM methodology for systematic reviews (Darrah et al., 2008). The Risk of Bias in Non-standardised Studies of Interventions (ROBINS-I) tool was used to assess the risk of bias, following the Cochrane Methods for non-randomised intervention studies (Sterne et al., 2016) and the Risk of Bias tool for randomized trials (RoB 2) was used to assess the risk of bias of randomised trials (Sterne et al., 2019). Quality assessment was conducted independently by two authors, and discrepancies resolved in discussion with the senior author.

Results

The final list of included articles and its main characteristics can be found in table 2. After duplicates were removed, 16,749 titles and abstracts were screened, then 200 full text manuscripts were screened for eligibility. 11 studies were retained for data extraction.

Participant Characteristics

The summary of the participant characteristics of each study can be found in table 2. Studies included children with multiple diagnoses such as autism spectrum disorder (ASD), intellectual disabilities, and physical disabilities.

Types of Interventions and Settings

The descriptions of the interventions for the included studies can be found in table 2. Two articles studied the impact of the “I Can Do It, You Can Do It” (ICDI) intervention (An et al., 2019; Kemeny & Arnhold, 2012). The ICDI intervention was a peer mentorship program to promote healthy lifestyles and physical activities. This program was implemented in the local recreational facilities (Kemeny & Arnhold, 2012) and in the school setting (An et al., 2019). The “Fit-2-Play” intervention and its effects were studied in two studies (Haney et al., 2014; Messiah et al., 2019); both in a public park setting. The Fit-2-Play program was an outcome-oriented recreation program that was implemented at the municipal-level (Haney et al., 2014) and at the school-level as an after-school program (Haney et al., 2014). The remaining studies reported the effects of distinctive interventions. Interventions in all 11 studies were group interventions implemented as programs. All interventions had aspects of a structured program implemented within organizations or promoted the collaboration between different organizations, studied in different settings: six in the school/classroom setting (An et al., 2019; Engelstad et al., 2020; Koenig et al., 2012; Locke et al., 2019; Shire et al., 2020; Shire et al., 2019), two in a public park setting (Haney et al., 2014; Messiah et al., 2019), two in a community centre setting (Kemeny & Arnhold, 2012; Temple & Stanish, 2011), and one in a camp (Zimmerman et al., 2019).

Intervention Properties Related to the Community Wellbeing Framework (CWF)

All 11 articles studied the interventions that can be linked to the *Cultural* domain of the CWF. Within this domain, most of the interventions aimed to facilitate aspects of 'Learning' and 'Play' for the children through the medium of group activity, peer mentorship, or instructor-child dyads, in the context of school, community facility, and public park programs (An et al., 2019; Engelstad et al., 2020; Haney et al., 2014; Kemeny & Arnhold, 2012; Koenig et al., 2012; Locke et al., 2019; Messiah et al., 2019; Shire et al., 2020; Shire et al., 2019; Temple & Stanish, 2011; Zimmerman et al., 2019).

All interventions also included aspects of 'Mobility' in the *Environment* domain*,* defined as interventions that provide opportunities for different levels of physical activity and different capabilities, and the opportunities to engage through movement in learning and play, in both formal and informal settings. Most interventions were driven by sports and/or leisure, incorporating physical activity and exercises in the program (An et al., 2019; Haney et al., 2014; Kemeny & Arnhold, 2012; Koenig et al., 2012; Messiah et al., 2019; Shire et al., 2019; Temple & Stanish, 2011; Zimmerman et al., 2019).

'Socialization' is defined as interventions that provide opportunities for interaction in the *Social* domain (CBOC, 2018). It was promoted through the provision of dedicated spaces for children with disabilities to interact and socially engage at both formal and informal levels, in all 11 studies (An et al., 2019; Engelstad et al., 2020; Haney et al., 2014; Kemeny & Arnhold, 2012; Koenig et al., 2012; Locke et al., 2019; Messiah et al., 2019; Shire et al., 2020; Shire et al., 2019; Temple & Stanish, 2011; Zimmerman et al., 2019). Additionally, nine studies consisted of

‘Support Systems’ defined as convenient access to facilities and services in the *Social* domain of the framework- the intervention included aspects of tailoring the intervention plans, specific activities, and elements of the context, to the needs of children with disabilities. (An et al., 2019; Engelstad et al., 2020; Haney et al., 2014; Koenig et al., 2012; Locke et al., 2019; Messiah et al., 2019; Shire et al., 2020; Shire et al., 2019; Zimmerman et al., 2019).

‘Integration’ in the *Political* domain of the framework, defined as meaningful integration of diverse perspectives into the intervention design, were present in all studies. Seven studies involved the implementation of school-level curriculum changes (An et al., 2019; Engelstad et al., 2020; Haney et al., 2014; Koenig et al., 2012; Locke et al., 2019; Shire et al., 2020; Shire et al., 2019), and four studies involved the implementation of community programs at different levels- local community (Locke et al., 2019), municipality (Messiah et al., 2019; Zimmerman et al., 2019), and nation-wide (Kemeny & Arnhold, 2012).

‘Collaboration’ was addressed in seven studies to create opportunities for different stakeholders to collaborate in order to implement the program (eg. research teams, school boards, community organizations, university institutions, municipal governments) (An et al., 2019; Engelstad et al., 2020; Kemeny & Arnhold, 2012; Koenig et al., 2012; Locke et al., 2019; Messiah et al., 2019; Shire et al., 2020; Shire et al., 2019; Zimmerman et al., 2019). In the ICDI intervention, at the organizational-level, nine recruited study sites were responsible for making collaborations with recreational facilities in their immediate area to provide indoor physical activity space for the program (Kemeny & Arnhold, 2012). The Temple & Stanish (Temple & Stanish, 2011) study partnered with the local YMCA to provide the space and instructions for children with intellectual disabilities to utilize the fitness centre (Temple & Stanish, 2011).

None of the interventions addressed the *Economic* domain of the CWF, which considers the affordability of the interventions and socio-economic status of the population.

Effectiveness of Interventions

Of the 11 studies included, four studies had either level I, II, or III evidence (Engelstad et al., 2020; Koenig et al., 2012; Locke et al., 2019; Shire et al., 2020). Six of the 11 studies measured outcomes linked to both the *Participation* and *Participation-related* domain of the fPRC framework (Engelstad et al., 2020; Locke et al., 2019; Shire et al., 2020; Shire et al., 2019; Temple & Stanish, 2011; Zimmerman et al., 2019), while two studies focused exclusively on measures of *Participation* (An et al., 2019; Kemeny & Arnhold, 2012), and three studies exclusively measured outcomes of the *Participation-related* domain (Haney et al., 2014; Koenig et al., 2012; Messiah et al., 2019). The outcomes that were measured in each study and their reported parameter estimates are presented in table 3. Of the higher level studies, the study by Locke and colleagues (Locke et al., 2019) conducted a school-based social engagement intervention, which trained school personnel to support children with autism. The intervention targeted a curriculum change with the addition of the training of personnel in the program delivery. In the intervention group, school staff received coaching to implement the social engagement intervention. The study showed that participation concepts, measured as peer engagement and social network inclusion, improved in the intervention group (Locke et al., 2019). Positive improvements were measured in each of the outcomes of interest, favouring the intervention group in the higher level studies. The remaining seven studies had low level evidence and their effectiveness is reported in table 3.

Quality and Bias Assessment

Quality assessment was performed on four studies as per the AACPDM quality assessment guidelines (Table 4). Three studies were deemed 'Strong' in quality (Engelstad et al., 2020; Locke et al., 2019; Shire et al., 2020). ROBINS-I was applied on all eight non-randomized interventions study articles (Table 5a) and two studies were deemed to be 'Moderate' risk of bias (Haney et al., 2014; Messiah et al., 2019); while the others were 'Critical' or 'Serious'. RoB 2 was applied on the randomized control trials and one study was deemed 'Low' risk of bias (Locke et al., 2019), one was 'Some concerns' (Shire et al., 2020), and one with 'High' risk of bias (Engelstad et al., 2020) (Table 5b).

Discussion

This systematic review identified eleven studies that investigated the effect of context-based interventions that incorporated different systems-level changes, on the participation of children with developmental disabilities. The majority of studies were cohort studies without concurrent control groups, and only one study identified was a randomized control trial with a large sample size. Eight interventions addressed aspects related to activity competence at the level of the individual child, with three higher level (I+II) studies addressing participation and participation-related outcomes. Although eight studies identified were of low quality with a high risk of bias, the interventions did have systems-level characteristics with properties related to the CWF. Among the four studies with evidence levels I, II and III, this review showed that curriculum and program changes at the systems-level (eg. classroom, school) did have a positive effect on children's participation and participation-related outcomes.

Although initially evaluated as distinct domains, the ICF designates Activity and Participation as one single category- the two domains are combined into one construct encompassing activities performed in daily life roles (WHO, 2007). A systematic review of participation outcomes following interventions for children with impairments found significant inconsistencies in the concept/language of participation (Adair et al., 2015). This inconsistency is indicated as another systematic review of the definitions for participation found that 'activity competence', defined as the ability to execute the activity being undertaken according to an expected standard, was a definition frequently used in the research literature (Imms et al., 2016). Hence, the use of the fPRC framework allowed for a consistent use of language while providing a clearer understanding of the construct. Using the fPRC, we saw that eight studies measured outcomes linked to participation as either attendance and/or involvement. Three studies measured outcomes of activity competence, sense of self, and preferences which are related to but not synonymous with participation (Adair et al., 2018). These three constructs are deemed as intrinsic factors that influence, and are influenced by participation (Imms et al., 2017). Understanding these factors can support building context-based systems wide interventions that include aspects related to them, with a final goal to promote participation.

One higher-quality study in this review showed a positive effect of a curriculum and program change in the school context on the specific outcome of challenging behaviors (Koenig et al., 2012). The Aberrant Behavior Checklist (ABC) was used to measure the primary outcome of challenging behaviors. Certain domains of the ABC have been shown to have moderate associations to the Vineland Adaptive Behavior Scales-II (VABS-II) (Kaat et al., 2014); and based on a content analysis of the VABS-II using the ICF, most of its concepts were coded as an activity and participation domain while about 30% of concepts were coded body function (Gleason & Coster, 2012). When compared to a special education program, an inclusive education program supported the inclusive pathway as the one providing more opportunities for children with disabilities to practice certain skills, achieve a sense of competence in an activity, and develop better connections with others (Shields et al., 2012). The school setting is the context within communities where children spend most of their time (Indicators, 2014). For children with disabilities, the school setting is often where most of their rehabilitation interventions occur (Statistics, 2020). It is important to note the potential positive impact that changes at the systems-level (e.g. educational program, classroom) in educational settings can have on the participation of children with disabilities (Beloin & Peterson, 2000). Rehabilitation professionals should partner with education and community organizations in a structured manner to contribute to curricular and programmatic changes that are more inclusive, to facilitate opportunities for behaviour changes and optimize participation as a consequence (Gross, 2015).

10 of the 11 studies in this review had interventions that included aspects of play, including all the higher-level evidence studies. As per the CWF, the play subdomain includes opportunities to participate in active, creative and recreation activities (CBOC, 2018). The presence of play in the majority of the interventions supports the existing evidence that play and having fun are major facilitators to participation and physical wellbeing among children with disabilities (Rosenbaum & Gorter, 2012; Shields et al., 2012). Socialization was an element present in all interventions included in this review that was consistent with the literature in facilitating participation. All interventions provided opportunities for interaction through the provision of dedicated spaces for children with disabilities to interact and socially engage with others. Children are more likely to participate if a certain activity includes interaction, encouragement, and assistance with their peers, friends, or siblings (Shields et al., 2012; Wright et al., 2019). Furthermore, structured programs with a variety of activities, staff that are trained about disability awareness, and activity modification/adaptation, have been noted to facilitate participation (Shields et al., 2012).

Previous studies with policy and community stakeholders demonstrated that structural changes in play and sports activities that include elements of staff training and ongoing capacity building, as well as structured funding systems to support inclusive initiatives, facilitated leisure participation of children with disabilities (Mogo et al., 2020). The economic domain of the CWF, which takes into account the economic feasibility, affordability of the interventions, and socio-economic status of the population, was not addressed in any of the studies. Several aspects of the economic domain, such as funding, cost of equipment, travel, and adapting facilities, have been identified as barriers to participation of children with disabilities (Shields et al., 2012; Wright et al., 2019). This omission denotes a gap in health and social research in emphasizing this important systemic change component: the cost-effectiveness of interventions and the scale-up and feasibility of implementation at a systems level. In order to affect changes at that level, interventions must consider these key implementation considerations as an integral part of measurement (Krahn et al., 2019).

The scarcity of high-level evidence studies on context-based interventions limited the synthesis and analysis of outcomes in this review and revealed an important knowledge gap in interventions that consider systems-wide changes to promote participation. However, many of the studies included in this review, albeit their low level of evidence, emphasized the importance of applying known facilitators to participation such as training of staff, peer mentorship, awareness raising, and development of partnerships. Additionally, the key words used for the search strategy may have missed some context-based interventions given that the concept or type of intervention itself is hard to articulate with specific key words. Furthermore, the key words used may not have captured other brain-based disabilities, through which some studies may have been included. Finally, the search being limited to the English language is a limitation as we may have missed studies published in different languages.

Though presenting a low level of evidence, this review supports that the creation of strong partnerships between relevant organisations can facilitate the creation of inclusive programs for children with disability (Jones, 2003). Partnerships and collaborations between university institutions, schools, municipalities, and community recreation facilities can facilitate the implementation of sports and other physical activity programs (Haney et al., 2014; Kemeny & Arnhold, 2012; Messiah et al., 2019). Other limitations of this review include the possibility of further evidence existing in other databases and/or grey literature that were not considered in this review. Additionally, the key words used for the search strategy may have missed some context-based interventions given that the concept or type of intervention itself is hard to articulate with specific key words. Furthermore, the key words used may not have captured other brain-based disabilities, through which some studies may have been included. Finally, the search being limited to the English language is a limitation as we may have missed studies published in different languages.

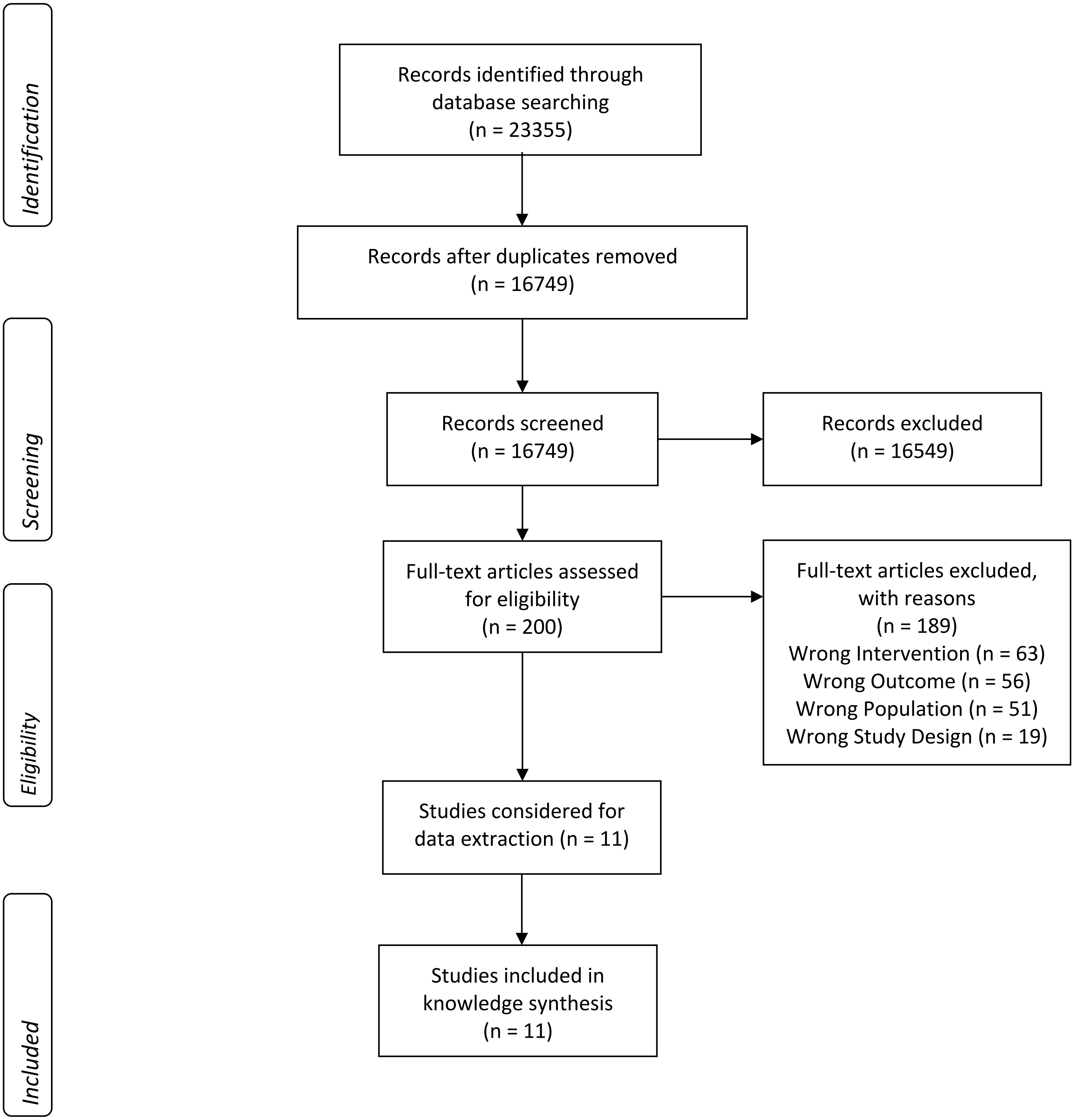
Although the interventions reported were applied in a broader context (i.e. did not target the immediate context of only one individual), all 11 interventions consisted of elements that measured outcomes at the individual level. There were no studies that investigated the effects of interventions involving policies and/or larger systems-level initiatives and measured outcomes at the systems levels such as collective awareness, or community inclusion. Policy intervention studies have been shown to be effective in other outcomes such as reducing non-communicable disease risk factors (Hyseni et al., 2017; Singh et al., 2017) and increasing immunization uptake (MacDonald et al., 2013; Ting et al., 2017). This represents an important gap and thereby an opportunity exists to expand our understanding of the use of policy-level, systems-wide interventions to promote the participation of children with disabilities. It also underscores the potential to inform policies with existing research evidence in order to promote participation as an important feature for community wellbeing and public health. Furthermore, future studies should also consider the cost-effectiveness of interventions and the scale-up and feasibility of implementation of these interventions at a systems level. Evidence-based and normative frameworks like the CWF and the CRPD can support the development of interventions that target systems-levels change such as inclusivity, accessibility, policies, and programs at the levels of schools, communities, cities, and countries.

Conclusion

This systematic review identified a significant gap in the literature, that few high-quality studies exist that investigate the effectiveness of systems-level interventions (e.g. educational or community programs) that consider systems-related variables included in the Community Well-being framework, focused on children with disabilities, and were aimed at enhancing participation and participation-related outcomes. Higher quality studies targeting participation at the systems level should include implementation considerations such as cost-effectiveness analysis, scale-up, opportunities for cross-sectorial collaborations, and implications for policy. Systems-wide considerations should aim to promote and foster partnerships and collaborations with and between different stakeholder groups such as clinicians, decision-makers, and families; to create interventions with considerations of established frameworks such as the CWF and the UN CRPD, and build on communities, policies, and programs that can collectively transform environments to optimize participation for children with disabilities.

Figures

Figure 1: Flow chart of the review process



Tables

Table 1: Study selection criteria

Inclusion Criteria	Exclusion Criteria
Population >50% of participants < 19 years old Acquired and/or congenital developmental disabilities Any location	Population Mental health conditions (eg. depression, anxiety) Chronic diseases (e.g. diabetes, asthma)
Intervention Context-based Systems level Community-based	Intervention Individualized Directed to single participant
Outcome Participation Activity	

Table 2: Summary of studies

Study	Level of Evidence[a]	Participants	Sample Size	Ages	Intervention	Comparator/ Control	Type	Duration	Setting	Description	Systems-level Characteristics	Community Wellbeing Framework
Koenig et al., 2012	III- Cohort study with concurrent control group	ASD, no known medical conditions preventing participation Intervention and control group with similar levels of adaptive functioning	46 Int=24 (Male= 19, Female= 5) Ctl=22 (Male= 18, Female= 4)	5-12y	Get Ready to Learn Yoga (GRTL)	Ctl- Standard morning routine- Getting the materials and room ready and having a morning meeting–type group activity, which may or may not have included physical exercise.	Group	15-20min/weekday mornings; 16 weeks	Classroom	Breathing exercises and physical postures to establish a quiet state, reducing extraneous distractions and contributing to the state of calm in the classroom.	School-level implementation of class curriculum	Cultural- Learning, Play; Environment- Mobility; Social- Socialization; Political- Integration
Kemeny & Arnhold, 2012	IV- Cohort study without concurrent control group	Variety of disabilities classified under IDEA legislation	660 (Male= 426, Female= 234)	4-29y	I Can Do It, You Can Do It (ICDI)	N/A	Organization; Peer-mentor	1 hour/week; 8 weeks	Community centre	Mentor-mentee partnership doing various physical activities based on preference in local fitness centre	Organizational-level Collaboration; Nine recruited sites responsible for making collaborations with recreational facilities in their immediate area to provide indoor physical activity space for the program	Cultural- Learning, Play; Environment- Mobility; Social- Socialization; Political- Collaboration, Integration
Temple & Stanish, 2011	IV- Cohort study without concurrent control group	ID, independent ambulation, no PD that would impair PA participation	20 (Male= 10, Female= 10)	15-21y	Peer-guided Fitness Program	N/A	Organization; Peer-mentor	1 hour, 2 days/week; 8 weeks	Community centre	Participant partnered with typical peer to follow an exercise plan developed by fitness instructors including: aerobic exercise, strength training, flexibility and core strength exercises	Implementation at the local YMCA centre	Cultural- Learning; Environment- Mobility; Social- Welcoming, Support Systems, Socializatio

										exercise, shunt and hydrocephalus review and questions, and private self-catheterization education sessions.	participate in adapted camp	Socialization; Political- Integration, Collaboration
Engelstad et al., 2020	II- RCT with smaller sample size	ASD	Int=15 (Male=9, Female=6) Ctl=16 (Male=13, Female=3)	Mean Months (sd) Int=48 (8), Ctl=46(6.7)	Early Achievements for Education Settings (EA-ES)	Ctl- Teachers delivered instruction and implemented regular curriculum as they would typically	Teacher-implemented; Classroom	Not reported	Classroom	EA-ES is a teacher-implemented naturalistic developmental behavioral intervention; Teachers in the EA-ES condition were trained to strategically engineer the learning environment. Children were placed in a classroom taught by teachers trained in EA-ES.	School-level implementation of class curriculum	Cultural- Learning, Play; Environment- Mobility; Social- Support Systems, Socialization; Political- Integration, Collaboration
Shire et al., 2020	I- Large RCT	ASD, DS	Int1=63 (Male=49, Female=14) Int2=50 (Male=40, Female=10)	Mean Months (sd) Int1=32.16(3.14), Int2=32.42(3.47)	Int1- JasPEER, an adapted JASPER	Int2- Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER) is a Naturalistic Developmental Behavioral Intervention implemented by the teaching assistant. It contains seven strategy subscales: supports for engagement and regulation, environmental arrangement,	Teacher-implemented; Classroom	11 weeks	Classroom	Adapted JASPER to include a peer; where two teaching assistants delievered the intervention with two children	School-level implementation of class curriculum	Cultural- Learning, Play; Environment- Mobility; Social- Support Systems, Socialization; Political- Integration, Collaboration

								activity, and (b) 20–30-min nutrition education lessons 1–2 times per week				
An et al., 2019	IV- Cohort study without concurrent control group	IDD	14 (Male= 9, Female= 5)	12-15y	I Can Do It, You Can Do It (ICDI)	N/A	Peer-mentor	60-70 min/session, 14 weeks; over a 4-month period.	School	Health promotion program with the purpose of creating a mentorship of health and wellbeing for individuals	School-based mentoring program	Cultural-Learning, Play; Environment- Mobility; Social-Support Systems, Socialization; Political-Integration, Collaboration
Shire et al., 2019	IV- Cohort study without concurrent control group	ASD	118 Yr1=56 (Male= 44, Female= 12) Yr2=63 (Male= 49, Female= 14)	Mean Months (sd) Yr1= 31.71 (2.94) Yr2= 32.16 (3.14)	Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER)	N/A	Dyad (Teacher-child) intervention	2 hours/day	School	Targeted intervention delivered in the context of play to increase engagement, play, and social communication skills Yr1- Children in their first year of JASPER Yr2- Children in their second year of JASPER	School-level implementation of class curriculum	Cultural-Learning, Play; Environment- Mobility; Social-Support Systems, Socialization; Political-Integration, Collaboration
Zimmerman et al., 2019	IV- Cohort study without concurrent control group	SB	63 (Male= 26, Female= 37)	6-17y	Camp VIP	N/A	Group intervention	3-day camp	Camp	Camp VIP- activities to enable campers to approach challenging thresholds and overcome them; educational activities such as wound-care education, orthotics fittings, adaptive	Collaboration between community organizations to provide resources and opportunity for children to	Cultural-Learning, Play; Environment- Mobility; Social-Welcoming, Support Systems,

												n; Political-Collaboration, Integration
Haney et al., 2014	IV-Cohort study without concurrent control group	Variety of disabilities (ADHD, ASD, CP, DS, PD, LD, ID, CD, lead poisoning at birth, PVR natal stroke, speech issues, severe asthma)	52 (Male= 39, Female= 13)	6-22y	Fit-2-Play	N/A	Park-based after school program	10 months	Park	Outcome oriented structured active recreation for children with focus on developing and improving motor skills, movement knowledge, social and personal skills	School-level after school program	Cultural-Learning, Play; Environment- Mobility; Social-Welcoming, Support Systems, Socialization; Political-Integration
Locke et al., 2019	II- RCT with smaller sample size	ASD, IQ>64	31 Int=17 (Male= 14, Female= 3) Ctl=14 (Male= 13, Female= 1)	K-Gr5	Remaking Recess (RR)	Ctl- School-based social engagement intervention, the intervention trains school personnel so that schools will be equipped to support children with autism	Social engagement intervention; didactic, coaching	45 min sessions, 2 sessions/week; 6 weeks	School	Int- Ctl with specified implementation support from coaches for school staff to implement RR	School-level implementation of recess curriculum	Cultural-Learning, Play; Environment- Mobility; Social-Welcoming, Support Systems, Socialization; Political-Integration, Collaboration
Messiah et al., 2019	IV-Cohort study without concurrent control group	ID, ASD	297 (Male= 214, Female= 83)	6-22y	Fit-2-Play	N/A	Community-based, park-based, structured afterschool programmes	4hrs/day; 5 days/week Afterschool, structured program: Monday–Friday, 2 pm–6 pm. it is a (a) 60 min of physical	Park	Outcome oriented structured active recreation for children with focus on developing and improving motor skills, movement knowledge, social and personal skills	Program implemented by Miami Dade County Parks, Recreation and Open Spaces (MDPROS) professionals and university faculty	Cultural-Learning, Play; Environment- Mobility; Social-Support Systems, Socialization; Political-Integration, Collaboration

						balancing imitation and modeling, establishing play routines, expanding play, language strategies, and programming for joint attention						

[a] Levels of evidence based on the hierarchy developed by the Centre for Evidence Based Medicine. ASD, autism spectrum disorder; IDEA, individuals with disabilities education act; ID, intellectual disabilities; PD, physical disability; PA, physical activity; Int, intervention; Ctl, control; ADHD, attention deficit hyperactivity disorder; CP, cerebral palsy; DS, Down syndrome; LD, learning disability; CD, cognitive disability; PVR, pulmonary vascular resistance; IDD, intellectual and developmental disabilities; SB, spina bifida

Table 3: Outcomes Linked to Family of Participation-related Constructs

Study	Level of Evidence[a]	Outcome Measured	Measurement Tool	Family of Participation-related Constructs		Statistics
				Participation	Participation-related	
Locke et al., 2019	II- RCT with smaller sample size	Peer Engagement	POPE-Solitary Play	Involvement	Activity Competence	Baseline-Exit: Cohen's f = 0.80 (+) Favouring Int Baseline-Follow Up: Cohen's f = 0.56 (+) Favouring Int
			POPE-Joint Engagement	Involvement	Activity Competence	Baseline-Exit: Cohen's f = 0.80 (+) Favouring Int Baseline-Follow Up: Cohen's f = 0.53 (+) Favouring Int
		Social network inclusion	Social network inclusion	Involvement		Baseline-Exit: Cohen's f = 0.41 (+) Favouring Int Baseline-Follow Up: Cohen's f = 0.37 (+) Favouring Int
Temple & Stanish, 2011	IV- Cohort study without concurrent control group	Attendance	Absences (count)	Attendance		Mean = 2.5, SD = 2.0
		Personal Barriers	Enjoyment, barriers, and preference questionnaire	Involvement		Pre-Post: Cohen's d = 0.54 (+) Favouring Int
		Preference for more vigorous activity	Enjoyment, barriers, and preference questionnaire		Preferences	Pre-post: Cohen's d = 1.8156 (+) Favouring Int
		Involvement	Participation Survey	Involvement	Sense of Self	Percentage of Participants that: Learned new exercises = 94% Made new friends = 94% Felt fitter and healthier = 83% Would participate again = 72%

Koenig et al., 2012	III- Cohort study with concurrent control group	Challenging behaviors	ABC-C		Activity Competence Self-regulation	Cohen's d = 1.19 (+) Favouring intervention
Kemeny & Arnhold, 2012	IV- Cohort study without concurrent control group	Enjoyment	Participation Survey	Involvement		Pre-Post: $p < 0.001$ (+) Favouring Int
		Length of Physical Activity	Participation Survey	Attendance		Pre-Post: $p < 0.01$ (+) Favouring Int
		Team Sport Participation	Participation Survey	Attendance		Pre-Post: $p < 0.01$ (+) Favouring Int
An et al., 2019	IV- Cohort study without concurrent control group	Exercise Time (min/day)	Self-report Form	Attendance		Pre-post: Effect size = 2.32 (+) Favouring Int
		Log Exercise Frequency (day/week)	Self-report Form	Attendance		Pre-post: Effect size = 0.64 (+) Favouring Int
Shire et al., 2019	IV- Cohort study without concurrent control group	Child Initiated Joint Engagement	Teacher-Child Interaction	Involvement	Activity Competence Self-regulation	Entry-Exit: Effect size = 0.85 (+) Favouring Int
		Initiating Joint Attention	Teacher-Child Interaction	Involvement	Activity Competence Self-regulation	Entry-Exit: Effect size = 0.75 (+) Favouring Int
		Time spent in Simple Play	Teacher-Child Interaction	Involvement	Activity Competence	Entry-Exit: Effect size = 0.2 (+) Favouring Int
		Time spent in Combination Play	Teacher-Child Interaction	Involvement	Activity Competence	Entry-Exit: Year 1- Effect size = 0.60; Year 2- Effect Size = 0.31 (+) Favouring Int
		Time spent in Pre-symbolic Play	Teacher-Child Interaction	Involvement	Activity Competence	Entry-Exit: Effect size = 0.62 (+) Favouring Int
		Initiating Joint Attention	SPACE	Involvement	Activity Competence	Entry-Exit: Effect size = 0.91 (+) Favouring Int
		Simple Play	SPACE	Involvement	Activity Competence	Entry-Exit: Effect size = 0.11 (+) Favouring Int
		Combination Play	SPACE	Involvement	Activity Competence	Entry-Exit: Effect size = 0.17 (+) Favouring Int

		Pre-symbolic Play	SPACE	Involvement	Activity Competence	Entry-Exit: Effect size = 0.37 (+) Favouring Int
		Symbolic Play	SPACE	Involvement	Activity Competence Capactiy	Entry-Exit: Effect size = 0.37 (+) Favouring Int
Zimmerman et al., 2019	IV- Cohort study without concurrent control group	Confidence	Participant Survey	Involvement	Activity Competence Sense of self	Percentage of Participants that: Reported increased confidence = 93%
		Independence	Participant Survey		Activity Competence	Percentage of Participants that: Reported increased independence = 86%
Messiah et al., 2019	IV- Cohort study without concurrent control group	Health and Wellness Knowledge	EmpowerMe4Life 9-item scale		Activity Competence Sense of self	Pre-post: p < 0.001 (+) Favouring Int
Haney et al., 2014	IV- Cohort study without concurrent control group	Health and Wellness Knowledge	EmpowerMe4Life 9-item scale		Activity Competence Sense of self	Pre-post: Normal weight group- Effect size = 1.01; Overweight/obese group- Effect size = 1.10 (+) Favouring Int
Engelstad et al., 2020	II- RCT with smaller sample size	Social Communication Behaviors	Initiation of Joint Attention	Involvement	Activity Competence	Pre-Post: Effect size = 0.9 (+) Favouring Int
		Nonverbal Skills	Mullen Scales of Early Learning- Nonverbal Composite Score		Activity Competence	Pre-Post: Effect size = 0.9 (+) Favouring Int
		Verbal Skills	Mullen Scales of Early Learning- Verbal Composite Score		Activity Competence	Pre-Post: Effect size = 0.5 (+) Favouring Int
Shire et al., 2020	I- Large RCT	Time in engagement	Time Jointly Engaged (TCX)	Involvement		Pre-Post: p = 0.02 (+) Favouring Int1 (jasPEER)

		Initiating Joint Attention	SPACE	Involvement	Activity Competence	Pre-post: Both Int1 (jasPEER) and Int2 (JASPER) showed significant improvement ($p < 0.001$), no significant between-group effect
		Behavioral Regulation	SPACE		Activity Competence	Pre-post: Both Int1 (jasPEER) and Int2 (JASPER) showed significant improvement ($p < 0.001$), no significant between-group effect
		Simple Play	SPACE	Involvement	Activity Competence	No significant between-group effect
		Combination Play	SPACE	Involvement	Activity Competence	Pre-Post: $p = 0.042$ (+) Favouring Int1 (jasPEER)
		Pre-symbolic Play	SPACE	Involvement	Activity Competence	Pre-post: Both Int1 (jasPEER) and Int2 (JASPER) showed significant improvement ($p < 0.001$), no significant between-group effect
		Symbolic Play	SPACE	Involvement	Activity Competence Capacity	Pre-post: Both Int1 (jasPEER) and Int2 (JASPER) showed significant improvement ($p < 0.001$), no significant between-group effect

[a] Levels of evidence based on the hierarchy developed by the Centre for Evidence Based Medicine. ASD, autism spectrum disorder;

Int, intervention; Ctl, control; CI, confidence interval; MD, standard deviation; ABC-C, aberrant behavior checklist-community;

POPE, playground observation of peer engagement; SPACE, short play and communication evaluation

Table 4: American Academy of Cerebral Palsy and Developmental Medicine quality of conduct of study

Study	Level[a] -Quality[b]	1	2	3	4	5	6	7
Koenig et al., 2012	III-W (2/7)	No	Yes	Yes	No	No	No	No
Locke et al., 2019	II-S (6/7)	Yes	Yes	Yes	Yes	Yes	Yes	No
Engelstad et al., 2020	II-S (7/7)	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Shire et al., 2020	I-S (6/7)	Yes	Yes	Yes	Yes	Yes	Yes	No

[a] Levels of evidence based on the hierarchy developed by the Centre for Evidence Based Medicine. [b] Quality refers to the score obtained using the guidelines provided by the American Academy of Cerebral Palsy and Developmental Medicine (AACPDM): the study can be judged as 'strong' ('yes' answer to six or seven out of seven questions), 'moderate' ('yes' answer to four or five out of seven questions), or 'weak' ('yes' answer to ≤3 out of seven questions) based on the answers to seven defined conduct questions: (1) Were inclusion and exclusion criteria of the study population well described and followed? (2) Was the intervention well described and was there adherence to the intervention assignment? (for 2-group designs, was the control exposure also well described?) Both parts of the question need to be met to score 'yes'. (3) Were the measures used clearly described, valid and reliable for measuring the outcomes of interest? (4) Was the outcome assessor unaware of the intervention status of the participants (i.e., were the assessors masked)? (5) Did the authors conduct and report appropriate statistical evaluation including power calculations? Both parts of the question need to be met to score 'yes'. (6) Were dropout/loss to follow-up reported and less than 20%? For 2-group designs, was dropout balanced? (7) Considering the potential within the study design, were appropriate methods for controlling confounding variables and limiting potential biases used? W, weak; M, moderate; S, strong

Table 5a: Risk of Bias in Non-standardised Studies of Interventions assessment (ROBINS-I)

Study	Level[a]	Confounding	Selection	Classification of Interventions	Deviations	Missing Data	Measurement of Outcomes	Reported Results	Overall
Kemeny & Arnhold [25]	IV	Moderate	Serious	Serious	No Information	No Information	Serious	Serious	Serious
Temple & Stanish, [33]	IV	Serious	No Info	Serious	Critical	Low	Serious	Serious	Critical
Haney et al. [26]	IV	Moderate	No Info	Low	Low	Low	Moderate	Moderate	Moderate
Messiah et al. [27]	IV	Moderate	No Info	Low	Low	Low	Moderate	Moderate	Moderate
An et al. [24]	IV	Serious	Low	Low	Low	Low	Moderate	Moderate	Serious
Shire et al. [31]	IV	Moderate	Serious	Low	Low	Low	Low	Moderate	Serious
Zimmerman et al., [34]	IV	Serious	Critical	Serious	No Information	Serious	Serious	Serious	Critical
Koenig et al. [29]	III	Critical	Low	Low	Low	Serious	Serious	Moderate	Critical

[a] Levels of evidence based on the hierarchy developed by the Centre for Evidence Based Medicine.

Table 5b: Risk of Bias for randomized trials (RoB 2)

Study	Level[a]	Randomization	Deviations	Missing Data	Measurement of Outcomes	Reported Results	Overall Risk
Locke et al., 2019	II	Low	Low	Low	Low	Low	Low
Engelstad et al., 2020	II	Low	High	Low	Low	Low	High
Shire et al., 2020	I	Low	Some concerns	Low	Low	Low	Some concerns

[a] Levels of evidence based on the hierarchy developed by the Centre for Evidence Based Medicine

Supplementary Table 1- Community Wellbeing Framework domains and indicators

Domains	**Indicators**
Social	Welcoming Support Systems Socialization
Cultural	Learning Play Sense of Belonging Cultural Vitality
Environmental	Delight & Enjoyment Natural Systems Mobility Resilience
Economic	Affordability Complete Community Life-cycle Value Local Economy
Political	Integration Collaboration Sense of Ownership

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Chapter 4: Integration of Manuscripts 1 and 2

4.1 Research objectives of Manuscripts 1 and 2

Manuscript 1: To synthesize existing evidence on the effect of context-based interventions on the participation of children with disabilities using the Family of Participation-related Constructs (fPRC) framework, and to study these context-based interventions and their properties of community inclusion using the Community Wellbeing Framework (CWF).

Manuscript 2: To develop the content of a measurement tool to assess the community health inclusion of children with disabilities in Canada.

4.2 Integration of Manuscripts 1 and 2

The systematic review conducted and presented in **Manuscript 1** synthesized the current knowledge and evidence on the effects of context-based interventions on participation of children with disabilities. In contrast to most interventions in literature that target the child directly (i.e. rehabilitation interventions focusing on adapting the the activity for one child), context-based interventions included interventions that targeted the environment (i.e. their local community) of children with disabilities in general, such as curricula, programs, policies, and public health initiatives. Through the systematic review, we found that there was a scarcity of literature on such interventions and those that existed were predominantly of low-level evidence. Furthermore, the outcome measures that were used in the studies were heterogeneous and measured diverse domains in the fPRC framework. Following this review, it became evident that there was a need for a measurement tool that considered the environment where children can participate in community-based activities.

The Community Health Inclusion Index (CHII) is a measurement tool identified in our review that assesses aspects of the community environment that can be facilitators and/or barriers to inclusion and participation. The CHII was developed with consideration of individuals with disabilities however it did not distinguish the specific needs of children with disabilities. Following consultation with the original author and developer of the CHII, **Manuscript 2** aimed to develop the content of a child version of the CHII with the specific needs of children with disabilities in the Canadian context considered.

Chapter 5: Manuscript 2

Content development of the Child Community Health Inclusion Index: An evaluation tool for measuring inclusion of children with disabilities in the community.

Paul Yejong Yoo, MSc., OT[a,b,e]; Annette Majnemer, PhD, OT;[a,b,e]; Laury-Anne Bolduc[a]; Karen Chen[a]; Erin Lamb[a]; Tanisha Panjwani[a]; Robert Wilton, PhD[c,d]; Sara Ahmed PhD, PT[a,b]; Keiko Shikako, PhD, OT[a,b,e]

[a] School of Physical and Occupational Therapy, McGill University, Montreal, QC, Canada H3G 1Y5
[b] Faculty of Medicine and Health Sciences, McGill University, Montreal, QC, Canada H3G 2M1
[c] School of Geography & Earth Sciences, McMaster University, Hamilton, ON, Canada L8S 4L8
[d] Faculty of Social Sciences, McMaster University, Hamilton, ON, Canada L8S 4L8
[e] McGill University Health Centre Research Institute, Montreal, QC, Canada, H4A 3J1

Corresponding author: Keiko Shikako
3654 prom Sir-William-Osler, Montréal, Québec H3G 1Y5
(514) 398-4400 ext 0802
keiko.thomas@mcgill.ca

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Abstract

Background: Addressing barriers in the environment can contribute to health and quality of life for children with disabilities and their families. The Community Health Inclusion Index (CHII) is a measurement tool developed in the USA to identify environmental barriers and facilitators to community health inclusion. The CHII adopts an adult viewpoint and aspects crucial for children may have been omitted.

Aims: To develop a comprehensive list of items that are relevant for the community inclusion of children with disabilities in the Canadian context.

Methods: The relevance and priority of items generated from a review of existing guidelines and best practice recommendations for community inclusion were rated as a dichotomous response and discussed by an expert panel consisting of experts in relevant fields working with children with disabilities.

Results: 189 items from 12 instruments and best practice guidelines identified. Expert consensus contributed to a relevant and comprehensive list of items. Expert suggestions were considered to refine and reduce the item list.

Conclusion: This study highlights the importance of a child version of a community inclusion tool, as the needs of children with disabilities differ from those of adults. It can help communities improve inclusion of children with disabilities and inform health promotion initiatives for this population.

Keywords: Community inclusion, childhood disability, tool development, participation, environment, health

Introduction

Inclusion in communities through accessible environments, public transportation, information, technology, and all public services and policies is a human right [1]. Participation in community-life is vital for children's development of competency, identity, and self-sufficiency [2] [3]. Despite the benefits and importance of inclusion as a fundamental human right, children with disabilities face restrictions in comparison to typically developing children [4, 5]. Children with disabilities are at high risk for unfavorable health outcomes [6]. This is in part due to environmental factors such as systems, programs, places, and institutions can limit positive health outcomes [7]. Identifying and addressing environmental barriers and fostering social supports can positively affect a child's participation in diverse activities [8].

There are different aspects of the environment that can act as a facilitator or barrier to participation: physical (e.g. accessibility), social (e.g. peer support), attitudinal (e.g. perceptions of disability and recreation), and institutional (e.g. policies, availability of adapted programs) [9]. It is necessary to identify and address these barriers to adequately develop, implement and evaluate policies and programs that address them [10, 11].

The Community Health Inclusion Index (CHII) is a comprehensive assessment tool developed to examine the scope and depth of factors that foster healthy, active living among people with disabilities [12]. The CHII assesses four sectors that make up the community: School, Health Care, Work Sites, and Community Institutions/Organizations. The community inclusion of these sectors is assessed through the lens of five inclusion domains: Built Environment, Equipment, Programs/Services, Staff, and Policies. These domains are made up of relevant items that the evaluator rates for their institution [12]. The measure however was not developed with special consideration for the needs of children and families. The activities and participation roles of children with disabilities differ from those of adults [13]. The UN affirmed these differences by including one specific guiding principle addressing children with disabilities out of the eight guiding principles of the Convention on the Rights of Persons with Disabilities (CRPD), and by establishing one entire convention related to the specific rights of children [1]. The CHII was also developed in the United States (US). A transcultural adaptation to the Canadian context is warranted, to accommodate the unique features of our publicly funded healthcare system and education system, the weather conditions, and the diverse realities of our distinctive Canadian multi-cultural communities, that in some ways differ from the US context, in addition to language validation in both official languages (English and French).

Currently, there are no comprehensive measures of community inclusion for children with disabilities focusing on diverse environmental factors (Yoo et al., submitted). The lack of measurement may contribute to the lack of implementation efforts and measurement of context-based strategies to promote inclusion through changes in the environmental factors. The main objective of this study was to develop the content of a measurement tool to assess the community health inclusion of children with disabilities in Canada.

Methods

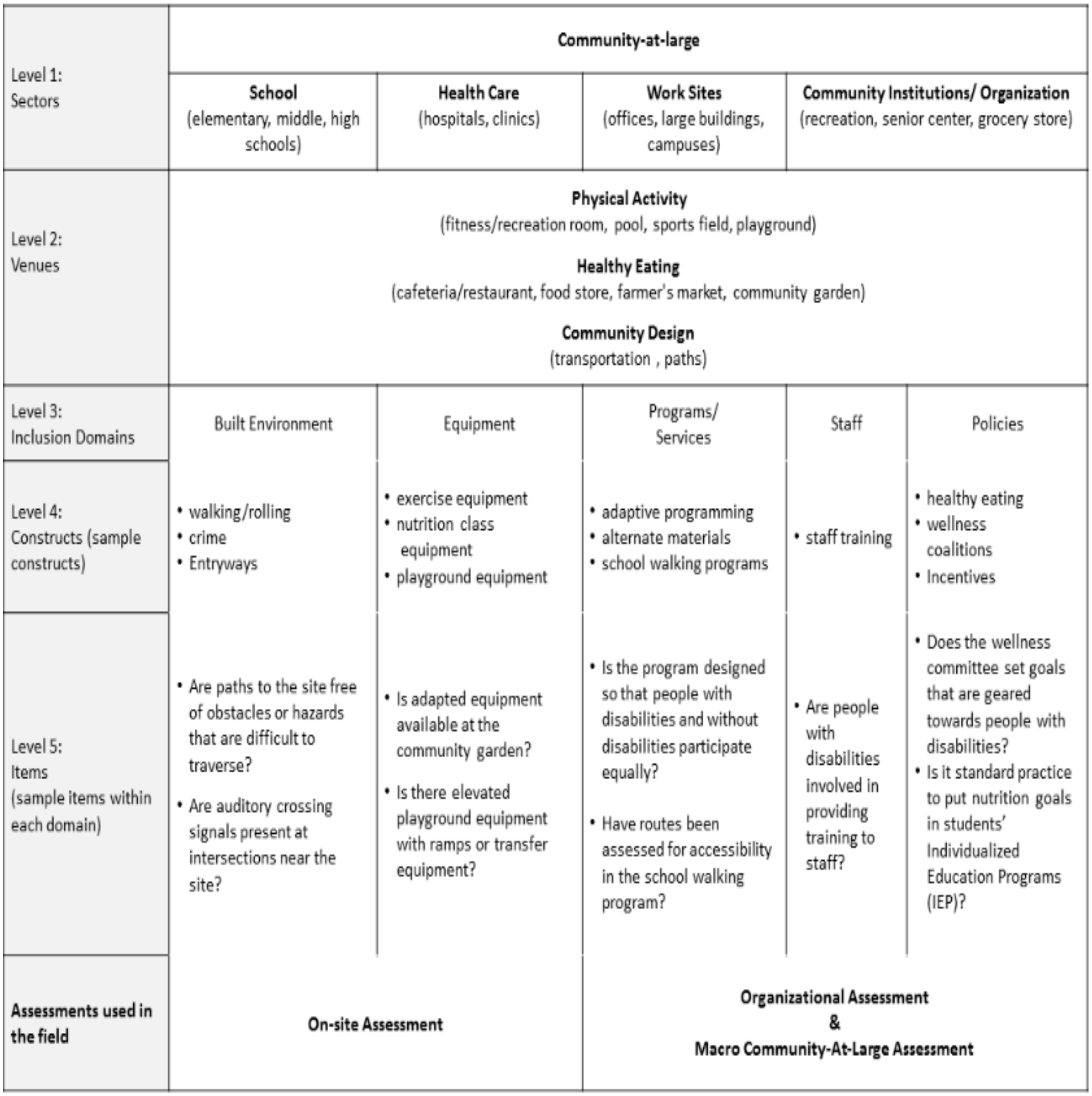
The content development for the Child Community Health Inclusion Index (CHILD-CHII) was done through: *item generation, item refinement,* and *expert panel* consultation. This study was the first of a sequence of studies for content development for the CHILD-CHII. A content validation study and a feasibility pilot testing study will follow for the full tool development. This project was approved by an institutional ethics review board.

Item Generation

An initial item list was generated using items from the original CHII. Items pertinent to children were maintained from the original CHII with language modified to better suit children. Any ambiguity that arose during this process was further discussed with the research team including the senior researcher (KS). The CHII framework (Figure 1) was modified with the “Work Sites” sector which was replaced by “Public Spaces”, “School” was generalized to “Education”, and “Health Care” was shortened to “Health”. For the venues, following discussions within the research team and the original author of the CHII, “Healthy Eating” was removed because it was beyond the scope of this research study and the measurement tool. “Community Design” was kept as is, and “Physical Activity” was modified to “Activity”. The five inclusion domains, constructs and the three assessments used in the field were also kept in the CHILD-CHII framework (Figure 2).

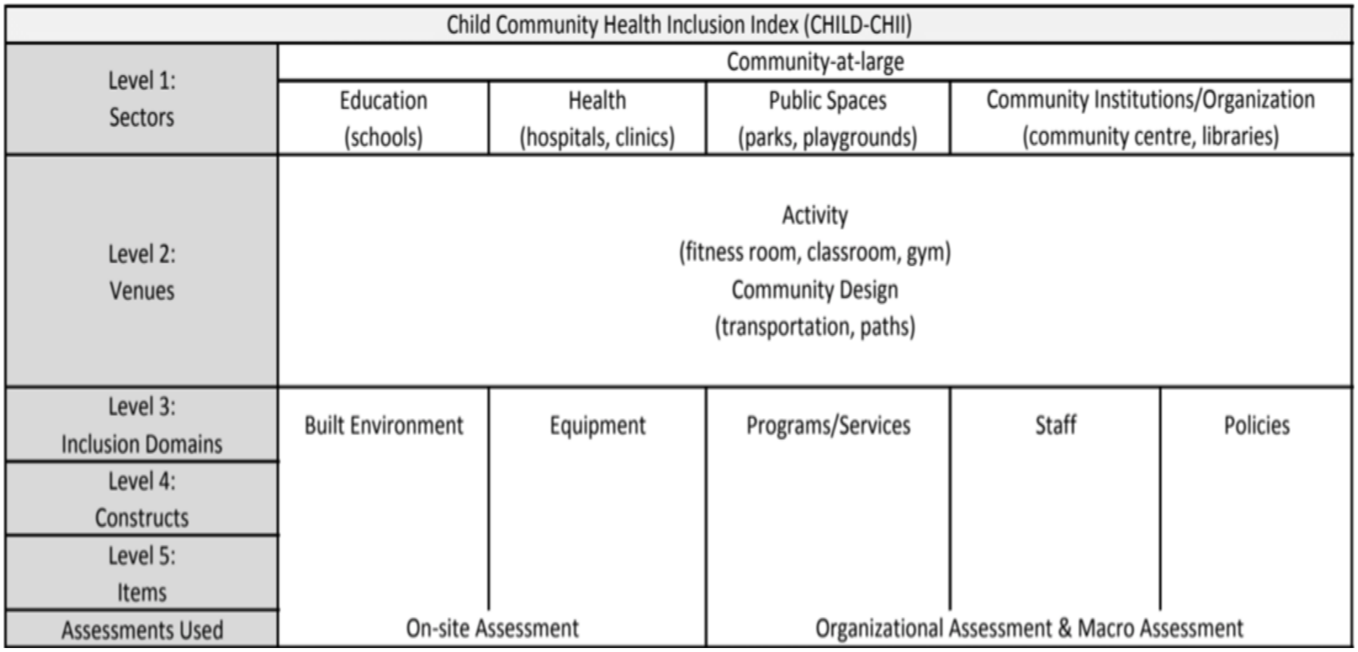
Second, we conducted a comprehensive research and gray literature review of existing outcome measures, checklists, and best practice guidelines addressing community accessibility and inclusion for children with disabilities. Search criteria was informed by an advisory expert panel. Inclusion criteria was: current tools, assessments, checklists, or government guidelines that measured or informed outcomes related to inclusion, accessibility, social integration or participation - terms often used interchangeably in literature [14, 15], with some (but not exclusively) considerations for children, specific to the disability community but not limited to a context (ie. physical building, social network, etc.).

Items from the online resources and measures were extracted when the items referred to: physical or social accessibility (staff training or accommodations), access to community-level services, access to activities, opportunities for people with a range of functional limitations to participate [12]. Two members from the research team extracted items from the literature found in the review and two members extracted items from outcome measures. The first set of results extracted by each reviewer was compared for agreement, and disagreements were discussed by the team and validated by a senior researcher at each round to clarify inclusion/exclusion criteria. Once reviewers achieved more than 90% agreement in the extraction of items for one measure, they proceeded with individual item extraction.



<table>
<tr><td rowspan="2">Level 1:
Sectors</td><td colspan="5">**Community-at-large**</td></tr>
<tr><td>**School**
(elementary, middle, high schools)</td><td>**Health Care**
(hospitals, clinics)</td><td>**Work Sites**
(offices, large buildings, campuses)</td><td colspan="2">**Community Institutions/ Organization**
(recreation, senior center, grocery store)</td></tr>
<tr><td>Level 2:
Venues</td><td colspan="5">**Physical Activity**
(fitness/recreation room, pool, sports field, playground)
Healthy Eating
(cafeteria/restaurant, food store, farmer's market, community garden)
Community Design
(transportation , paths)</td></tr>
<tr><td>Level 3:
Inclusion Domains</td><td>Built Environment</td><td>Equipment</td><td>Programs/
Services</td><td>Staff</td><td>Policies</td></tr>
<tr><td>Level 4:
Constructs (sample constructs)</td><td>• walking/rolling
• crime
• Entryways</td><td>• exercise equipment
• nutrition class equipment
• playground equipment</td><td>• adaptive programming
• alternate materials
• school walking programs</td><td>• staff training</td><td>• healthy eating
• wellness coalitions
• Incentives</td></tr>
<tr><td>Level 5:
Items
(sample items within each domain)</td><td>• Are paths to the site free of obstacles or hazards that are difficult to traverse?
• Are auditory crossing signals present at intersections near the site?</td><td>• Is adapted equipment available at the community garden?
• Is there elevated playground equipment with ramps or transfer equipment?</td><td>• Is the program designed so that people with disabilities and without disabilities participate equally?
• Have routes been assessed for accessibility in the school walking program?</td><td>• Are people with disabilities involved in providing training to staff?</td><td>• Does the wellness committee set goals that are geared towards people with disabilities?
• Is it standard practice to put nutrition goals in students' Individualized Education Programs (IEP)?</td></tr>
<tr><td>**Assessments used in the field**</td><td colspan="2">**On-site Assessment**</td><td colspan="3">**Organizational Assessment**
&
Macro Community-At-Large Assessment</td></tr>
</table>

Figure 1- CHII Framework



<table>
<tr><th colspan="6">Child Community Health Inclusion Index (CHILD-CHII)</th></tr>
<tr><td rowspan="2">Level 1:
Sectors</td><td colspan="5">Community-at-large</td></tr>
<tr><td>Education
(schools)</td><td>Health
(hospitals, clinics)</td><td>Public Spaces
(parks, playgrounds)</td><td colspan="2">Community Institutions/Organization
(community centre, libraries)</td></tr>
<tr><td>Level 2:
Venues</td><td colspan="5">Activity
(fitness room, classroom, gym)
Community Design
(transportation, paths)</td></tr>
<tr><td>Level 3:
Inclusion Domains</td><td rowspan="3">Built Environment</td><td rowspan="3">Equipment</td><td rowspan="3">Programs/Services</td><td rowspan="3">Staff</td><td rowspan="3">Policies</td></tr>
<tr><td>Level 4:
Constructs</td></tr>
<tr><td>Level 5:
Items</td></tr>
<tr><td>Assessments Used</td><td colspan="2">On-site Assessment</td><td colspan="3">Organizational Assessment & Macro Assessment</td></tr>
</table>

Figure 2- CHILD-CHII Framework

Item refinement

The initial item list was refined by removing and/or merging duplicates of items with similar concepts that were pertinent to children and the Canadian context. Some items were reworded to suit the Canadian community context and/or the pediatric population (e.g. terminology specific to US policies such as the Americans with Disabilities Act and/or items that address ‘individuals’ or ‘people’ to ‘children’ and ‘families of children’). This process was done in discussion by the research team in consultation with the expert panel to validate key decisions. The items were grouped together according to corresponding domains defined by the original CHII (Figure 1).

Expert panel - Individual interviews

The expert panel was interviewed to appraise the generated list of potential items. The inclusion critera for the expert panel purposeful convenience sample of experts were: individuals with knowledge and experience in universal accessibility and childhood disability including: researchers, healthcare professionals, teachers, special educators, counselors (e.g. inclusive camps and leisure program staff), decision makers (municipal and provincial accessibility specialists), urban designers, parents of children with disabilities and individuals from community inclusion and disability organizations; who have at least 5 years of experience working with children with disabilities. Through discussion with the research team including the senior investigator, several pertinent experts were identified and recruited by the researchers via email.

Each expert participated in a 1-hour individual, semi-structured online interview using *Zoom*. Interviewers underwent training with their research supervisor to ensure consistency with the conduct of the interviews and followed an interview guide. After consent and prior to the interviews, the item-list was sent to the experts one week before the scheduled interview for review. The scheduled interviews with each expert were completed within a two-week period. Following the individual interviews, the list of items that were deemed not important, less relevant, or repetitive by the experts were removed. Items that had conflicting ratings or viewpoints were retained, to be discussed during the consensus meeting. The remaining items were re-classified according to the CHII domains and translated to French.

Expert panel - Consensus meeting

A consensus meeting was carried out in two groups of experts to finalize the item list. Each two-hour meeting was facilitated by the research lead and was done via *Zoom*. The session was recorded with the consent of all the participants. The expert group was provided with the refined list of items and asked to come to consensus on the relevance and priority of the final items. Experts also provided general comments and suggestions on the categorization of items, the content of items (i.e. if any essential concepts or items are missing), and any nuances or terms that may be considered for the French-Canadian translation for the CHILD-CHII.

Data collection

All items were extracted from the online resources and pre-existing measures were collected in an Excel spreadsheet and coded by five members of the research team (PY, LB, EL, KC, TP) to one of the four sectors and one of the five domains of the original CHII framework: Built Environment, Equipment, Programs/Services, Staff, Policies (Figure 1).

Data from the expert panel for both the individual interviews and the group consensus meetings were collected as responses by the experts in terms of "relevance" and "priority" as a dichotomous response (Yes/No). Comments and suggestions were considered and incorporated in the final steps of refinement. To ensure anonymity and confidentiality throughout the process of data handling, expert files including the recordings were assigned number codes. The audio recording was de-identified and accessible only to the research team.

Data analysis

Priority and relevance were recorded as a dichotomous variable (Yes/No). To demonstrate consensus, items that were rated as a priority and relevant by all the experts were retained for the CHILD-CHII. The items that were deemed as not relevant and/or not priority by at least one expert were reviewed further by the research team and were removed from the list. Items were modified based on the comments and suggestions made by the experts.

Results

The comprehensive literature review included five online resources containing practices/guidelines from large government and/or organizational bodies ([16],[17],[18],[19],[20]) and seven validated outcome measures for accessibility and inclusion ([21],[22],[23],[24],[12],[25],[26]). The Sydney Psychosocial Reintegration Scale measure was discarded as the items included in the measure were not applicable to the community context.

The initial item list generated from the online resources and pre-existing measures included 153 items. Several items contained multiple questions pertaining to multiple concepts, therefore these items were divided into single items pertaining to one concept. This division resulted in a list of 759 items. The item list then underwent multiple stages of refinement, integrating the suggestions and ratings from the individual expert interviews. The final list of items presented to the expert consensus group meeting included 199 items, with items coming from eight different resources (Table 1). The On-Site assessment contained the greatest number of items, followed by the Macro-Community assessment and Organizational assessment (Table 2).

Table 1: Final number of items included, differentiated by their sources

Number of Items	**Source**
92	CHII [12]
41	London’s Accessibility Indicator [17]
39	Americans with Disabilities Act Checklist [22]
37	United Nations Good Practices of Accessible Urban Development [18]
16	Social and Community Opportunities Profile [24]
6	Craig Hospital Inventory of Environmental Factors [25]
3	Craig Handicap Assessment and Reporting Technique [23]
2	European Union Accessible Cities Award [16]
0	Cumulative Opportunities Measure [21]
0	United Nations Report on Good Practices [20]
0	Sydney Psychosocial Reintegration Scale [26]
0	‘What Would a Truly Disabled-Accessible City Look Like?’ report [19]

Table 2: Final number of items for each component of the CHILD-CHII assessment

CHILD-CHII Measurement Tool	Number of Items
Macro-Community Assessment	54
Organizational Assessment	33
On-Site Assessment	102

Expert panel - Individual interviews

With a total of nine experts participating, eight experts reviewed the On-Site assessment, five experts reviewed the Organizational assessment, and five experts reviewed the Macro-Community assessment (Table 3). From the 199 items, a total of ten items were deemed not relevant and/or not a priority. Experts suggested that the items be grouped together to create a more concise and user-friendly list. An expert in municipal child accessibility noted that many of the items were suited for children with mobility difficulties and suggested that items should be tailored to children of all disabilities.

In all three CHILD-CHII assessments, experts pointed out that some items were very specific while others were very general and difficult to apply. The items noted as too general were reformulated for clarity. The more specific items were broadened to prioritize important constructs (e.g. ‘pavement equipped with a heating system to improve snow/ice covered surfaces’ was reworded to ‘sidewalks that are accessible and cleared of snow/ice, regardless of the method’). As the CHILD-CHII is intended to be user-friendly for public health professionals and community coalitions, experts suggested adding contextual information and images to certain items in order to improve clarity and comprehensibility (e.g. pictures of curb cuts or a visual countdown for crossings).

Table 3: Expert characteristics

Expert Type*		**N***
	Researcher	5
	Government	3
	Parent	2
	Clinician	2
	Design	1
	Educator	1
Expertise*		**N***
	Inclusion	4
	Policy	3
	Inclusive Design	2
	Parent Experience	2
	Community Health	2
	Measurement	1
Total Experts		**N**
		9

*Individual experts were categorized under multiple expert types with multiple expertise.

Expert panel – Consensus meeting

The tool and its items were further simplified by making items less specific and more rooted in universal accessibility principles, updated to the reality of children who may be accompanied by their caregivers in most public spaces. For instance, an initial item was 'to have accessible pay phones installed in case of emergency'. Experts discussed that this is not always feasible, and that the focus should be on access to a telephone in case of emergencies (e.g. at the front desk). For items that required specific metric measurement, it was suggested to be more inclusive and look at a range of measures starting with the minimum measure attainable for children with disabilities instead of requiring a specific measurement (e.g. height). In addition, the importance of pictograms and wayfinding was mentioned as principal to facilitate children's ability in using these spaces. As per the CHII, wayfinding signs are indoor or outdoor systems of signs that help people orient and navigate to desired locations in a community and pictograms are pictures that represent a word or an idea, used to help communicate written information for persons with developmental disabilities [12].

A challenge that often arose was that accessibility guidelines vary between municipalities and provinces. As such, adherence to those guidelines may not be enforced and specifications may vary. Hence, an expert suggested modifying some items into open-ended and proactive questions (prompting the person that is completing the measure to verify the local legislation or accessibility code), which may facilitate the user-friendliness of the tool as not all facilities will have the same criteria of accessibility in place for that specific item (e.g. snow removal/heating system).

After applying the suggestions following the expert panel group meetings, the final result was the generation of a list of 189 items. Examples of the items in each domain can be found in table 4. The final list of items is undergoing a Delphi process and back translation and pilot testing for final validation of the measure will be reported elsewhere. The list of items that resulted from this study underwent further organization and clean up as suggested by the experts before going on to the Delphi process. Items that addressed the same object or theme were merged into one item (e.g. items addressing the adapted equipment in the bathroom), redundant and repetitive items were removed, and suggestions for re-wording were incorporated. This item list can be found in supplementary materials.

Table 4- Example items in each domain

CHILD-CHII Domain	Example
Built Environment	Which of the following features does the playground have? Check all that apply: ● Ground material that can be traversed using a mobility device ● Large signage/pictograms at child-friendly height ● Tactile map ● Other *Text box to describe*
Equipment	Is adaptive equipment available for children with disabilities to participate in given activities? a) Yes b) No c) N/A If yes, please list the equipment *Text box*
Programs/Services	Is the activity/program designed so that children with disabilities and without disabilities participate equally, such as adapting movements and rules? a) Yes b) No c) Not applicable If yes, please specify which activities/programs *Text box*
Staff	Which of the following components are covered in disability awareness training? Check all that apply:

	● Providing services to children with different types of disabilities and/or their families ● Adapting the environment for children with disabilities ● Communicating with children/parents of children with different types of disabilities ● Using person-first terminology ● Other *Text box to describe*
Policies	Are the following things integrated in overall policymaking in the community? Check all that apply: ● Organising a round table with policymakers and children with disabilities and/or parents of children with disabilities ● Presence of Disability Advisory Group, who represent children with a broad range of impairments ● Other *Text box to describe*

Discussion

This study aimed to develop the content for the CHILD-CHII, an adaptation of the CHII to the Canadian pediatric population. This was achieved by developing a comprehensive list of items refined by integrating interdisciplinary expertise in a multi-stepped approach. The interdisciplinary experts allowed for a rich discussion of applicability and comprehensiveness of items. Important aspects related to the community inclusion of children with disabilities and their families were highlighted and incorporated into the measurement items. The transcultural adaptation to the Canadian context also accounted for accessibility of public spaces under extreme weather conditions, and the jurisdictional governance structure regulating universal accessibility principles in Canada, in addition to considerations regarding language translation.

In article 1 of the CRPD, persons with disabilities are described as those who have long-term physical, mental, intellectual, or sensory impairments, which in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others [1]. Considering that the CHILD-CHII is meant to be inclusive to all children with disabilities, the scope of the measurement tool was broadened with the input of the experts, to ensure that every item is applicable for a wide spectrum of disabilities, including physical, intellectual, cognitive, auditory, and visual limitations. Each item was regarded with this broadened approach to address aspects of the environment that would act as facilitators or barriers of inclusion of children with any disabilities. To ensure that the items were comprehensive for all disabilities, a universal design approach was a key consideration brought forwards in the literature and with our expert consultations. Universal design is defined as "design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. Universal design shall not exclude assistive devices for particular groups of persons with disabilities where this is needed" [1].

Multiple aspects need to be considered when generating an assessment tool that aims to provide guidance in addressing barriers to participation in the environment. These aspects not only include physical accessibility, but also the design of programs and the sociopolitical infrastructure such as transportation to and from the facility, opportunities for multi-generational leisure, and safety [27, 28]. Other aspects often neglected in universal design include negative attitudes of others, lack of adequate services, lack of support from staff and service providers, time, cost, complexity of planning/schedules, and negotiating the environment [29, 30]. Additional macro-context barriers to community inclusion are lack of information, non-comprehensive policies, limited disability awareness, program costs, and transportation [4, 6, 31]. All these concepts were addressed in the item generation and item refinement process in developing the content of the CHILD-CHII.

The generalizability of the measure across jurisdictions in Canada, and accounting for different realities (e.g. urban versus rural communities, indigenous reserves) was also a key point highlighted by the expert panel and considered during the refinement process. This was consistent with a previous study which found that children in rural areas experienced significant barriers related to their neighbourhood environment and local infrastructure compared to children in suburban areas while children in urban communities faced barriers related to traffic and safety [32]. Additionally, the different regulations and standards for different regions in Canada and the dynamic nature of society and its needs result in environmental accessibility standards being inconsistent [33]. With the changing nature of standards over time and location, it was important to ensure that the components of each item were generalizable and not limited to a specific standard. With policy-related items, it was crucial to note that regulations would differ based on location and jurisdiction, therefore the items must reflect policy principles (e.g. accessible public transportation options) rather than strict mandates (e.g. specific parameter of what type of transportation may be available). \]] as generalizable aspects that should be considered for organizations to further improve their inclusivity.

The item generation for the CHILD-CHII made evident the challenge of developing a comprehensive community inclusion measure for children with disabilities, along with the critical need for it. Most environments in the community are not designed for children with disabilities and community contexts have been identified as the ones where most participation restrictions are experienced [34]. Even spaces that are designed for children such as playgrounds and public play spaces are often not inclusive for children with different types of disabilities, resulting in social exclusion and unequal access to the right to play and belong [28]. This disparity can be perceived as youth with disabilities' grow and report a preference for community and social activities, but very limited actual participation [35, 36], and time expenditure is mostly in solitary, sedentary, passive, and predominantly home-based activities [37, 38]. Participation restrictions are also highly influenced by contextual factors such as the design and layout of built environments, attitudes of peers and staff, and the limited provision of programs and services [6, 9, 39].

Community organizations may lack the knowledge to identify the barriers and adapt their facilities and programs to meet the needs of children with disabilities and may not have the availability of staff to accompany or support the children [6, 40, 41]. This study highlighted need for a comprehensive measurement tool that evaluates community environments and their inclusion of children with disabilities, and concurrently filled that need. Communities and community organizations/facilities can use this tool to identify current existing barriers and take action to enhance facilitators in the identified areas for improvement. Some practical items may help identifying concrete possible changes such as inclusion of elements of play or toys available in different formats for children with disabilities in waiting rooms and changing tables in public restrooms or areas that can accommodate older, larger children who need diaper changes, not just the conventional changing table for small infants.

Limitations and future directions

The preliminary list of items was meant to identify components of the community that is important in the inclusion of children with disability in this context. Even though the list was comprehensive, it is difficult to determine that the content developed for the measure addresses all facets of a child's life while ensuring the tool is user-friendly in terms of length and complexity. The several layers of refinement underscored the substantial considerations that needed to be made to develop a measurement tool for children with disabilities. Furthermore, initially, the items were intended to be generated through a literature review as well as on-site observations. Due to COVID-19, the on-site observations could not take place, and items were generated exclusively through the literature review. To compensate for this limitation, during the expert interviews, experts were asked to identify any important items or content missing from the generated list. Additionally, there were challenges in coordinating individual schedules of the experts during the COVID-19 pandemic to ensure adequate attendance from the experts. To account for this, there were two consensus meetings with two different groups of experts. It is also important to note that the experts were recruited through convenience sampling and may not possibly represent the expertise within their field. Hence, the generalizability of their input may be limited.

Given the fact that the unit of measure for this measurement tool is at the facility-level and assesses the facility and the surrounding environment, policies, and location, the measurement tool does not extensively take into consideration the environment most proximal to the child, the family. Family-level characteristics have been found to influence the association between neighbourhood environments and children's development [42]. Furthermore, the tool does not extensively take into consideration the socio-demographic factors including the intersection of ethnicity, socioeconomic status, gender, and family structure of the surrounding area which has been found to have an influence on child health development [42, 43]. However, the CHILD-CHII and the results of the tool can be utilized to present the potential impacts of these underlying factors on a child's health, participation, and inclusion in the community.

Additionally, the scoring of the measure will be further discussed and developed as the full tool development process continues in future studies. The utility of the score will also be discussed based on the original CHII scoring. The original CHII scores are used to develop strategies to address the gaps that have been identified by the CHII within the constructs seen in Figure 1.

Conclusion

Multiple levels of item generation and item refinement were completed to develop the preliminary content of the CHILD-CHII, a measurement tool to assess the community health inclusion of children with disabilities in Canada. The development process highlighted the need for a specific tool tailored for children with disabilities and their idiosyncratic needs and functions that are not always the same as adults. The refinement process underscored the importance of considering the diverse needs of children with various disabilities. It also emphasized the need for the items to have a universal design approach while ensuring that the items are generalizable across different regions. Once developed, this tool can be used to support communities in identifying areas for improvement regarding the inclusion of children with disabilities within their facilities, while presenting ways to address those needs. Moreover, this tool can be used to measure the effects of health promotion initiatives and context-based interventions such as the implementation of accessibility and leisure policies in the community for children with disabilities; and may help to foster future health promotion initiatives for these children and their families. This tool will be further validated and tested so that it can be available for the community.

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Supplementary

CHILD-CHII Item List

On-site Assessment

Transit

1. Is there at least one public transit stop near the site entrance?

a) Less than 15 min b) 16-30 min c) Over 30 min

2. How often does the bus/train/van come during the non-peak periods (nights, weekends)?

a) Less than 30 min b) 31-60 min c) Over 60 min

3. Which of the following components, are available on public transportation vehicles that have a stop near the site? Check all that apply:

-Level boarding from ramp or lowered vehicle -Auditory announcements Visual display of stops -Other *Text box*

4. Which of the following elements, if any, are observed at the **public** transit stop? Check all that apply:

-Transit shelter, bench or other seating -Signage with TTY number (Telecommunication Device for the Deaf) -Enough space to maneuver using a mobility device -Stable and firm landing pad surface Light posts or other lighting infrastructure at or next to the stop -Other *Text box*

Getting Around the Site

5. Is it safe/possible to get around on the paths on and around the site?

a) Yes b) No

6. Indicate if the following characteristics that could deter children with disabilities from getting around the site are present in the blocks around the site. Check all that apply:

-People loitering Graffiti Litter -Vacant buildings -Street harassment -Uneven terrain -Low lighting

7. Assess the Path from the transit stop to the site if available, otherwise, complete for the path from the parking area. Check all that apply:

-At least 5 feet wide -Free of obstacles or hazards that are difficult to traverse
-Surface smooth and firm -Note any obstacles or hazards below. *Text box*

8. Indicate if the following characteristics that make getting around the site more accessible are present. Check all that apply:

-Some form of boundaries around common areas to avoid children from leaving the area without noticing, and avoid incoming undesired traffic -Wide aisles -Obstacles and edges are detectable for someone using a cane -Routes are free of obstacles -Slip-resistant materials -Circle or a T-shaped space for a person/child using a wheelchair to reverse direction or to turn their wheelchair completely -Contrasting colours -Even terrain -Other *Text box*

9. Are there any driveways, street crossings, or level transitions on the path to the site where a curb cut is needed but not existent?

a) Yes b) No

10. For the curb cuts anywhere on a path, indicate whether the following characteristics are observed. Check all that apply:

-Gradual slope Free of barriers or hazards that obstruct it -Free of breaks in the surface -Detectable warning in good working condition -Tactile warning panels
-Other *Text box*

11. Indicate whether the following features are present in the pedestrian crossings near the site. Check all that apply:

-Crosswalk is well marked with stripes/paint/bricks -Free of obstacles or hazards that are difficult to traverse -Curb cuts at each end of the crossing -Tactile paving guides -Other *Text box*

12. Do the intersections around the site have a traffic signal?

a) None b) Some c) Many d) All

13. Indicate whether the following elements are present on the traffic signals near the site. Check all that apply:

-Auditory crossing signal, -Visual countdown, -Other *Text Box*

14. Is a parking lot available at the site?

a) Yes b) No

15. Are any of the following observed in the parking lots? Check all that apply:

-Accessible spaces designated with International Symbol of Accessibility on an upright sign -Access aisles adjacent to accessible parking spaces -Designated van accessible parking spaces -Other *Text box*

16. Is the pathway towards the site clear of ice and snow?
    a) Yes b) No c) Not applicable

Inside the Site

17. Are the following accessible features present at the main entrance? Check all that apply:

-Ramp Lift Non-slip surface -Tactile indication for steps and ledges -Stairs with continuous rails on one or both sides -Power assist or automatic door -Other *Text box*

18. If no adaptations at the main entrance, does an alternate accessible entrance exist? Check all that apply:

-Ramp Lift Non-slip surface -Tactile indication for steps and ledges -Stairs with continuous rails on one or both sides -Power assist or automatic door -Other *Text box* -No alternate entrance

19. Can the alternate entrance be used without additional assistance?
a) Yes b) No

20. Are the accessible drop off areas/parking spaces closest to the accessible entrance?
    a) Yes b) No

21. Do all inaccessible entrances have signs indicating the location of the nearest accessible entrance?
    a) Yes b) No c) Not applicable

22. On each floor of the site, is there an accessible route to all the essential public areas (Eg. Bathroom, Emergency exit)?
a) Yes b) No

23. Do the doors at the site have the following accessible features? Check all that apply:
-Automatic operation -Gliding doors -Wide enough for a wheelchair -Flush threshold -Other *Text box*

24. Which of the following features are found in rooms and shared spaces at the site. Check all that apply:
-Facilitated communication with people who use sign language (e.g. people facing each other) -Appropriate acoustics -Noise reduction measures in place
-Adequate lighting -Other *Text box* -N/A

25. Are any of the following present for navigating around the site? Check all that apply:
-Elevator -Ramp -Lift -Tactile indicators -Other *Textbox* -N/A

26. Does the signage for navigating around the site have any of these features? Check all that apply:
-High-contrast lettering -Large print -Pictograms -Braille -Other *Text box* -N/A

Bathroom

27. Is there a bathroom that is fully accessible?
a) Yes b) No

28. Are the following accessible features found with bathroom entrances at the site? Check all that apply:
-Automatic operation -Open corridor entrance -Wide enough for a wheelchair
-Flush threshold -Other *Text box*

29. Are the following accessible features used to identify bathrooms at the site? Check all that apply:
-Pictograms/Symbols -Raised characters -Braille -Low enough for children to see -Other *Text box*

30. Are the following accessible features found in bathrooms at the site? Check all that apply:
-Adequate space for up to two caregivers -Adult-sized changing station -Adapted toilet with grabbars -Tilted mirror -Low sink -Low hand dryer -Low soap dispenser
-Other *Text box*

Telephone

31. Is there access to a telephone in a public space?
    a) Yes b) No

Information

32. Are information materials (Eg. pamphlets, flyers) offered in any of the following formats? Check all that apply:
-Electronic version in plain text -Large print -Pictograms -Audio -Braille -N/A
-Other *Text box*

33. Do promotional materials for programs indicate the program is inclusive of children with disabilities (through images of individuals with disabilities participating or descriptions of the programs?)
a) Yes b) No c) N/A If yes, please describe *Text box*

34. Which of the following accessible features are found at the front/information desk? Check all that apply:
-Low enough for children to access -Tactile cues -Large color contrasted signage -Other *Text box*

Emergency

35. Which of the following emergency features are found at the site? Check all that apply:
-Emergency call/help points -Emergency alerts with lights -Emergency alerts with sounds -Other *Text box*

Please provide any comments and/or suggestions about the clarity and/or importance of the Emergency section, if you have any.

Guide Dogs

36. Is there a designated space for guide dogs at the site?
a) Yes b) No

Locker Rooms

37. Which of the following inclusive features do the locker rooms have? Check all that apply:

-N/A -Wide entrance -Locker door handles can be reached by an individual seated in a mobility device -Paths in the locker room are free of obstacles -Clear space in front of lockers -Other *Text box*

38. Which of the following accessible features do the showers have? Check all that apply:
-N/A -Grab bars on the wall -Stable seat -Threshold of roll-in shower is level with the floor -Hand held spray hose -Other *Text box*

39. Is there an accessible family change room at the site?
    a) Yes b) No c) N/A

Exercise Equipment/Space

40. Is adaptive equipment available for children with disabilities to participate in given activities?
a) Yes b) No c) N/A If yes, please list the equipment *Text box*

41. Are child-friendly instructions for the use of the equipment readily available and accessible?
a) Yes b) No c) N/A If yes, please describe *Text box*

42. Which of the following features do the aisles/paths in the activity area have:
-Wide enough for mobility devices -Free of obstacles or hazards that are difficult to traverse -Tactile cues -Other *Text box*

43. What are the opportunities that children with disabilities have for exercise/fitness? Please describe. -N/A *Text box*

Pools

44. Which of the following features are present at the pool? Check all that apply:
-Zero-depth entrance -Ramp or lift to enter -Flotation devices -Slip-resistant flooring around the pool -Heated/therapeutic section of the pool -Contrasting colours -Tactile cues -Large pictograms -Large signs/indicators -Other *Text box*

Playgrounds

45. Which of the following features does the playground have? Check all that apply:
-Ground material that can be traversed using a mobility device -Large signage/pictograms at child-friendly height -Tactile map -Other *Text box*

46. Which of the following features does the playground equipment have? Check all that apply:
-Varying heights for use by children -Knee clearance providing wheelchair access -Accessible reach ranges -Sensory elements -Other *Text box* Please describe the sensory elements *Text box*

47. Which of the following features are found around the playground? Check all that apply:
-Bench -Picnic table -Shelter/Shade -Drinking fountain -Accessible bathroom -Other *Text box*

Water Fountain/Splash Pad

48. Which of the following features are present at the water fountain/splash pad? Check all that apply:
-At least one fountain with clear floor space -Tactile cues on floor -Varying fountain heights, some low enough for wheelchair access -Control mounted on child-friendly height -Benches or rest area -Accessible bathroom nearby -Other *Text box*

Multi-use Trail

49. Which of the following features does the multi-use trail have? Check all that apply:
-Benches or rest areas -Firm, smooth surface -Wide enough for a wheelchair -Free of obstacles or hazards that may be difficult to traverse -Navigational aids, such as pictograms/signage -Tactile cues -Other *Text box*

Waiting Room

50. Is there a waiting room available at the site?
a) Yes b) No c) N/A

51. Which of the following features are present in the waiting room? Check all that apply:
-Wide enough for a wheelchair -Free of obstacles or hazards -Interactive screens -Toys -Other *Text box*

Exam Room

52. Which of the following features does the exam/diagnostic room have? Check all that apply:
-N/A -Transfer support available for moving to exam table, such as transfer board or lift -Adjustable exam table -Sufficient space provided for maneuvering inside the room in a mobility device -Weighing scale that has railings for stability -Wheelchair-accessible scale that can accommodate children and their wheelchair -Other *Text box*

Final Overall Questions

53. Are there any other aspects of the site that are supportive for children with a disability to participate in the activity? *Text box*

54. Are there any other aspects of the site that are a barrier for children with a disability to participate in the activity? *Text box*

Organizational Assessment

Activity

1. Is at least one activity program/class available on-site for children with disabilities?

a) Yes b) No c) Not applicable

2. Are activities/programs held in an accessible location?

a) Yes b) No c) Not applicable If yes, please specify which activities/programs *Text box*

3. Is the activity/program designed so that children with disabilities and without disabilities participate equally, such as adapting movements and rules?

a) Yes b) No c) Not applicable If yes, please specify which activities/programs *Text box*

4. Are accommodations provided so children with disabilities can participate, such as allowing an aide or caregiver to attend?

a) Yes b) No c) Not applicable

5. Are there any other aspects related to activity at the site that are either supportive or may be a barrier to persons/children with disabilities?

a) Yes b) No c) Not applicable If yes, please specify *Text box*

Materials

6. Are any Instructional/Educational materials available for the activites/program(s)? a) Yes b) No c) Not applicable

7. Which of the following alternative formats are readily available for the Instructional/Educational materials? Check all that apply:

-Braille -Electronic version -Large print -Pictograms -Audio -Video with captions
-Other *Text box*

Staff

8. Are staff provided any type of disability awareness training either on-site or through outside education?

a) Yes b) No

9. Which of the following components are covered in disability awareness training? Check all that apply:

-Providing services to children with different types of disabilities and/or their families -Adapting the environment for children with disabilities -Communicating with children/parents of children with different types of disabilities -Using person-first terminology -Other *Text box*

10. Which of the following policies apply to the disability awareness training? Check all that apply:

-Disability awareness training is part of human resource policies -Staff at all levels receive disability awareness training -Persons with disabilities are involved in providing the training -Other *Text box*

11. Which of the following information is included in the training materials that are available to the staff? Check all that apply:

-Facing different groups of children and recommendations on how to facilitate participation for these groups
-Emergency situations that may arise
-Comprehensive overview of barrier-free participation -Definitions and/or descriptions of different types of disabilities -Basic sign language -Strategies for conflict resolution with children and/or family members -Other *Text box*

Policymaking

12. When organizing committee groups for overall policymaking at the facility, are children with disabilities and/or parents of children with disabilities included?

a) Yes b) No If yes, describe their involvement: *Text box*

Wayfinding

13. Which services are available to help children with disabilities navigate around the facility? Check all that apply:

-Personalized mapping photos/schemes with labels -Accompaniment by a staff
-Other *Text box*

Schools

14. Are there accommodation programs available for children with disabilities to get to school?

a) Yes b) No If yes, describe the program *text box*

15. Which of the following policies on inclusion are adopted by the school (or school district)? Check all that apply:

-Physical activity goals are included in students' Individual Education Programs (IEPs) -Adapted sports program are available in the school -Students of all abilities participate in PE class together
-Other *Textbox*

Healthcare Sites

16. Are obesity screenings available for children with disabilities?

a) Yes b) No

17. Do healthcare providers ask children with disabilities about their level of physical activity?

a) Yes b) No

18. Are healthcare providers able to weigh a child using a mobility device who is unable to stand using a roll-on or lift scale?

a) Yes b) No

Readiness for Change

19. How aware is the organization about the inclusion of children with disabilities in health promotion?

1 (Not at all), 2, 3, 4, 5 (Very aware)

20. How much of a concern is inclusion in health promotion in your organization?

1 (Not at all), 2, 3, 4, 5 (Very great concern)

21. Would the leadership support additional efforts toward inclusion in health promotion?

a) Yes b) No Please explain *Text box*

22. Is the organization currently planning for any additional efforts/services towards inclusion in health promotion for persons/children with disabilities?

a) Yes b) No If yes, explain *Text box*

23. Have any plans been adopted for making the building/site more accessible?

a) Yes b) No c) I don't know d) N/A If yes, please explain *Text box* If yes, explain *Text box*

24. What are the primary obstacles to efforts addressing inclusion of children with disabilities in health promotion in the organization? *Text box*

Audit

25. Is there an accessibility auditing in place? (an assessment of a building, best-practice standards to benchmark its accessibility)

a) Yes b) No

26. Is there a mechanism in place to make the changes recommended by the audit? a) Yes b) No If yes, please explain *Text box*

<u>Macro Community-At-Large Assessment</u>

Transportation

1. Is at least one form of fixed route, Public Transportation available in the community, such as a public bus, train, and/or subway?

a) Yes b) No

2. Is there a program in the community that provides travel training for children with disabilities in using public transportation?

a) Yes b) No c) N/A

3. Are there subsidies that are available for public transit for the following groups of people (children with disabilities, low income)

a) Yes b) No If yes, please describe *Text box*

4. Is information on the accessibility of the transit system and stops posted on the transportation agency's website?

a) Yes b) No

5. Which of the following accessibility features are provided regarding the information on transportation? Check all that apply:

-Plain text documents -Large print, pictograms -Tactile map of transportation system -Audio -Braille information -Other *Text box*

6. Which of the following other types of transportation services for children with disabilities are available in the community? Check all that apply:

-Paratransit (door-to-door) -Volunteer-run service -Wheelchair accessible taxis -Other *Text box*

7. Are there support systems in place to help children with disabilities at transportation hubs in the community?

a) Yes b) No If yes, please describe *Text box*

Transportation Staff Training

8. Does the public transportation staff receive disability awareness training?

a) Yes b) No c) N/A

9. Which of the following are a part of the staff's disability awareness training? Check all that apply:

-Communicating with people with different types of disabilities -Using person-first terminology -Other *Text box*

10. Which of the following policies apply to the transportation staff's disability awareness training? Check all that apply:

-Disability awareness training is part of human resource policies -**Staff** at all levels receive disability awareness training -Persons/children/parents of children with disabilities are involved in providing training -Other *Text box*

Community Design

11. Which of the following inclusive policies or regulations exist in the community? Check all that apply:

-Development of biking and walking/rolling infrastructure -Transit-oriented development of the community -Installment of wayfinding signage in the community, such as for biking or walking routes -Wayfinding signage inclusive of children with disabilities by having large print, pictograms and Braille -Program or service to maintain sidewalks, such as for clearing snow or removing water near curb cuts -Funding available in the community to improve accessibility at business locations and community facilities -Other *Text box*

Awareness Initiatives

12. Are training and resources on how to become accessible available to businesses in the community?

a) Yes b) No

13. Does a program generating dialogue between children/families of children with disabilities and service providers/policy makers in the community exist?

a) Yes b) No

Healthcare Access

14. Are opportunities to access healthcare for a physical health condition readily available in the community?

a) Yes b) No

15. Are the following accessible features present at the main entrance? Check all that apply:

-Ramp -Lift -Non-slip surface -Tactile indication for steps and ledges -Stairs with continuous rails on one or both sides -Power assist or automatic door -Other *Text box*

16. Are opportunities to access healthcare for a mental health condition readily available in the community?

a) Yes b) No

General Programs/Services

17. Are there any community groups, clubs, or organizations for children with disabilities in the community?

a) Yes b) No If yes, please describe *Text box*

Leisure

18. Do leisure opportunities exist for children with disabilities in the community?

a) Yes b) No If yes, please describe *Text box*

Please provide any comments and/or suggestions about the clarity and/or importance of the Leisure section, if you have any.

Volunteer/Work

19. Do volunteer/work opportunities exist in the community for children with disabilities?

a) Yes b) No If yes, please describe *Text box*

Education

20. Are any of the following in the area accessible for children with multiple disabilities? Check all that apply:

-School -Workshops -Educational sessions -Tutoring -Other *Text box*

Social

21. Are there opportunities in the community for family participation?

a) Yes b) No If yes, please describe *Text box*

22. Are there opportunities in the community for children with disabilities to meet other people in the community?

a) Yes b) No If yes, please describe *Text box*

23. How would you describe the community members' attitudes towards children with disabilities within the community at large? *Text box*

Technology

24. Are there opportunities in the community for children with disabilities to access computer technology and technology services?

a) Yes b) No If yes, please describe *Text box*

Please provide any comments and/or suggestions about the clarity and/or importance of the Technology section, if you have any.

Web Mapping

25. Do web and mobile mapping existing for the community?

a) Yes b) No If yes, please describe *Text box*

Accessibility Policies

26. Are there any accessibility policies and/or initiatives in the community?

a) Yes b) No If yes, please describe *Text box*

27. Does an accessibility recognition seal exist in the community?

a) Yes b) No c) N/A

28. Are the following things integrated in overall policymaking in the community? Check all that apply:

-Organising a round table with policymakers and children with **disabilities** and/or parents of children with disabilities -Presence of Disability Advisory Group, who represent children with a broad range of impairments -Other *Text box*

Chapter 6: Integration of Manuscripts 2 and 3

6.1 Research Objectives of Manuscripts 2 and 3

Manuscript 2: To develop the content of a measurement tool to assess the community health inclusion of children with disabilities in Canada.

Manuscript 3: To establish the content validity and improve the clarity of the Child Community Health Inclusion Index (CHILD-CHII).

6.2 Integration of Manuscripts 2 and 3

The content development of the CHILD-CHII, described in **Manuscript 2,** consisted of a thorough review of existing indicators and measurement tools related to the inclusion of children with disabilities for new items generation, followed by multiple iterations of item generation and item reduction with the input of an array of experts. Following the development of the initial content, the importance of each item with regards to the inclusion of children with disabilities in their community needed to be established for content validity. The items also needed to be further refined to ensure sufficient clarity for the evaluator, so as to enhance the reliability of the scoring of items. Therefore, the aim of **Manuscript 3** was to establish content validity and improve the clarity of the items of the CHILD-CHII. The content/items generated for the CHILD-CHII from **Manuscript 2** underwent two rounds of validation and clarification in **Manuscript 3**. Between the completion of the content development study and the start of the content validation study, the items generated in **Manuscript 3** were further organized by merging items addressing the same aspect of the community, to reduce the number of total items. Hence, the 189 items resulting from the initial content development study were reduced to 106 items to validated.

Chapter 7: Manuscript 3

Content validation of the child community health inclusion index: a modified e-Delphi study

Paul Yejong Yoo[a,d], Annette Majnemer[a,d], Robert Wilton[b,c], Sara Ahmed[a], Keiko Shikako [a,d]

[a] School of Physical and Occupational Therapy, Faculty of Medicine and Health Sciences, McGill University, Montreal, QC, Canada H3G 1Y5
[b] School of Geography & Earth Sciences, McMaster University, Hamilton, ON, Canada L8S 4L8
[c] Faculty of Social Sciences, McMaster University, Hamilton, ON, Canada L8S 4L8
[d] Research Institute of the McGill University Health Centre, Montreal, QC, Canada, H4A 3J1

Corresponding author: Keiko Shikako
3500 Blv Decarie, room 439, Montreal, Quebec, H4A3J5
(514) 488-5552 ext. 1141
keiko.thomas@mcgill.ca

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Abstract

Participation is a human right and a key component of health and development in children with disabilities. Inclusive communities and environments facilitate participation. Currently, there are no measures that comprehensively assess the inclusion of children with disabilities in Canadian communities. This study aims to establish the content validity and improve the clarity of the Child Community Health Inclusion Index (CHILD-CHII). A modified e-Delphi technique was conducted. A purposeful convenience sample of community stakeholders was recruited. The importance and clarity of each item were rated on a Likert scale in two separate rounds. Depending on consensus, items were retained, modified, or omitted. 48 participants completed the first round of the Delphi technique and 38 completed the second. 106 items were presented of which 101 items were rated important with high consensus and were retained. 17 items were modified for clarity and presented in the second round. In the second round, all 17 modified items were deemed clearer. The CHILD-CHII and its validated content assess aspects of the community that align with social determinants of health. Measuring these aspects may identify barriers to inclusion and inform the development of interventions, health strategies, and policies to improve community inclusion and child health.

Keywords: Child; Health; Measures; Community; Environment; Inclusion

Geolocation Information

The CHILD-CHII has been developed for the Canadian pediatric population. Canada.

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Disclosure

The authors report there are no competing interests to declare

Introduction

The guiding principles of the Convention on the Rights of Persons with Disabilities (CRPD) calls for full and effective participation and inclusion in society. Persons with disabilities, including children, should be included in communities where they live through an accessible physical environment, to include equal access to public transportation, information and communications technology, and other facilities and services available to the public (1). Multiple national and international treaties, policies, and recommendations emphasize the importance of creating inclusive communities where all marginalized groups have equal opportunities to thrive and enjoy a holistic definition of health. For instance, the United Nations Sustainable Development Goals of 2030 include emphasis on reducing inequities, promoting health, and creating sustainable cities (2).

In Canada, a historical landmark was established when the Accessible Canada Act was ratified, an act promoting accessibility of public spaces and programs and services of federal jurisdiction (3). While promoting their inclusion in the community, participation in community-life and recreational activities is vital for a child's development of competency, identity, and self-sufficiency (4). Participation in leisure activities is a key component in promoting physical and mental health for children with disabilities and their families (5).

Despite the benefits and importance of inclusion as a fundamental human right, children with disabilities face restrictions in comparison to children without disabilities (6, 7). Children with disabilities are at high risk for unfavorable outcomes in relation to their health and well-being and are often marginalized in public spaces and their needs are often neglected in public health initiatives and public policy (8). In Canada, there are over 800,000 children with developmental disabilities. Forty-four percent of children with disabilities aged 5-14 years reported having a disadvantage in transportation or leisure services and many may be denied access to programs, facilities, public parks and playgrounds, limiting their ability to partake in community activities (Statistics 9). In addition, there are significant barriers in accessing recreational opportunities for youth with disabilities including untrained staff, lack of adapted equipment or information on accessible programs (4, 10). These environmental barriers to physical activity and recreation for youth with disabilities are important social determinants of health and limited access to these opportunities may result in significant health disparities with lasting impacts on child development and family well-being (4).

Environmental factors are described as systems, programs, places, and institutions that are crucial for health and functioning, and closely related to participation opportunities or restrictions (11). Addressing environmental barriers, such as eliminating built environment barriers to accessibility, and fostering social supports can positively affect a child's participation in diverse activities (12). To successfully implement and evaluate policies and programs promoting community inclusion by reducing environmental barriers, a method to adequately measure their impact is essential (13). The usefulness of measurement of policies, programs, and structures depends on the extent to which one can rely on the data to represent accurate and meaningful indicators of behaviors, attributes or phenomena (14). The measurement of community inclusion can be applied to evaluate the current state of a given community and/or an individual within a community and can also be used as an outcome measure to track the impact of an intervention on community inclusion of individuals with disabilities (15).

The Community Health Inclusion Index (CHII) is a comprehensive assessment tool developed to be used by public health professionals and community coalitions to examine the scope and depth of factors that foster healthy, active living among people with disabilities (16). This measure evaluates potential barriers and facilitators in the community that may influence the participation of individuals with disabilities. The measure was developed for use with adults and includes items not relevant to children (e.g. access to shopping and employment facilities), and does not include special consideration for the needs of children with disabilities and their families. Furthermore, the CHII was developed in the United States. In addition to verifying content for use in children, a transcultural adaptation to the Canadian context was warranted, to accommodate the unique features of our public healthcare system, the weather conditions, and the diverse realities of Canadian communities, in addition to language validation in both official languages (English and French).

The adaptation of CHII to the pediatric population and to the Canadian context, and the content development for the Child Community Health Inclusion Index (CHILD-CHII) is reported elsewhere (Yoo et al., submitted). The comprehensive review of existing measurements and tools conducted in the previous phase highlighted the need for a specific tool tailored for children with disabilities and the community spaces they occupy. The development process considered the diverse needs of children with various disabilities with a generalizable, universal design approach (Yoo et al., submitted). Following the content development, the objective of this study was to establish the content validity and improve the clarity of the CHILD-CHII. This study will further validate and develop the CHILD-CHII for its feasibility pilot testing.

Methods

Study design

A modified e-Delphi technique was carried out to establish the content validity and improve clarity of the items in the CHILD-CHII. The Delphi technique is an iterative process to collect and synthesize specific and anonymous input. It is performed to reach a consensus among a group of experts, particularly upon topics of uncertainty with limited evidence (17, 18). Originally done through in-person meetings and several rounds of refinement, in this study, a modified web-based Delphi technique was conducted where the Delphi was administered using the *LimeSurvey* platform as an online web survey, done in two separate rounds (19). Ethics approval for this study was granted by McGill University's Faculty of Medicine and Health Sciences Institutional Ethics Review Board.

Measurement Tool

The CHILD-CHII is an index comprised of three assessments that address different inclusion domains of a single facility or location (Figure 1). For the child version of the index, we expanded and adapted the content based on an extensive review of inclusion measures pertinent for children. Following the content development process (Yoo et al., submitted), the CHILD-CHII On-site assessment consisted of 53 items that address the 'Built Environment' and 'Equipment' inclusion domains of the CHILD-CHII. The Organizational Assessment with 26 items and the Macro Community-At-Large Assessment with 27 items addressed the inclusion domains of 'Programs/Services', 'Staff', and 'Policies' as related to the facility and the surrounding community.

Participants

We recruited a purposeful sample of stakeholders across Canada through convenience sampling adopting a maximum variation sampling strategy to recruit stakeholders in each of the community sectors outlined in the CHILD-CHII framework (Figure 1): Education, Health, Public Spaces, Community Institutions/Organizations. These stakeholders included health care professionals, teachers, special educators, researchers, counselors, and policymakers who have previous experience working with children with disabilities, in childhood disability, and/or individuals accessibility programs and policy development. Participants also included parents or legal guardians of children between ages 5 and 18 (school age or adolescents) who have an acquired or developmental disability and children between ages 5 and 18 who have an acquired or developmental disability, and we aimed at recruiting anglophone and francophone participants in all groups. Participants were recruited by email and through notices on different social media platforms including Facebook and Twitter. Interested participants were contacted and informed about the nature of the study through email and asked to consent to the study.

Sample size

For the Delphi technique, no a-priori sample size is required, however most Delphi studies have used around 10-15 participants (20). With four sectors of the CHILD-CHII (Figure 1) we aimed to recruit 10-15 from each sector for a total of 40-60 participants.

Delphi technique

The Delphi technique was conducted in two rounds. Both rounds were in the form of online questionnaires on the *LimeSurvey* platform available in both English and French, according to participants' preference. Participants were provided a link to the online questionnaire via email. Each questionnaire was pilot tested by two members in the research lab and two senior researchers. The questionnaire itself was divided into three parts, corresponding to the three different assessments within the measurement tool: On-site Assessment, Organizational Assessment, Macro Community-At-Large Assessment. Examples of items in each assessment can be found in Supplementary Table 1.

First round

The first round of the online questionnaire listed all the items identified for the CHILD-CHII in their respective sections and participants were asked to rate the *Importance*- how important the item was in relation to the inclusion of children with disabilities in the community, and *Clarity*- how clearly the items were articulated and if the item was understandable. Ratings of importance and clarity of the items were on a four-point Likert scale (i.e. Very Important/Very

Clear, Important/Clear, Somewhat Important/Somewhat Clear, Not Important/Not Clear). The participants were also asked to provide comments and suggestions to further clarify the wording of items. The advisory committee, made up of four researchers from diverse backgrounds in childhood disability, community inclusion, and measurement, reviewed the responses and comments obtained in the first round. Based on the survey findings, they determined which items would be retained and which would be eliminated (see data analysis below).

Second round

For the second round, the same participants were sent an online questionnaire that contained only the items that were collectively agreed to be unclear based on ratings from the first round, coupled with new items that were modified based on comments and suggestions from the first round. The participants were presented with the original and new version of the wording of items and asked to choose which version they thought was clearer for these items, and to add suggestions for further clarification or modifications where necessary. First reminder email was sent to all participants two weeks after the online questionnaire for the second round was sent. A second reminder email was sent to all participants two weeks after the first reminder email. Due to the anonymity of the responses, missing data between the first and second round was difficult to address.

Data Analysis

First round

Items that were rated ‘Very Important’ or ‘Important’ and ‘Very Clear’ or ‘Clear’ with consensus (≥70% of the participants) were retained to be included in the CHILD-CHII (20). Items that were rated ‘Very Important’ or ‘Important’ with <50% agreement were discarded. Items with 50-69% agreement were reviewed by the expert supervisory committee and discussed to be modified, retained, or discarded. Items that were rated ‘Very Important’ or ‘Important’ with ≥70% agreement but rated ‘Very Clear’ or ‘Clear’ with <70% agreement, these items were modified using the comments and suggestions provided by the participants. All modified items were sent out to the participants for round two for further input.

Second round

The version of the item that was chosen to be clearer with ≥70% agreement was retained for the CHILD-CHII. Items with 50-69% agreement were reviewed by the expert supervisory committee and discussed to be either retained or discarded (20).

Results

First round- Importance

The characteristics of the participants can be found in Table 1. Of the 48 participants who completed this round, 31 (65%) responded to the English survey and 17 (35%) completed the French survey. For both the English and French versions of the questionnaire, there was a high consensus (≥70% participants), with the majority of the items being important or very important (Table 2 & 3). After the review by the advisory committee, four items with lower consensus (<70%) from the On-site assessment and one item from the Organizational assessment were removed (Supplementary Table 2). Two items from the Macro Community-At-Large assessment were retained and re-worded to be reviewed in the Second Round of the Delphi procedure.

First round- Clarity

Table 2 shows the consensus results for the English questionnaire. From the English version, out of the 18 items that had lower consensus on its clarity (<70%), 13 items were modified and re-worded based on participants' comments to go on to the second round. The five other items were removed due to their low consensus on importance rating (<50%). From the French version (Table 3), there were 11 items that had lower consensus on clarity (<70%); these 11 items were also re-worded and modified based on participants' comments. Additionally, six separate items that were modified in the English version had the modifications translated into French, resulting in 17 items that were modified to be reviewed in the Second round.

Second round

The characteristics of the participants of the second round of the Delphi can be found in Table 4. There was an attrition of participants with a total of 38 who completed the second round. There were no specific reasons for the attrition provided by the participants following the reminder emails. Of the participants, 25 (66%) participants responded to the English survey and 13 participants (34%) completed the French survey. The modified items that moved on to the second round can be found in Supplementary Table 3. Most of the respondents (≥70%) agreed that the modified version was clearer than the previous version for all 17 of the items that were included in the second round.

Discussion

This study aimed to validate the content of the CHILD-CHII measurement tool. This was done through two rounds of a modified e-Delphi technique with a group of childhood disability and accessibility experts of differing backgrounds and training. They were presented a list of items related to community inclusion of children with disabilities that were developed in a previous study (Yoo et al., submitted), and were asked to rate the importance of each item regarding inclusion of children with disabilities in the community, and the clarity of the items in English and French.

It is important to emphasize that with 48 participants and 38 participants for the First and Second rounds of the modified e-Delphi technique, respectively; the sample size was appropriate and representation was sufficient for a Delphi process (20)."

This study found that most items that were identified through the adult version of the tool (CHII), a literature review of existing measures, and input from an expert panel (Yoo et al. submitted), were indeed very relevant in assessing the community health inclusion of children with disabilities. Only five items were removed due to low consensus on the importance rating and review by the expert committee. The five items addressed concepts that were perceived as less relevant (ie. addressing the existence of vandalism and empty buildings around the facility), potentially outdated (ie. existence of public telephone), and redundant (ie. item addressing transit during peak times that is addressed in another item). This study showed that the Delphi technique was effective in validating the items proposed, and in improving the clarity of items through structured group input from diverse experts (21, 22). This diverse expert input centred around defining certain keywords, specifying the target audience or location, and using better syntax and/or diction to improve understanding of what the item is asking. This led to a strong consensus that all revised items that moved on to the second round based on the ratings and suggestions from experts provided in the first round, were clearer than the previous version of the item.

Through the successful content validation of the CHILD-CHII measurement tool, and the retention of 101 of 106 items through high consensus on their importance, this study highlighted the importance of measuring the inclusion of children with disabilities in the four sectors of the community (ie. Education, Health, Public Spaces, Community Institutions/Organizations) and the five domains in these sectors (ie. Built Environment, Equipment, Programs/Services, Staff, Policies) found in the CHILD-CHII framework (Figure 1). This is in line with the effort of the WHO and the Public Health Agency of Canada (PHAC) to improve the social determinants of health (SDH) of individuals with disabilities (23). SDH are aspects of life that determine the health of an individual and their chances of leading a flourishing life (24). The CHILD-CHII and its validated items address and assess aspects of the community that align with the SDH listed by PHAC- education, social support, social opportunities, physical environments, childhood experiences, and access to health services (23). Furthermore, the validated content of the CHILD-CHII can act as a comprehensive guideline for community facilities and community-based providers through which they can identify areas for improvement and develop strategies to address them. This can further promote inclusion and increase the facilities' willingness to be more inclusive of children with disabilities (25).

This study consisted of participants from diverse backgrounds and disciplines with varying levels of experience working with children with disabilities, including parents with children with disabilities. In the sphere of health and healthcare services, parent involvement in treatment service improvement has been deemed to be a priority (26, 27). Additionally, interdisciplinary approaches and the tailoring of measurement tools to children have been identified as crucial in healthcare service delivery (27). The input from diverse participants also included community partners and decision-makers who can apply the knowledge obtained by completing this measurement, in order to develop programs and policies. The high consensus reached among these participants have ensured the quality and robustness of the content. A feasibility pilot test of the measurement tool will follow to determine the feasibility of applying the CHILD-CHII measurement tool to community facilities. There is methodological recommendation for the simultaneous content validation and translation from English to French, as a facilitator for the development of a measure that is validated for francophone users (28).

Measuring aspects of the environment that influence a child's inclusion is crucial to inform the development of targeted interventions, public health strategies and policies to improve community inclusion and health of children with disabilities. In particular, understanding the needs of children and families in the context of public spaces is essential to decrease marginalization and expand the spaces for dialogue, inclusion, and the creation of equitable services and programs.

Limitations

Although the participant pool was diverse, the selection and recruitment through convenience sampling may limit the generalizability of the results. The participants of the study that were recruited from each of the sectors of the CHILD-CHII may not be a true representation of the Canadian population in their specific fields. In addition, the participation attrition from the first round to the second round brought the sample size lower than the 40 participants that this study aimed for. Another limitation was that only one youth with disabilities participated, and only in the first round of the Delphi technique. The limited number of French-speaking participants may also constitute a limitation. The clarity of items that were translated may require further assessment.

Conclusion

The content of the CHILD-CHII measurement tool was validated through two rounds of the Delphi technique with participants from diverse roles and from different disciplines with varying levels of experience working with children with disabilities. The retention of 101 items of the CHILD-CHII further underscored the importance of measuring the inclusion of children with disabilities in the community and emphasized its appropriateness to the Canadian context. The CHILD-CHII and its validated content assess aspects of the community that align with the social determinants of health laid out by WHO and PHAC. Measuring these aspects of the community environment can help identify areas that lack inclusion of children with disabilities and inform the development of targeted interventions, public health strategies and policies to improve community inclusion and health of children with disabilities.

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Figures

<table>
<tr><th colspan="6">Child Community Health Inclusion Index (CHILD-CHII)</th></tr>
<tr><td rowspan="2">Level 1:
Sectors</td><td colspan="5">Community-At-Large</td></tr>
<tr><td>Education
(Schools)</td><td>Health
(Hospitals, Clinics)</td><td>Public Spaces
(Parks, Playgrounds)</td><td colspan="2">Community Institutions/Organizations
(Community Centres, Libraries)</td></tr>
<tr><td>Level 2:
Venues</td><td colspan="5">Activity
(Fitness room, Classroom, Gym)
Community Design
(Transportation, Paths)</td></tr>
<tr><td>Level 3:
Inclusion Domains</td><td>Built Environment</td><td>Equipment</td><td>Programs/Services</td><td>Staff</td><td>Policies</td></tr>
<tr><td>Assessments Used</td><td colspan="2">On-site Assessment</td><td colspan="3">Organizational Assessment &
Macro Community-At-Large Assessment</td></tr>
</table>

Figure 1- CHILD-CHII Framework

Tables

Table 1- First round: Participant characteristics

Characteristic		n (%)
Gender	Female	41 (85%)
	Male	5 (11%)
	Not Reported	2 (4%)
Experience working with children with disabilities	Less than 1 year	3 (6%)
	1-3 years	8 (17%)
	4-9 years	9 (19%)
	10-15 years	10 (21%)
	16+ years	12 (25%)
	Not Reported	6 (12%)
Profession/Role (primary)	Researcher	13 (27%)
	Clinician	9 (19%)
	Parent	8 (17%)
	Government	7 (15%)
	Community	6 (12%)
	Teacher	2 (4%)
	Youth	1 (2%)
	Other	2 (4%)

Table 2- First round: English questionnaire consensus ratings

Assessment	Total Items	Rating	Consensus [n (%)]		
			≥70%	50-69%	<50%
On-site Assessment	53	Very Important/Important	49 (92%)	4 (8%)	0 (0%)
		Very Clear/Clear	40 (75%)	11 (21%)	2 (4%)
Organizational Assessment	26	Very Important/Important	25 (96%)	1 (4%)	0 (0%)
		Very Clear/Clear	26 (96%)	1 (4%)	0 (0%)
Macro Community-At-Large Assessment	27	Very Important/Important	26 (96%)	0 (0%)	1 (4%)
		Very Clear/Clear	23 (85%)	3 (11%)	1 (4%)

Table 3- First round: French questionnaire consensus ratings

Assessment	Total Items	Rating	Consensus [n (%)]		
			≥70%	50-69%	<50%
On-site Assessment	53	Very Important/Important	49 (92%)	4 (8%)	0 (0%)
		Very Clear/Clear	48 (90%)	3 (6%)	2 (4%)
Organizational Assessment	26	Very Important/Important	25 (96%)	1 (4%)	0 (0%)
		Very Clear/Clear	25 (96%)	1 (4%)	0 (0%)
Macro Community-At-Large Assessment	27	Very Important/Important	26 (96%)	0 (0%)	1 (4%)
		Very Clear/Clear	22 (81%)	4 (15%)	1 (4%)

Table 4- Second round: Participant characteristics

Characteristic		**n (%)**
Gender	Female	36 (95%)
	Male	2 (5%)
Experience working with Children with Disabilities	Less than 1 year	1 (3%)
	1-3 years	5 (13%)
	4-9 years	8 (21%)
	10-15 years	9 (24%)
	16+ years	8 (21%)
	Not Reported	7 (18%)
Profession/Role (primary)	Clinician	9 (24%)
	Parent	8 (22%)
	Researcher	8 (22%)
	Community	5 (14%)
	Teacher	3 (8%)
	Government	2 (5%)
	Youth	0 (0%)
	Other	2 (5%)

Supplementary Table 1- Example of items found in the different assessments of the CHILD-CHII

Assessment	**Section**	**Item**
On-site	Inside the Site	Are the following accessible features present at the main entrance? Check all that apply: -Ramp -Lift -Non-slip surface -Tactile indication for steps and ledges -Stairs with continuous rails on one or both sides -Power assist or automatic door -Other *Text box*
	Guide Dogs	Is there a designated space for guide dogs at the site? a) Yes b) No
Organizational	Activity	Is at least one activity program/class available on-site for children with disabilities? a) Yes b) No c) Not applicable
	Staff	Are staff provided any type of disability awareness training either on-site or through outside education? a) Yes b) No
Macro Community-At-Large	Transportation	Is there a program in the community that provides travel training for children with disabilities in using public transportation? a) Yes b) No c) Not applicable
	Community Design	Which of the following inclusive policies or regulations exist in the community? Check all that apply: -Development of biking and walking/rolling infrastructure -Transit-oriented development of the community -Installment of wayfinding signage in the community, such as for biking or walking routes

		-Wayfinding signage inclusive of children with disabilities by having large print, pictograms and Braille -Program or service to maintain sidewalks, such as for clearing snow or removing water near curb cuts -Funding available in the community to improve accessibility at business locations and community facilities -Other *Text box*

Supplementary Table 2- Items removed following the results of the first round

Assessment	**Section**	**Item**
On-site	Transit	How often does the bus/train/van come during the non-peak periods (nights, weekends)? a) Less than 30 min b) 31-60 min c) Over 60 min
	Getting Around the Site	Is it safe/possible to get around on the paths on and around the site? a) Yes b) No
	Getting Around the Site	Indicate if the following characteristics that could deter children with disabilities from getting around the site are present in the blocks around the site. Check all that apply: -People loitering -Graffiti -Litter -Vacant buildings -Street harassment -Uneven terrain -Low lighting
	Telephone	Is there access to a telephone in a public space? a) Yes b) No
Organizational	Healthcare Sites	Are obesity screenings available for children with disabilities? a) Yes b) No

Supplementary Table 3- Modified items that were in the second round and the number of participants that deemed the modified version to be clearer

Assessment	Section	Modified Item	n (%)
On-site	Transit	Is there at least one public transit stop near the site entrance? a) Yes b) No If Yes, how close? a) Less than 50 m b) 50-100 m c) More than 100 m	35 (92%)
	Getting Around the Site	Indicate if the following characteristics that make getting around (outside) the site more accessible are present. Check all that apply: -Some form of physical boundary around common areas that lessens the likelihood of children wandering into unsupervised areas -Wide aisles -Obstacles and edges are detectable for someone using a cane -Routes are free of obstacles -Slip-resistant materials -Circle or a T-shaped space for a person/child using a wheelchair to reverse direction or to turn their wheelchair completely -Contrasting colours -Even terrain -Other *Text box*	33 (87%)
		Are there any driveways, street crossings, or changes in levels on the path to the site where a curb cut (pavement graded down to meet lower, adjoining street) is needed but does not currently exist? a) Yes b) No	31 (82%)
		Do the intersections (street crossings) around the site have a traffic signal? a) None of them b) Less than 50% of them c) 50% of them d) More than 50% of them e) All of them	35 (92%)
	Inside the Site	B) If there are no adaptations at the main entrance, does an alternate accessible entrance exist? a) If yes, Check all that apply: -Ramp Lift Non-slip surface -Tactile indication for steps and ledges -Stairs with continuous rails on one or both sides -Power assist or automatic door -Other *Text box* b) No	36 (95%)
		Do the doors at the site have the following accessible features? Check all that apply: -Automatic operation-Sliding doors	35 (92%)

		-Wide enough for a wheelchair -Flush threshold (doorway flooring is flat/level) -Other *Text box*	
		Which of the following features are found in rooms and shared spaces (accessed by the child) at the site. Check all that apply: -Facilitated communication with people who use sign language (e.g. people facing each other) -Appropriate acoustics -Noise reduction measures in place -Adequate lighting -Other *Text box* -N/A	30 (79%)
	Exercise Equipment/ Space	What opportunities do children with disabilities have to engage in exercise/fitness (eg. adapted exercise activities)? Please describe. -N/A -*Text box*	31 (82%)
	Playgrounds	Lesquelles des caractéristiques suivantes de l'équipement de terrain de jeu possède-t-il? -Hauteurs variables à l'usage des enfants -Dégagement des genoux permettant l'accès en fauteuil roulant -Divers niveaux de portée accessibles -Éléments sensoriels -Veuillez décrire les éléments sensoriels *Boîte de texte* -Autre *Boîte de texte	12 (92%)*
Organizational	Materials	Are any Instructional/Educational materials regarding activities/program(s) available to children and families? a) Yes b) No c) Not applicable	34 (89%)
	Staff	Des formations de sensibilisation au handicap sont-elles offertes au personnel sur place ou à l'externe? a) Oui b) Non	12 (92%)*
		Laquelle des informations suivantes est incluse dans le contenu de formation mis à la disposition du personnel? Cochez toutes les réponses qui s'appliquent : -Interagir avec différents groupes d'enfants et recommandations sur la manière de faciliter la participation de ces groupes -Situations d'urgence pouvant survenir -Comprendre la participation sans obstacle -Définitions ou descriptions des différents types de handicap -Langage des signes de base -Stratégies pour la résolution des conflits avec les enfants ou les membres	

		de la famille -Autres *Bôite de Texte *	
Macro Community-At-Large	Transportation	Y a-t-il des systèmes de soutien pour aider les enfants en situation de handicap dans les centres de transport de la communauté? a) Oui b) Non Si oui, veuillez décrire *Bôite de Texte *	12 (92%)*
	Education	Are any of the following, in the community surrounding the facility, accessible for children with multiple disabilities? Check all that apply: -School -Workshops -Educational sessions -Tutoring -Daycare centre -Other *Text box*	35 (92%)
	Social	Are there opportunities in the community for families to participate together in social activities? a) Yes b) No If yes, please describe *Text box*	36 (95%)
	Web Mapping	Are any mobile Apps such as apps listing activities, accessible buildings, accessible routes, or adapted transit available to the community? a) Yes b) No If yes, please describe *Text box*	35 (92%)
	Accessibility Policies	Are there any accessibility or inclusion awards/recognitions or certifications/seals available to incentivize accessibility and inclusion in the community at large? (eg. attributed to the municipality) a) Yes b) No c) I don't know	38 (100%)

*Of the French respondents

Chapter 8: Integration of Manuscripts 3 and 4

8.1 Research Objectives of Manuscripts 3 and 4

Manuscript 3: To establish the content validity and improve the clarity of the CHILD-CHII.

Manuscript 4: To estimate the feasibility of applying the CHILD-CHII measurement tool on facilities found in the community.

8.2 Integration of Manuscripts 3 and 4

The content validation of the Child Community Health Inclusion Index (CHILD-CHII) in **Manuscript 3,** which entailed 2 rounds of input from stakeholders, resulted in the final number of items to be included in the tool. This process also aimed to further clarify the specific items, to enhance understandability. Following the content validation, clarification and reduction of items, the feasibility of using the tool on facilities needed to be determined. The study presented in **Manuscript 4** applies the latest version of the CHILD-CHII items following the content validation presented in **Manuscript 3**, to a feasibility test that was piloted by different evaluators representing different sectors and different community facilities that provide community-based services for children with disabilities. The aim of **Manuscript 4** was to estimate aspects of feasibility in the application of the CHILD-CHII measurement tool in actual environments and facilities relevant to children in their community. Through this study, we ascertained several feasibility challenges such as the length of the index and time needed for completing the tool, difficulty obtaining the information to respond to some items, clarity of the items in real-world settings, and value of the tool and the information generated. These objective findings were indicators of the overall feasibility of applying the tool on community facilities, and suggested need for further revision to enhance feasibility, prior to ongoing psychometric testing of the CHILD-CHII.

Chapter 9: Manuscript 4

Application of the Child Community Health Inclusion Index- an evaluation tool for measuring health inclusion of children with disabilities in the community: A feasibility study

Paul Yejong Yoo[a,d], Annette Majnemer[a,d], Robert Wilton[b,c], Sara Ahmed[a], Keiko Shikako [a,d]

[a] School of Physical and Occupational Therapy, Faculty of Medicine and Health Sciences, McGill University, Montreal, QC, Canada H3G 1Y5
[b] School of Geography & Earth Sciences, McMaster University, Hamilton, ON, Canada L8S 4L8
[c] Faculty of Social Sciences, McMaster University, Hamilton, ON, Canada L8S 4L8
[d] Research Institute of the McGill University Health Centre, Montreal, QC, Canada, H4A 3J1

Corresponding author: Keiko Shikako
3500 Blv Decarie, room 439, Montreal, Quebec, H4A3J5
(514) 488-5552 ext. 1141
keiko.thomas@mcgill.ca

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Abstract

Background: Participation in the community is a fundamental human right for children with disabilities and is a key component of their health and development. Inclusive communities can enable children with disabilities to participate fully and effectively. The Child Community Health Inclusion Index (CHILD-CHII) is a comprehensive assessment tool developed to examine the extent to which community environments foster healthy, active living for children with disabilities. The actual utility of the tool depends on

Objectives: To assess the feasibility of applying the CHILD-CHII measurement tool across different community settings.

Methods: Participants recruited through maximal representation, purposeful sampling from four community sectors (Health, Education, Public Spaces, Community Organizations) applied the tool on their affiliated community facility. Feasibility measured as: length, difficulty, clarity, and value; rated on a 5-point Likert scale. Participants provided comments for each indicator through the questionnaire and a follow-up interview, which were considered for tool refinement.

Results: Of the 12 participants, 92% indicated that the tool was ‘long’ or ‘much too long’; 66% indicated that the tool was clear; 58% indicated that the tool was ‘valuable’ or ‘very valuable’. No consensus on difficulty indicator. The comments provided by the participants are highlighted in the article.

Conclusion: Although the length of the tool was regarded as long, it was seen to be comprehensive and valuable for stakeholders in addressing the inclusion of the children with disabilities in the community. Further refinement and psychometric testing are granted, perceived value and the evaluators’ knowledge, familiarity, and access to information can facilitate use of the CHILD-CHII.

Keywords: Community inclusion, childhood disability, measurement, feasibility, participation

Highlights:

- Tool for assessing community inclusion of children with disabilities is valuable
- Perceived value of a measurement tool can facilitate its use.
- Evaluators’ knowledge, familiarity, and access to information should be considered
- Contextual factors can enable or prevent the use of the tool

- An online version of the measurement tool made it more feasible to use.

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Introduction

Participation is a fundamental human right for all individuals including children with disabilities affirmed by the United Nations (UN) Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD) [1, 2]. The latter calls for the individual's full and effective participation and inclusion in society. Communities need to be inclusive through an accessible physical environment, equal access to public transportation, information and communications technology, and other facilities and services available to the public for children with disabilities to participate fully and effectively. For children, participation in community life has been found to be important for their health and development of competency, identity, and self-sufficiency. Participation in leisure activities is a key component in promoting physical and mental health for children with disabilities and their families.

The Community Health Inclusion Index (CHII) is a comprehensive assessment tool developed to be used by public health professionals and community coalitions to examine the scope and depth of factors that foster healthy, active living among people with disabilities [3]. This measure evaluates potential barriers and facilitators in the community that may influence the participation of individuals with disabilities. The need for a specific tool tailored for children with disabilities and the community spaces they occupy in Canada was highlighted in previous studies [4]. This warranted the adaptation of the CHII to the pediatric population in the Canadian context.

Through an extensive literature review, expert panel consultation, and a systematic iterative process, the content of the CHILD-CHII was developed [4]. The content was then validated through a modified e-Delphi technique with input from diverse stakeholders [5]. Following these steps, the objective of this study was to estimate the feasibility of applying the CHILD-CHII measurement tool on facilities found in the community.

Methods

Study design

This feasibility study was conducted following the guidelines for reporting non-randomised pilot and feasibility studies for development of patient-reported outcome measures [6]. The guideline suggested the combined use of the Consolidated Standards of Reporting Trials (CONSORT) extension to randomised pilot and feasibility trials and CONSORT Patient-Reported Outcomes guideline when conducting and reporting the results of the study [7, 8]. This study was approved by the McGill University Institutional Ethics Review Board and the Center for Interdisciplinary Research in Rehabilitation of the Greater Montreal Ethics Review Board.

Participants

Participants were recruited through maximal representation purposeful sampling. Participants were recruited from each of the four community sectors involved in the definition of community space: Health, Education, Public Spaces, Community Organizations, as described in the previous study of content developed and depicted in the CHILD-CHII framework (Figure 1). The maximum variance purposeful sample included: from the 'Health' sector, rehabilitation clinicians and program managers and staff providing care and services for children with disabilities; from the 'Education' sector, teachers and school administration staff working with children with disabilities; for 'Public Spaces', municipalities staff working in inclusion and family policy; for 'Community Organizations', program coordinators and staff of organizations that offer activities and services for children with disabilities. Participants were contacted through email and asked to consent to participation. A sample size of 2-3 participants per sector was deemed adequate to test the feasibility of the tool.

Measurement Tool

The CHILD-CHII is comprised of three assessments that address different inclusion domains of a single facility (Figure 1). The On-site Assessment consists of 49 items that address the 'Built Environment' and 'Equipment' inclusion domains of the CHILD-CHII. The Organizational Assessment with 25 items and the Macro Community-At-Large Assessment with 27 items address the inclusion domains of 'Programs/Services', 'Staff', and 'Policies' as related to the facility and the surrounding community. As such, the unit of measure is at the facility-level.

Procedures

The three assessments of the CHILD-CHII were provided to the participants as a PDF that could be printed and completed by hand, and as an online version on the Google Forms platform, in both English and French. The CHILD-CHII manual and the Glossary of Terms were also sent to the participants in English and French. The participants were asked to apply the tool on the facility where they work or are affiliated with. After the application of the tool, 30-minute, semi-structured interviews were held with each participant by phone or *Zoom* to discuss their experience applying the tool during which the participants asked to rate each feasibility indicator and expand on their ratings. Each interview was structured similarly, following the four feasibility indicators as the main questions. After the interview, the participants completed a demographic survey.

Measures

The primary outcome was feasibility, measured as four indicators addressing the length of the tool, difficulty obtaining the information in order to respond to the items, clarity of the items in live settings, and value of the tool and the generated information. These indicators were established *a priori* based on important aspects of applying the measurement tool that were brought up during the content development and validation phases of the CHILD-CHII (Yoo et al., submitted). Each feasibility indicator was rated on a 5-point Likert scale (ie. Length- Much too long, …, Much too short; Difficulty- Very easy, …, Very difficult; Clarity- Very clear, …, Unclear; Value- Very valuable, …, Not valuable). Participants had the opportunity to expand on their ratings adding comments. Participants were also asked probing questions related to each indicator that were pre-established during the follow-up interview.

Data Analysis

For the ratings of the feasibility indicators, descriptive analyses were performed to estimate the feasibility of the CHILD-CHII measurement tool. Comments and answers to the probing questions provided by the participants were transcribed and then summarized. From the summaries, suggestions and comments related to the feasibility and refinement of the CHILD-CHII were discussed and the content was analyzed by the first and senior authors.

Results

A total of 12 participants applied the tool on the facilities in which they work. Table 1 displays the participants' characteristics.

Length

All but one participant indicated that the length of the tool was 'Long' (67%) or 'Much too long' (25%) (Table 2). The one participant who thought the length was 'just right', indicated that they were able to answer the items based on knowledge of the facility and assumptions. They were not able to physically go into the facility to assess due to the SARS-CoV-2 (COVID19) pandemic. They did mention that if they were to go and retrieve specific information on the items, it may have taken longer.

The longer time duration was predominantly linked to the scope of the tool with its three assessments, being perceived as too large by the participants. The fact that parts of the tool require information from other sources like coordinators, managers, and potentially community representatives in addition to web searches, made the assessment longer to go and find the appropriate sources who would have the information. Hence, the items that the participants were able to respond by themselves did not take too long but the items that required information from other sources took much longer to obtain. In relation, participants stated that highlighting the type of information that may be required and having examples of the people who may have that information, at the beginning of each assessment, would facilitate the process. Furthermore, making it clear that some parts may be skipped if not related nor applicable to the facility, would also reduce the time taken to complete the index.

The format and sequence of the items themselves were mentioned by the participants in relation to the length; items and sections of items should be arranged so that evaluators can evaluate aspects of the facility in a logical and physical sequence. For example, it was mentioned that having items that require the physical evaluation of spaces that are close to one another should be placed subsequently. As well as items or sections that address specific areas of a facility to be placed in a logical sequence (eg. items related to the parking lot leading to items addressing the entrance to the facility, then to features of the door).

Difficulty

The rating for the difficulty of gathering the required information to complete the tool were quite heterogenous (Table 2). Based on the comments by the participants, the difficulty level was dependent on the evaluator's familiarity of the concepts brought forth in the tool. Participants who were already working in the field of accessibility for their institution found the items easier to obtain information for completion. Additionally, participants in the coordinator or managerial positions as well as government staff were able to respond to items addressing the 'Programs/Services', 'Staff', and 'Policies' inclusion domains without difficulty while clinicians and participants working more directly with children with disabilities found those items more difficult to gather information and respond. However, participants working closer with children with disabilities found it easier to respond to items related to the 'Built Environment' and 'Equipment' inclusion domains.

Clinicians and community organization staff reported that it was easier to respond to the On-site assessment as they were well aware of their specific institution. Participants generally found the Organizational and Macro Community-At-Large assessments more difficult to complete as they did not have access to the information and simply did not possess the knowledge related to the Programs/Services', 'Staff', and 'Policies' inclusion domains; identifying the proper people who have access to the information required to respond to the items in these assessments were reported to be difficult. Subsequently, finding the information to respond to these questions were also reported to be difficult.

Parent participants completed the tool based on their knowledge of the institution and did not apply the tool physically at the site due to the ongoing COVID19 pandemic. Hence, based on this fact, they reported that the completion of the tool was not difficult, but they did foresee its difficulty if and when they would need to apply it in person.

Both clinician and parent participants mentioned that it was and would be difficult to go further beyond their self and close colleagues to obtain the required information. For clinicians, due to the large patient caseload and paperwork already part of their daily work, it was difficult to take the time to obtain all the required information. For parents, they stated that it would be difficult to reach out to other people and research the information while caring for their child with disabilities and other life tasks.

Having the option to complete the tool on the online platform was mentioned to be useful and participants stated that an online version of the CHILD-CHII should be further refined and used in future versions.

Clarity

Eight participants (66%) indicated that the items in the tool were 'Clear' (33%) or 'Very clear' (33%) in what they were asking. Participants reported that access to the glossary was helpful in clarifying some of the terminology (Table 2). One participant who rated the items as 'Somewhat clear' stated that they did not know of the glossary initially and referred to the glossary afterward and mentioned that the glossary did make it clearer. The need for the existence of the glossary to be highlighted in the manual and the tool itself was reported.

It was also mentioned that the purpose and objectives of each assessment type (ie. On-site, Organizational, Macro Community-At-Large) should be clearly stated at the beginning of each section, which will inform and help clarify what the evaluator will be doing and achieving in the particular section.

Participants also found items addressing specific rooms and places of a facility to be unclear in terms of which rooms and places should be considered when responding to the items. For example, for facilities with multiple bathrooms, it was unclear which one should be chosen to answer the items in the 'Bathroom' section. They were unsure if they had to respond for all the bathrooms in the facility or a single one. In most cases, the multiple bathrooms had different levels of inclusive features.

Value

Seven participants (58%) rated the information gathered by the tool to be 'Valuable' (25%) or 'Very valuable' (33%) (Table 2). These participants reported that the tool is valuable for facilities that are looking to make changes in their accessibility and inclusion and gives a good understanding of the current state of the facility and what is in and around it. Participants valued the items and how they built upon one another while addressing the overarching concept of inclusion. One participant mentioned that it was "thought-provoking" and led to reflections on their “own interventions and practices”. The tool itself brought to light some aspects of the facility that are important for inclusion of children with disabilities, but they were not aware of, which they valued. A participant from the government sector mentioned that the tool could be a common platform that connects the different departments within the municipal government- the building department, engineering department, and inclusion department- the assessment would be “helpful to bring everyone together”. Participants also reported that the CHILD-CHII shed light on areas of the facility that they did not previously think about with regards to inclusion of children with disabilities. For example, public transportation routes and accessible signage for getting around inside the facility.

Five participants (42%) rated the information to be ‘Moderately valuable’ (Table 2). These participants were involved in the accessibility/inclusion sphere of their corresponding institutions and stated that they were already aware of most of the things outlined by the tool- “being in the field, [participant] already know the thing that need to be changed”, “tool was not necessarily needed to know what to change”. For community organizations that are solely focused on accessibility and inclusion, “accessibility and inclusion are already considered” and the facility was built on accessibility and inclusion. However, these participants did state that the tool and the information gathered by the tool would be valuable and helpful to facilities that are not involved in the field and require support in establishing accessibility and inclusion.

One interesting theme brought forth by the participants was in regard to the possibility of change and their capacity to make a change. They found that some aspects of the assessment, especially the inclusion domains related to ‘Programs’, ‘Staff’, and ‘Policies’ is “too removed from what [they] can do” and “directly impact”. This theme was more prominent among clinicians and community organization staff who worked more closely on the ground. Some of the aspects of the tool are “beyond the possibility of the institution” or the individual and could be discouraging for the evaluator as some evaluators “do not have the power to make a change”. If the evaluator does not see that they are able to make a change within a certain domain, they may not find “value or worth for the evaluator”; some “would not be able to do anything with the information”. However, participants did find that the results of the tool “can be brought to a higher manager to target and address the gaps that were found” and saw that it can be used to advocate for change.

Clinician and parent participants stated that have more opportunities to comment/describe on certain responses to items would make the tool more valuable. Parents also mentioned that having access to the scores of the facilities in their community would be valuable to access and know and access for their child and family.

Parents highlighted the value of being more specific in addressing the aspects of the facility while the other participant groups found that being too lengthy and out of reach for their scope or sphere of practice could be of less value. Most participants mentioned that the perceived value of the tool and the information gathered would determine the worth of time and effort put into completing the tool.

Discussion

This study aimed to estimate the feasibility of the CHILD-CHII measurement tool and its application on community facilities. Feasibility was estimated as ratings on four feasibility indicators and related comments provided by participants representing each of the sectors in the CHILD-CHII framework (ie. Health, Education, Public Spaces, Community Organizations), after they had the opportunity to complete and apply the tool on the facilities in which they work or are affiliated. The length of the CHILD-CHII was found to be long or much too long by the participants. There was no clear indication of the difficulty of the tool based on the ratings while the comments did offer pertinent and valuable indication of the difficulty. In terms of clarity of the items, most participants found the tool to be clear or very clear. None of the participants rated the tool be not valuable and a majority of the participants rated the value to be valuable or very valuable.

The participant's knowledge, familiarity, and access to the information required to complete the tool were major factors in indicating the feasibility of using and applying the tool, especially with regards to the perception of length and difficulty of applying the CHILD-CHII. This is consistent with evidence indicating that the knowledge, understanding, and familiarity of outcome measures increase the likelihood of their use in practice amongst healthcare professionals [9]. When the participants claimed to have more knowledge about inclusion and accessibility or have worked within the field of inclusion and accessibility, they found that tool easier to apply. All participants mentioned that items/sections addressing aspects that they were familiar with did not take as long to complete. This was also consistent with the individual assessments in the CHILD-CHII as participants who work at the facility, staff working on the ground, found the On-site assessment easier to complete but found the Organizational and Macro Community-At-Large assessments more difficult. While participants in managerial and coordinator roles working closer with policies and planning of services did not find the Organizational and Macro Community-At-Large assessments as difficult to complete. Hence, the familiarity with the concepts and topics addressed by the items in each of the assessments made it easier for the participants to respond.

The time it takes to complete a measure has been found to be a major barrier in its use by both healthcare professionals and community organizations [10, 11]; in both developing and developed countries [12]. With this considered, the reported perceived length of the tool found in this study may suggest a decreased feasibility in applying the tool. However, the participants did state that the perceived value of the tool determines the worth of time and effort required in completing the tool. This is consistent with literature that found that perceived value and relevance facilitates the use of that outcome measure [13]. The importance of each of the items included in the tool was rated and considered in the content validation of the CHILD-CHII which involved participants from multiple stakeholder groups including clinicians, families of children with disabilities, government and community workers [5]. This was further affirmed as all of the participants in this study indicated that the CHILD-CHII was moderately to very valuable, this may indicate a higher affinity to utilize the tool despite the time required to complete the tool. Furthermore, the clarification of each item included in the tool that was also undertaken with the input of multiple stakeholders during the content validation of the CHILD-CHII ensured the clarity of the CHILD-CHII [5].

Having an online version of the CHILD-CHII was found to be beneficial and easier to apply for some participants. The option of completing the CHILD-CHII on a web-based platform can make it more feasible to use and apply for evaluators [14]. Participants actually preferred electronic versions as opposed to paper-based for patient reported outcome measures in a prior study [15].

The context in which the evaluator is functioning (ie. working) could be both a facilitator and barrier to the use of an outcome measure [9, 16]. Organizational factors like the priority and focus on inclusion set by the organization can be increase the use of the measure. Participants working in the inclusion field found that the CHILD-CHII was less difficult to apply. However, some clinicians found that the length of time required to complete the tool would make it hard for them to use the tool as they have other clinical duties and paperwork. Hence, having the organizational support in prioritizing inclusion and allocating time for assessing inclusion of the facility would help with the feasibility of the CHILD-CHII use [9, 10]. This highlights the importance of having an institutional and cultural shift in the prioritization of inclusion and accessibility as integral parts of clinical interventions, and not as an aspect perceived as important. Stakeholders value the use of measurement tools when the tools are useful for their decision-making process [14]. This was evident in this feasibility study as participants in decision-making positions (ie. managers, coordinators, government workers) found that the results of the CHILD-CHII would be beneficial for their facilities and institutions in implementing further actions to improve the inclusion; and as participants mentioned, shed light on areas and aspects of the facility that they did not consider with regards to inclusion. This study showed the potential of the CHILD-CHII providing awareness about detailed gaps and potential areas of action for the inclusion of children with disabilities, how it can be achieved, and where improvements need to be made. In a way, the CHILD-CHII has the potential to highlight the importance and value of inclusion. The detailed aspect of the items can provide specific suggestions that could be included in policies and program planning at the level of the individual child in health and education, and at the macro level of building communities and improving universal accessibility. The measurement of these aspects can generate indicators put forth by all major international agendas and organizations such as the World Health Organization Urban Health Agenda and the International Classification of Functioning, Disability, and Health [17, 18]; the UN CRPD, CRC, and Sustainable Development Goals [1, 2, 19]; and the public health Community Well Being framework [20]. Awareness about how to integrate the CHILD-CHII as indicators into these agendas would further facilitate the use of the tool.

Limitations

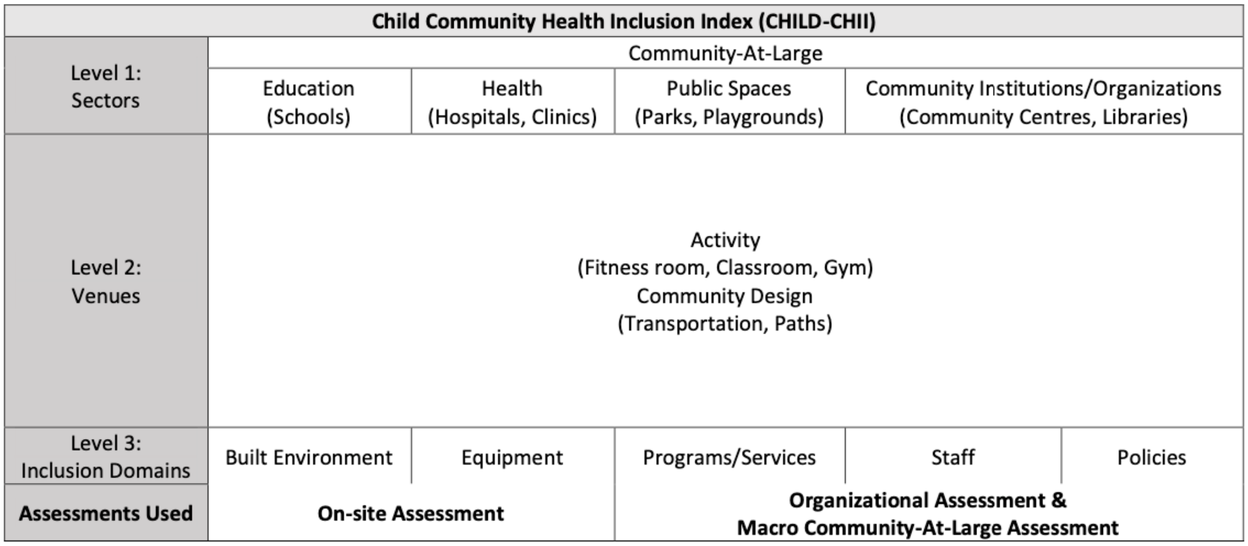
One limitation of this study was the small sample size that was recruited through convenience sampling of participants in Quebec, Canada. Although the results may not be generalizable, as a feasibility study, the sample was adequate to provide good indication of the feasibility of applying the CHILD-CHII while providing important comments that will be implemented in refining the measurement tool. The second limitation is the lack of participants from the Education sector. Although we had clinicians working in the school setting, teachers could not be recruited after much effort. This gap in participation from the education sector may indicate challenges that have been previously identified in Canada: the challenge of coordinating health and education sectors when providing services for children with disabilities, and may also indicate how different sectors prioritize accessibility and inclusion.

Future directions

This study allowed for the testing of feasibility and provided valuable input from eventual target users of the tool. With the modifications made following the suggestions by the participants, a more feasible version of the measurement tool will be utilized in larger field-testing and psychometric studies to further validate the measurement tool. Ultimately, the use of this tool can inform clinicians in the development of interventions, institutions and governments in the development of services and policies that address the inclusion of children with disabilities to foster community participation and healthy living.

Conclusion

The feasibility testing of the CHILD-CHII provided insight on the feasibility of its use in community settings. The clarity of the items in the tool were confirmed to be clear and suggestions were made by the participants to help make the tool easier to complete. Although the length of the tool was regarded as long, the information gathered and provided by the tool was seen to be valuable for community facilities that provide services and programs for children with disabilities. The knowledge, familiarity, and access to the information of the evaluators should be considered and the scope of each assessment should be clearly provided to make it easier for them to use the CHILD-CHII. The perceived value of the measurement tool can be a strong facilitator for its use. The CHILD-CHII can be a valuable tool to inform multiple stakeholder groups including clinicians, parents, institutions, community organizations, and governments in addressing and improving the inclusion of the children with disabilities in the community to foster community participation and healthy living.



Child Community Health Inclusion Index (CHILD-CHII)					
Level 1: Sectors	Community-At-Large				
	Education (Schools)	Health (Hospitals, Clinics)	Public Spaces (Parks, Playgrounds)	Community Institutions/Organizations (Community Centres, Libraries)	
Level 2: Venues	Activity (Fitness room, Classroom, Gym) Community Design (Transportation, Paths)				
Level 3: Inclusion Domains	Built Environment	Equipment	Programs/Services	Staff	Policies
Assessments Used	**On-site Assessment**		**Organizational Assessment & Macro Community-At-Large Assessment**		

Figure 1- CHILD-CHII Framework

Table 1- Participant characteristics

Characteristic		**n**	**%**
Gender	Female	10	83%
	Male	1	8%
Profession/Role	Clinician	3	25%
	Parent	2	17%
	Government	2	17%
	Community	4	33%
	Other	1	8%
Community Sector	Education	2	17%
	Health	3	25%
	Community Organization/Institution	5	42%
	Public Spaces	2	17%
Experience working with children with disabilities	Less than 1 year	1	8%
	1-3 years	1	8%
	4-9 years	3	25%
	10-15 years	1	8%
	16+ years	2	17%
	Not applicable	3	25%
Years working at the current facility	Less than 1 year	2	17%
	1-3 years	1	8%
	4-9 years	2	17%
	10-15 years	4	33%
	16+ years	0	0%
	Not applicable	2	17%

Table 2- Ratings for feasibility indicators

Feasibility Indicator		**n**	**%**
Length	Much too long	3	25%
	Long	8	67%
	Just right	1	8%
	Short	0	0%
	Much too short	0	0%
Difficulty	Very easy	2	17%
	Easy	4	33%
	Neutral	2	17%
	Difficult	3	25%
	Very difficult	1	8%
Clarity	Very clear	4	33%
	Clear	4	33%
	Neutral	1	8%
	Somewhat clear	3	25%
	Unclear	0	0%
Value	Very valuable	4	33%
	Valuable	3	25%
	Moderately valuable	5	42%
	Slightly valuable	0	0%
	Not valuable	0	0%

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Chapter 10: Discussion

10.1 Summary of findings

The overarching objective of this doctoral thesis was to develop a tool to measure the context-based factors that can impact the community inclusion and participation of children with disabilities in the communities where they live. To that end, the CHILD-CHII was developed as a comprehensive measurement tool that identifies and assesses the barriers and facilitators to inclusion in community facilities and environments, that can affect the participation of children with disabilities. The CHILD-CHII was adapted from an existing adult-oriented measure, the CHII. Through the process of development of this tool, the CHII was reviewed, as well as other aspects of the environment that are important for the participation and inclusion of children with disabilities in the community. Items were identified, prioritized, and tested for relevance and feasibility in real community settings. The tool was developed in relation to international indicators of community inclusion with consideration of the Canadian context and was simultaneously developed in English and Canadian French.

The overall process involved a systematic review of the literature about context-based interventions promoting participation and inclusion, which informed the selection of key indicators of inclusion, and the identification of other measures that had related constructs. This review together with retention of relevant items on the CHII supported the content generation for the new CHILD-CHII measurement tool. The items generated were then refined and validated through expert consultation and input from a diverse group of stakeholders. Finally, we conducted a feasibility study by applying the tool in different community settings by community-based evaluators.

Manuscript 1 is presented in Chapter 3 and was a systematic review of evidence on the effects of context-based interventions on the participation of children with disabilities. The aim was to identify factors in the environment that potentially influence inclusion in the community (for item generation). In addition, the outcome measures used in these studies were also reviewed. The systematic review of literature between 2008 and 2021 identified 11 studies that were retained for knowledge synthesis. The outcome measures used in the studies were heterogeneous and the use of participation as an outcome, and its conceptualization were inconsistent. This is consistent with the findings of a systematic review of participation outcomes conducted by Adair and colleagues (Adair et al., 2015). However, each of the interventions in the systematic review conducted for this thesis work, identified systems-level characteristics as described in relation to the domains of the Community Wellbeing Framework, that had a positive influence on the participation of children with disabilities. Ten of the 11 studies in the review had interventions that had aspects related to play, including all the higher-level evidence (I + II) studies. This involved the intervention providing opportunities to participate in play and socialization. According to the CWF, participation in play and opportunities for socialization and social engagement help build social connectedness, and thus reduces isolation (CBOC, 2018). This connectedness helps build a sense of community, belonging, and inclusion, which contribute to overall community wellbeing (CBOC, 2018). This underscored the importance of creating opportunities for children with disabilities to play and socialize, to foster community inclusion.

The systematic review of **Manuscript 1** identified the scarcity of high-level context-based interventions that aim to improve participation of children with disabilities and the outcome measures that were used in the studies were inconsistent. However, the studies that were included in the review emphasized the importance of having dedicated spaces, activities, and opportunities for children with disabilities to participate. They also emphasized the importance of proper staff training, awareness raising, and the development of partnerships between stakeholders involved in disability awareness and inclusion. This study helped underscore the need for a comprehensive measurement tool that identifies and assesses the barriers and facilitators in different community level facilities and environments that affect the participation of children, that can be used consistently in future studies.

To address the need presented above, **Manuscript 2** aimed to identify a comprehensive way to measure community inclusion for children with disabilities and develop the content for this measurement tool. The main objective of **Manuscript 2** was to develop the content of a measurement tool to assess the community health inclusion of children with disabilities in Canada. This was achieved by adapting the original Community Health Inclusion Index to address the specific needs of children with disabilities with consideration in particular to the Canadian context (i.e. the CHILD-CHII).

The content development started with generation of an initial item list for the tool using items from the original CHII and modifying the language to better suit children and spaces frequented by children. Furthermore, a comprehensive literature review of existing measures, checklists, and best practice guidelines addressing community accessibility and inclusion for children with disabilities was conducted. The identified resources and measures, including the outcome measures identified in the systematic review of **Manuscript 1**, were used to generate the initial item list of 759 items. Items were further refined through consultation with an expert panel that included experts on universal accessibility and childhood disability. After a final expert panel consensus meeting, a reduced list of 189 items were proposed. The items generated and refined through the process resulted in a list of items that addressed the diverse needs of children with various disabilities. This process emphasized the need for the items to have a universal design approach, not tailored to one specific disability but considering all abilities.

Similar to the original CHII, the items generated addressed different environmental aspects of community inclusion, extending beyond the physical accessibility of buildings and equipment, to include the design of inclusive programs and services, provision of leisure opportunities, development of sociopolitical infrastructure such as accessible transportation, training of staff and personnel, and attitudes toward disability. This study further highlighted the need for a tool that could encompass all these aspects of community inclusion. This initial development process also made clear the crucial need to validate the items. After a comprehensive item list was generated from multiple sources, it was important to determine which items were most relevant to consider when measuring the inclusion of children with disabilities, and if the items were clear to understand.

Manuscript 3 addressed the content validation process. The main objective of **Manuscript 3** was to establish the content validity and improve the clarity of the CHILD-CHII. This validation process was done through two rounds of a modified e-Delphi technique. In this study, participants from diverse disciplines and backgrounds, with varying levels and types of experience working with disabilities were asked to rate the importance and clarity of each item of the CHILD-CHII. From the 106 items presented to the participants, 101 items were retained through this process. These items were deemed important on the basis of a high degree of consensus among participants. Feedback further highlighted the importance of addressing and measuring the inclusion of children with disabilities in the community. The five items that were rated as low importance were removed because participants deemed them less relevant to the inclusion of children with disabilities (i.e. addressing the existence of vandalism and empty buildings around the facility), were outdated (i.e. existence of public telephone), or redundant (i.e. item addressing transit during peak times that is addressed in another item). Participants also provided input to improve the clarity of the items. This input centred around defining certain keywords, specifying the target audience or location, and using different wording to improve clarity and understanding of what the item is asking. The study underscored the importance and benefit of having diverse stakeholder input in the development and validation of measurement tools so as to enhance usability of the tool.

Following the content validation of the CHILD-CHII, **Manuscript 4** aimed to test the feasibility of applying the tool to diverse community facilities. Feasibility was estimated through four indicators: length, ease of use, clarity of the items, and the value of the information gathered by the tool. A purposeful sample of stakeholders representing different sectors of the community were recruited. Of the 12 participants, 66% deemed the CHILD-CHII to be clear, and suggestions were made by the participants to make the tool easier to complete. The tool was found to be long by 92% of the participants, but nonetheless the information gathered by the tool was considered valuable for community facilities that provide services and programs for children with disabilities. The study confirmed that the perceived value of the measurement tool can be a strong facilitator for its use and the knowledge, familiarity, and access to the information of the individual applying the tool also influence the feasibility of the tool.

Overall, it was found that the CHILD-CHII is a much-needed comprehensive measurement tool of attributes that can contribute to community inclusion of children with disabilities. The tool development process also made evident that stakeholder input was essential in creating a product that is feasible and useful to measure inclusion to limit participation restrictions and as an outcome measure for context-based interventions. The feasibility testing also shed light on important nuances in the practical use of the tool by diverse stakeholder groups including clinicians, parents, and individuals representing institutions, community organizations and governments. Stakeholders in different sectors may use the tool differently to inform program development and evaluation, intervention planning, and policy directions aiming at promoting the participation of children with disabilities in the community and ultimately the creation of inclusive and health promoting communities.

10.2 Original contributions to literature and implications for practice

10.2.1 Overall contributions to knowledge

Children with disabilities have the right to participate and to be included in the communities where they live. The environment surrounding the child plays a key role in their ability to participate (Shikako-Thomas et al., 2008; Anaby et al., 2014). Currently, there is limited evidence of context-based interventions addressing participation of children with disabilities and a scarcity of comprehensive measures for assessing their inclusion in the community. This thesis contributed to addressing this gap by identifying environmental factors that are important for community inclusion of children with disabilities; and then developing, validating, and testing a measurement index of community inclusion for children with disabilities by adapting a validated and reliable measurement tool developed for individuals with disabilities (Eisenberg et al., 2015).

The systematic review that was conducted (**Manuscript 1**), demonstrated the scarcity of literature on context-based interventions. This revealed the limited evidence on the implementation of broader interventions that exist at the systems-level and target the environment where the child lives and functions. The use of the CWF in synthesizing the knowledge helped to frame the characteristics around indicators that contribute to community wellbeing. The majority of the interventions addressed elements of play and socialization, creating opportunities for both, so as to promote an inclusive and connected community (CBOC, 2018). The findings also emphasized the importance of proper staff training, awareness raising, and the development of partnerships between stakeholders involved in disability awareness and inclusion which relate to the social and attitudinal environment surrounding the child. The opportunities for participation are created through the actual built environment, providing an accessible space by all members of the community, including children with disabilities. Additionally, these opportunities are created through programs and services, and policies addressing the needs of children with disabilities.

Although the interventions included in the review partially addressed the environmental aspects that facilitate the participation of children with disabilities, there were no clear indicators that comprehensively outline the environmental aspects that can facilitate participation. The focus was still predominantly on addressing the activity limitations of the child. While focus on activity limitations can lead to improvements at the activity level of the ICF, these improvements do not necessarily result in improved participation (Novak et al., 2013). Thus, this highlighted the need for a comprehensive index of indicators that shift the focus from the child, their functioning and activity limitations, to the environmental factors that are also important in facilitating the participation of the child (ICF) (WHO, 2001). Furthermore, the heterogeneity of the outcome measures that were used in the limited studies emphasized the need for a community-based outcome measure that may guide researchers, clinicians, and policymakers in their efforts to design, implement, and monitor community interventions.

These gaps identified from the systematic review shaped the objective of this thesis. The need for a comprehensive measurement tool that takes into account the environment of the child led to the adaptation of the CHII. The CHII comprehensively examines the aspects of the environment that make the community inclusive of individuals with disabilities so that they can lead healthy and active lives (Eisenberg et al., 2015). While the CHII was developed and validated through rigorous processes, the specific needs of a child with disabilities were not explicitly nor extensively addressed. Additionally, the CHII was developed in the US and a measurement tool specific to the Canadian context (e.g. weather, health and education services, multicultural context, policies) did not yet exist in literature. Hence, the product of this thesis, the CHILD-CHII, provided a transcultural adaptation of the CHII to the Canadian context while simultaneously initiating the translation to French (**Manuscript 2**). Adding to the content of the CHII, a literature review identified five online resources containing practices/guidelines from large government and/or organizational bodies and seven validated outcome measures for accessibility and inclusion. Items generated from the CHII and the identified resources from the literature review were refined to address the Canadian pediatric population. Specific examples of this included: accounting for accessibility of public spaces under extreme weather conditions (e.g. snow, ice), and the jurisdictional governance structure regulating the different community sectors in Canada. For example, the provision of free universal healthcare under provincial jurisdiction, and the provision of public transit services under municipal jurisdiction. In addition, the CHII addressed different aspects of the environment to include five inclusion domains: Built environment, Equipment, Program/Services, Staff, and Policies (Eisenberg et al., 2015). These domains were retained in the CHILD-CHII. Multiple aspects are considered when generating an assessment tool that aims to provide guidance in addressing barriers to participation in the environment. These aspects not only include physical accessibility, but also the design of programs and the sociopolitical infrastructure such as transportation to and from the facility, opportunities for multi-generational leisure, and safety (Dahan-Oliel et al., 2012, Moore and Lynch, 2015). Other aspects often neglected in universal design include negative attitudes of others, lack of adequate services, lack of support from staff and service providers, time, cost, complexity of planning/schedules, and negotiating the environment (Anaby et al., 2013, Mogo et al., 2020). Additional macro-context barriers to community inclusion are lack of information, non-comprehensive policies, limited disability awareness, program costs, and transportation (Bedell et al., 2013, Palisano et al., 2009, Shikako-Thomas and Law, 2015). All these aspects were addressed in the item generation and item refinement process in developing the content of the CHILD-CHII.

10.2.2 Methodological contributions

Stakeholder engagement was key component to this thesis work. Engagement of youth and families, and other stakeholders is being more recognized as essential in elevating the relevance and impact of research (Hoffman et al., 2010). Stakeholder engagement contributes to identifying research questions that are relevant to practice and to addressing real world challenges for children with disabilities, their families, healthcare professionals, and other decision-makers (Esmail et al., 2015). Stakeholder engagement also improves the relevance and transparency of the research endeavour and accelerates the adoption of new knowledge into practice and implementation (Alemanno, 2015). The engagement of stakeholders in all phases of this thesis work such as the research question development, were purposefully integrated in this research and the benefits were evident. The construct of the CHILD-CHII is community inclusion, hence, the target users of the measurement tool were all members of the community that are involved in including children with disabilities in local community-based activities. Therefore, the consultation of experts of childhood disability and universal design in the content development phase (**Manuscript 2**) included clinicians, researchers, as well as parents of children with disabilities and government workers. This provided rich and valuable knowledge and expert guidance when creating the content of the CHILD-CHII. Experts from diverse backgrounds allowed for the consideration of diverse perspectives on what inclusion means. For example, an expert in municipal child accessibility noted that many of the items were suited specifically for children with mobility difficulties and suggested that items should be tailored to children with a broader range of disabilities (eg. visual or hearing loss, cognitive or mental health challenges). Experts working in government suggested further defining some terms that may not be familiar to some user groups. This included, for example, reference to curb cuts or a visual countdown for crossings. As a result of this feedback, a glossary with definitions was created and embedded into the measure. Additionally, an expert in interior design underscored the importance of elements in the interior space, such as lighting and placement of chairs and tables that can more optimally facilitate communication. This diverse yet specialized expertise in accessibility and inclusion allowed for the simplification of items with full consideration of the childhood context and different types of disabilities and their families. For example, items that required specific metric measurement were suggested to be more universal and look at a range of measures starting with the minimum measure attainable for children with disabilities instead of requiring a specific measurement (e.g. height of bathroom sink). In addition, the importance of pictograms and wayfinding was deemed important to facilitate children's agency in using these spaces. The initial engagement of the diverse group of. expert stakeholders in childhood disability and universal accessibility in the content development of the CHILD-CHII contributed to the understanding that stakeholder engagement allows for translatable research that is representative of the perspectives of the population of interest (Kirwan et al., 2017).

Moreover, during the content validation phase of the CHILD-CHII (**Manuscript 3**), a larger group of stakeholders were recruited to validate and clarify the content. Stakeholders including clinicians, teachers, individuals from community organizations and governmental bodies, youth with disabilities, and parents had the opportunity to determine if the items within the tool were indeed important for the inclusion of children with disabilities in the community and should be measured. They also had the opportunity to offer suggestions for modification to improve the clarity of the items. Following the ratings of importance by the participants, the omission of only five items affirmed the value of stakeholder engagement in the content development phase, in representing the perspectives of the population of interest (Kirwan et al., 2017). Furthermore, with increased stakeholder input through the modified e-Delphi technique, the content was validated. This validation phase also underscored the importance of a French language version for use in Canada. Indeed, some items that were clearly understood in the English version were unclear and required modification in the French version. Examples of these included French translation of terms like travel training programs for children with disabilities in the community (systèmes de soutien pour aider les enfants en situation de handicap dans les centres de transport de la communauté) and descriptions of specific elements of adapted playgrounds (e.g. Hauteurs variables à l'usage des enfants, dégagement des genoux permettant l'accès en fauteuil roulant). Stakeholders had input into the creation of a measurement tool that they could ultimately use to assess and enhance community inclusion. Research can be more impactful when the end users are involved from the beginning of the research process (Mitton et al., 2007). In the case of the thesis work, the target users of the measurement tool were involved in the development, validation, and feasibility testing of the tool. As a result, future users of the CHILD-CHII would find this tool user-friendly and meaningful because target user groups were incorporated in its development and validation. Furthermore, stakeholder involvement helped to elaborate uptake strategies that are relevant in the current political context and the system capacity (e.g. infrastructure, technical and human resources) (El-Jardali & Fadlallah, 2015; Lavis et al., 2009). This is important as context-based interventions that address community inclusion and participation of children with disabilities can be in the form of policies and the CHILD-CHII can be used to identify gaps that limit inclusion in the community. This can further inform policymakers in making decisions that are meaningful and helpful to the individuals affected by the policy, (i.e. children with disabilities), and raising awareness on the importance of inclusion and the potential impact on the lives of their citizens.

10.2.3 Contributions to practice and policy

The feasibility testing (**Manuscript 4**) found that the knowledge and familiarity of concepts addressed in the CHILD-CHII facilitated the use of the measurement tool. Interestingly, the knowledge and familiarity of the concepts was evidently different between user groups. Participants in the coordinator or managerial positions as well as government staff were able to respond to items addressing the ‘Programs/Services’, ‘Staff’, and ‘Policies’ inclusion domains without difficulty. In contrast, clinicians and participants working more directly with children with disabilities found those items more difficult to respond to. However, participants working directly with children with disabilities (e.g. clinicians, community organization staff) found it easier compared to coordinators, managers, and government staff to respond to items related to the ‘Built Environment’ and ‘Equipment’ inclusion domains. These findings showed the limited knowledge between those working at the managerial, decision-making level and those working directly on the ground, within communities. The CHILD-CHII aims to addresses community inclusion comprehensively. Hence, the difficulty that these groups faced in completing the tool due to the lack of knowledge about the different domains, suggests the potentially limited nature in the way each group addresses community inclusion of children with disabilities. This discrepancy in the type of knowledge displays the 'silo mentality' that we see in health and social services (Alves & Meneses, 2018). This silo mentality acts as a barrier to communication and information sharing between groups within an organization (Fenwick et al., 2009), which ultimately hinders the quality of service provided to the members of the community (Alves & Meneses, 2018). Clinicians and community organization staff reported that it was easier to respond to the On-Site assessment, as they were well aware of their specific institution. Participants generally found the Organizational and Macro Community-At-Large assessments more difficult to complete as they did not have access to the information and simply did not possess the knowledge related to the Programs/Services', 'Staff', and 'Policies' inclusion domains; identifying the proper people who have access to the information required to respond to the items in these assessments was reported to be difficult. In addressing this difficulty, participants in the feasibility study suggested that the CHILD-CHII provide examples of people who may have the information that is required for the tool (e.g. program coordinators) so that the users of the tool can quickly identify and approach the right people for the information. This in part would facilitate the completion of the tool and foster collaboration between different stakeholders. Collaboration of clinicians and managers have shown increased knowledge, changed attitudes, and improved engagement between the two groups (Houston & Morgan, 2018). The collaboration fostered by the CHILD-CHII and its use can create initial connections and relationships between decision-makers, families, and staff. This can then act as a springboard in collaborative efforts to identify gaps in community inclusion, strategies to address these gaps, and continue to monitor the implementation of these strategies.

For decision-makers within a facility or a community, the CHILD-CHII can be used as a common platform that connects different departments within governments or institutions (e.g. the building department, engineering department, and inclusion department) that have roles to play in creating an inclusive community. Having a common reporting method with contributions from different government agencies has been suggested to improve collaboration between the agencies (Ryan & Walsh, 2004). Participants in decision-making positions who applied the CHILD-CHII in the feasibility study (**Manuscript 4**) found that the results of the CHILD-CHII would be beneficial for their facilities and institutions in implementing further actions to improve the inclusion while shedding light on aspects of the facility that they did not consider with regards to inclusion. Stakeholders value the use of measurement tools when the tools are useful for their decision-making process (Boyce et al., 2014). The CHILD-CHII can indeed be useful for decision-making processes. It can also be used to raise awareness about the inclusion of children with disabilities, how it can be achieved, and where improvements need to be made. In a way, the CHILD-CHII has the potential to highlight the importance and value of inclusion, which would further facilitate the use of the measurement tool. Ultimately, it can initiate and supplement an institutional and cultural shift in the prioritization of participation and inclusion of children with disabilities, within a facility, institution, and/or community.

The CHILD-CHII adopts many elements of the frameworks that have been found in literature and outlined in this thesis with regards to community inclusion, specifically the ICF. The CHILD-CHII and its items have become and can be used as tangible indicators of the domains found in these key frameworks that are essential for health, participation, and inclusion of children with disabilities. The ICF is a framework for “describing and organising information on functioning and disability” and “recognizes the role of environmental factors in the creation of disability” (WHO, 2001). It aims to provide a conceptual and scientific basis for measuring and studying health and disability related outcomes (WHO, 2001). The CHILD-CHII is a comprehensive, rigorously developed tool that captures the fundamental elements of the ICF as they relate to environmental factors that determine health and disability. The CHILD-CHII structure closely aligns with the ICF framework, and its items address the components or subdomains within the ‘Environmental Factors’ element of the ICF. These subdomains include ‘Products and Technology’ which includes equipment and technology in an individual’s immediate environment (WHO, 2001). This subdomain is addressed in the CHILD-CHII as the ‘Equipment’ inclusion domain with items such as “Is adaptive equipment available for children with disabilities to participate in given activities?” and “Are there opportunities in the community for children with disabilities to access computer technology and technology services?”. The ‘Natural environment and human-made changes to environment’ subdomain of the ICF is addressed as the ‘Built environment’ inclusion domain of the CHILD-CHII through items addressing the presence of ramps and automatic doors at the entrance, and items related to the use of large print and high-contrast lettering for signage found in the facility. The ‘Support and relationships’, ‘Attitudes’ subdomains of the ICF are addressed as the ‘Staff’ inclusion domain with items like “Are staff provided any type of disability awareness training either on-site or through outside education?” and items addressing the disability training for staff. The ‘Services, systems and policies’ subdomain of the ICF is addressed as the ‘Programs/Services’ and ‘Policies’ inclusion domains in the CHILD-CHII with items addressing the presence of inclusive policies, staff training policies, and the involvement of children with disabilities and their families in policymaking. The CHILD-CHII can act as both a map and recipe in navigating through the ‘Environmental Factors’ domain of the ICF. Evaluators using the tool are led through the different subdomains by being invited to assess the different environmental aspects of a community facility. While responding to the items, the evaluators are guided through both the built space of the facility and the inner workings of its governance- from the parking lot to the main entrance, to the shared spaces, to the bathrooms; then through the organization of the facility- from the staff to the activities and programs provided by the facility; then finally through the community-at-large surrounding the facility- from public transportation to policies and policymaking. Through this guided tutorial, the CHILD-CHII sheds light on aspects of the environment that may not have been considered before with regards to inclusion of children with disabilities and helps the evaluator reflect on how these aspects can act as barriers and facilitators to participation in these spaces. This in turn can provide a different perspective of the environment and how it is used by those with disabilities (Parent, 2016).

The CHILD-CHII can help directly respond to the articles and measures outlined in the Convention Rights of Persons with Disabilities (CRPD). The main objective of the CRPD is to promote, protect, and ensure the full and equal enjoyment of all human rights and freedoms by all people with disabilities, including children (UN, 2006). The CRPD recognizes that disability is an evolving concept resulting from the interaction between the individual with disabilities and the attitudinal and environmental barriers that hinder their full and effective participation in society (UN, 2006). It also recognizes the importance of accessibility to the physical, social, economic, and cultural environment to enable the individual with disabilities to participate fully in the community.

Article 7 of the CRPD affirms the importance of taking all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms. Article 7 is considered by the CHILD-CHII as the measurement tool outlines specific features in the environment that can facilitate participation of children with disabilities within an inclusive community. Specific items address the existence of opportunities for leisure, healthcare, education, work, transportation, technology, and socialization.

Article 8 calls for awareness measures in the form of public campaigns and training programmes in order to combat stereotypes and negative attitudes towards individuals with disabilities and to promote positive perceptions, social awareness, and recognition of their merits and abilities. Items such as "Are staff provided any type of disability awareness training either on-site or through outside education?" and items that address disability awareness and attitudes toward children with disabilities are in relation to this article.

Article 9 calls for appropriate measures to ensure the individuals with disabilities have equal and full access to the physical environment, transportation, information and communications, and to public facilities and services in the community; specifically, to implement standards and guidelines for the accessibility of public facilities and services, to train stakeholders on accessibility, and to develop accessible information and communications for individuals with disabilities (UN, 2006). Article 19 calls for the equal right to live in the community with equal choices with appropriate measures to facilitate full inclusion and participation in the community. Like Article 7, the CHILD-CHII and its items can act as guidelines to ensure equal and full access to the elements outlined in Article 9 and full inclusion and participation in the community as outlined in Article 19.

With these articles calling for the recognition of the rights of individuals with disabilities, the CRPD also states that nations that have ratified the Convention shall designate one or more focal points within their government and establish a framework to implement and monitor the implementation of the Convention. Specifically, Article 35 calls upon the nations that have ratified the CRPD, to submit reports to the Committee on the measures that have been adopted to recognize the rights of persons with disabilities, including children, and the progress made to date in relation to each of the 54 Articles. In 2010, Canada ratified the CRPD and has since made its initial report in 2014 (CCD, 2014). The CHILD-CHII can be used as one of the instruments to monitor the implementation of the CRPD. The CHILD-CHII and its inclusion domains address many of the Articles outlined in the CRPD and suggests ways in which the Articles can be acted upon and implemented in society. Monitoring these rights involves the "systematic collection and evaluation of comprehensive evidence about the extent to which rights are being protected, promoted, and fulfilled" (DRPI, 2010). It includes steps in: 1) the collection of information; 2) legal and information analysis; and 3) documentation and reporting/corrective action and follow-up (UN, 2010). The use of the CHILD-CHII can inform the process of collecting information. Specifically, the collection of information on policies and programs, and the opportunities for participation experienced by children with disabilities in the community (UN, 2010). It can also inform the process of analyzing the information to determine if the Articles of the CRPD are being respected and fulfilled in the community (UN, 2010). Finally, it can inform the process of reporting and follow-up by providing a structured tool in gathering and presenting the information related to inclusion of children with disabilities. Article 33.3 of the CRPD requires "civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process". As the CHILD-CHII has been developed for diverse users including parents of children with disabilities, and community organizations, the CHILD-CHII can be used to monitor the implementation of CRPD while upholding this specific article with regards to persons with disabilities and representative organizations participating in the monitoring process.

Article 4.3 of the CRPD calls for nations to "consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations" in all aspects of implementing the Convention, including policy development processes and independent mechanisms (Hoffman et al., 2016). This was upheld in the stakeholder engagement that took place in the development of the CHILD-CHII tool, as specified above. With regards to community inclusion in Canada, civil societies like the Council of Canadians with Disabilities (CCD) and other organizations are and should continue to be involved in communicating and directing future policy development, decisions, and implementation. For children with disabilities and their families, focus on the best interests of the child can support the creation of health, education and social services that respond to their needs, allocating resources to the most pressing issues indicated by children and families, valuing their priorities, and raising awareness about persistent rights violations (Shikako-Thomas & Shevell, 2018). The relevance and importance established by the involvement of these implicated groups would facilitate the implementation and continuation of policies surrounding community inclusion and participation, because they have stemmed from a real, direct, immediate need. These implicated groups can also be clinicians working in the units, on the floors; teachers and educators interacting directly with students with disabilities. These implicated groups are those that navigate through and experience first-hand, the barriers and facilitators found in the environment. The CHILD-CHII can provide these groups with the tool to comprehensively and logically assess their surrounding environments. It can identify the gaps that need to be addressed in terms of inclusion and have a validated outcome to present these gaps to decision makers in order to promote change. This can empower parents, families, clinicians, teachers, and those who may not have a direct method to make systems-level changes to their facilities and communities. Active engagement of these implicated groups can help shape research and communication with policy (Mogo et al., 2020) The combination of research, stakeholder input, and organized information through a policy dialogue can inform community programming and policy development (Mogo et al., 2020). The CHILD-CHII can be a means to facilitate dialogue between these groups and decision-makers in the facility or community.

Knowledge, familiarity, and access to information were found to be key facilitators in the feasibility of using the CHILD-CHII (**Manuscript 4**). The CHILD-CHII can also provide knowledge, familiarity, and information regarding community inclusion within a facility to its users. This can empower the evaluators and target users to initiate discussions surrounding inclusion of children with disabilities, present environmental gaps, and offer systems-level solutions. In the recent development of the Accessible Canada Act, it was found that the participation of people with disabilities in policymaking through meaningful engagement and clear communication can empower them to provide meaningful, relevant feedback in the policymaking processes (ARCH, 2021). Participation in the process is critical in ensuring that policies address the needs of people with disabilities and achieve real improvements in accessibility and inclusion for people with disabilities across Canada (ARCH, 2021). It has been found that stakeholders' knowledge of the policy and regulation processes lead to better stakeholder engagement in policy development (Moon & Baker, 2012). With the use of the CHILD-CHII, groups that are directly impacted by barriers in the community can help inform the development of policies that will impact them.

The items of the CHILD-CHII also align closely with the international and national efforts to improve the social determinants of health- specifically, education, social support, social opportunities, physical environments, childhood experiences, and access to health services (Canada, 2013). In the 'Explanatory hemisphere' of the Canadian Framework for Social Determinants of Health and Wellbeing among children with neurodisabilities and their families, policy and structural dimensions and community assets and environmental dimensions are two of the four determinants of health and wellbeing (Filipe et al., 2021). The 'Policy and structural dimensions' include policies and programs for children with disabilities; the 'Community assets and environmental dimensions' refer to the characteristics of the environment surrounding the child and the family (Filipe et al., 2021). The CHILD-CHII can be used to assess these two dimensions by responding to the items in the five inclusion domains (Built Environment, Equipment, Programs/Services, Staff, and Policies) for a given community facility. It can then inform strategies in the 'Action-oriented hemisphere' where the need for change can be identified at the organizational level, community level, and macro-systemic level (Filipe et al., 2021). Each level can be informed by the On-site Assessment, Organizational Assessment, and Macro Community-At-Large Assessment of the CHILD-CHII. Hence, the CHILD-CHII can be used as a comprehensive parameter for communities, institutions, governments, and community facilities to develop actionable strategies to improve inclusion, and ultimately health of children with disabilities by addressing its social determinants in the environment.

The information collected by the CHILD-CHII by different user groups can provide diverse and valuable perspectives on the needs of children with disabilities (Willis et al., 2016). This information can be readily available to be used at the 'windows of opportunity' or priorities set by a government that make specific information more relevant or timely (Snare, 1996). A recent article regarding the promotion of physical and leisure participation for children with disabilities highlighted the windows of opportunity that exist now (Mogo et al., 2020). These windows include:

1. The increased global focus on inclusion and equity as reflected in the UN Sustainable Development Goals ("Sustainable Development," 2017).

2. The increased recognition of rights-based approaches in Canada including Canada's recognition of the Convention on the rights of the child ("Rights of the Child", 2017) and Canada's first report on the Convention on the Rights of Persons with Disabilities.
3. The presence of the Interdepartmental Working Group on Children's Rights ("Government of Canada," 2017), co-chaired by the Public Health Agency of Canada and the Department of Justice, Canada, which aims to promote a collaborative approach to children's rights that facilitate the necessary intersectoral linkages.

Hence, the CHILD-CHII is timely in its development and usage in efforts to identify gaps in the implementation of the CRPD and CRC that call for full inclusion of children with disabilities, to inform the creation of strategies and best practices in upholding these conventions and promoting inclusion, and to help monitor the implementation these strategies over time.

The ongoing collaboration with stakeholders in a participatory research approach drove the entire process of this thesis work. A group of stakeholders that are collaborators and participants of other research projects that were conducted in parallel to this thesis work greatly informed its steps. This project was developed initially in the context of the Jooay App project, that consists of an established research group that has parents of children with disabilities, community organizations, and other policy and community stakeholders. These stakeholders have been continuously engaged in finding solutions to promote participation at the community level for children with disabilities. Stakeholders were engaged in the identification of the research question- in particular, the involvement in the creation of a municipal accreditation process of creating child-friendly cities in Quebec with the Accréditation Municipalité amie des enfants, led to the discovery of the CHII measurement tool and the subsequent perceived need for a specific community inclusion measurement tool for children with disabilities (Espace Muni, 2021). Additionally, a rapid review conducted for the City of Montreal on good practices in universal accessibility supplemented the literature review for the content development of the CHILD-CHII (Cardoso et al., 2021). These peripheral research projects helped create partnerships and identify key stakeholders that were needed in the development of the CHILD-CHII. With the objective of creating a comprehensive measure that takes into account multiple aspects of the environment, these stakeholders, particularly in the realm of policy and government, were instrumental in the development and validation of the tool.

Concurrently, a large portion of this thesis work was being conducted and completed during the precarious and uncertain landscape of the SARS-CoV-2 (COVID-19) pandemic and its challenging and unprecedented implications. This led to the development of rigorous approaches to unconventional methods of research and shed light on the power of informal communication and relationships. Specifically, a research project on the usage of the Jooay mobile app during COVID-19 pandemic (Yoo et al., 2021), and another on the perspectives of community organizations and parents on online leisure activities (Movahed et al., in preparation), highlighted the potential of social media and mobile applications in identifying stakeholders and recruitment of participants. Hence, many of the stakeholders that were recruited through convenience sampling for this thesis work were collaborators in other projects that were conducted in parallel to this thesis work. With the nature of the inclusion as a construct and disability research requiring the input and engagement of stakeholders, collaboration with known civil society groups, municipalities, community organizations, and parents were critical. Additionally, with the COVID-19 pandemic, many of the stakeholders were understandably occupied with the proximal challenges of the pandemic. Hence, the efficient utilization of time, effort, and resources was also crucial in conducting these studies. All of these initial challenges also provided opportunities to understand the reality of measuring constructs in the "real world" of community organizations and policymakers. The priorities shift rapidly, and research and measurement must be flexible to adapt and respond to these new demands. This work during the pandemic revealed the reciprocal nature of collaboration with stakeholders and the need for researchers to be attentive and sensitive to the needs of the stakeholders. The pandemic also revealed the priorities of certain sectors of the community. With the immediate risks and threats of the virus and the restrictions of the pandemic, it was difficult for many community sectors to consider the participation and inclusion of children with disabilities as was found during the recruitment process and the overall conduct of the validation and feasibility testing of the CHILD-CHII. The conduct of this thesis work and the participation (or lack of) stakeholder groups in the research during the COVID-19 pandemic, further highlighted the need to include marginalized groups, such as the disability advocates, and children and youth, in the development of new strategies and solutions during emergency responses and in future community life (Pineda & Corburn, 2020). These needs should be considered in future development and psychometric testing of the CHILD-CHII, and brought to the elaboration of programs and services for children with disabilities.

10.3 Limitations

This thesis work and its studies have their limitations. The interventions studied in **Manuscript 1** as well as the development of the CHILD-CHII measurement tool did not consider the specific needs of children with mental health disorders/psychological impairments. Additionally, the CHILD-CHII does not take into consideration the environment most proximal to the child, the family. Family-level characteristics have been found to influence the association between neighbourhood environments and children's development (Minh et al., 2017). This deliberate choice of assessing the macro environment is practical (there are already a large amount of items to be considered with the community environment) but has a theoretical underpinning as the ICF has distinct items for the community environment and the family environment (WHO, 2001). Several measures exist addressing the Family environment and the most proximal constructs of the child, whereas fewer instruments exist assessing the community environment.

Furthermore, the tool does not extensively take into consideration the socio-demographic factors including the intersection of ethnicity, socioeconomic status, gender, and family structure of the surrounding area which has been found to have an influence on child health development (Minh et al., 2017; Christian et al., 2017). However, the CHILD-CHII and the results of the tool can be utilized to present the potential impacts of these underlying factors on a child's health, participation, and inclusion in the community.

The participants who took part in the development process of the CHILD-CHII, outlined in **Manuscript 2, 3, 4**, were recruited through convenience sampling which can limit the generalizability of the results. Concerted efforts were made to actively recruit and consult all key stakeholder groups in the different community sectors, but limitations in data collection during the COVID-19 pandemic limited our ability to reach for some specific groups like schools. Though convenience sampling is a widely used method for expert consultation and the Delphi method, we must acknowledge that the participants recruited to represent the different community sectors of the CHILD-CHII (i.e. Health, Education, Public Spaces, Community

Organization/Institution) do not comprehensively represent the Canadian population and the specific community sectors. Additionally, in the development process, only one youth with disabilities partially participated (i.e. First round of the Delphi technique outlined in **Manuscript 3**) which was a limitation in having the input of youth with disabilities in the development of a measurement tool that addressed their needs.

The limited number of French-speaking participants in the content validation (**Manuscript 3**) and feasibility testing (**Manuscript 4**) process may also be a limitation. The simultaneous creation/translation process is perceived as a methodological advantage (Salbach et al., 2006). However, the French translation of the CHILD-CHII, the clarity of the items and the feasibility of the tool in French may need further development/evaluation.

10.4 Directions for future research

Through this thesis work, the CHILD-CHII measurement tool was developed, and its content was validated through stakeholder input. The tool was then tested for feasibility by eventual target users of the tool. Following the suggestions made in the feasibility study, further refinements will be made for a more feasible version of the CHILD-CHII. This version will be utilized in larger scale field-testing which will include further psychometric studies. The quality of a measure is often determined by the reliability, validity, and responsiveness of the measure (Gadotti et al., 2006). According to COSMIN, reliability is “the extent to which scores for patients who have not changed are the same for repeated measurement under several conditions: for example, among the items (internal consistency), over time (test–retest), by different persons on the same occasion (inter-rater) or by the same persons (i.e., raters or responders) on different occasions (intra-rater)” (Mokkink et al., 2010). Following the norms established in the literature, future studies should be conducted to determine the reliability of the CHILD-CHII. Validity consists of content validity which is the degree to which the content of the measure is an adequate reflection of the construct to be measured (Mokkink et al., 2010). For the CHILD-CHII, content validity was ensured through consultation of expert panels in the content development and validation through the modified e-Delphi technique. Construct validity is “the degree to which the scores of a health-related patient-reported outcome instrument are consistent with hypotheses (for instance with regard to internal relationships, relationships to scores of other instruments, or differences between relevant groups)" (Mokkink et al., 2010). Analysis to determine construct validity should be included in future studies. Responsiveness is the ability of a measure to detect change over time in the construct to be measured (Mokkink et al., 2010). To determine responsiveness, future pre-post studies should be conducted with the CHILD-CHII as the primary outcome measure, where the intervention involves changes to a facility to enhance inclusion (e.g. renovation). With further rigorous testing of the measurement properties, the CHILD-CHII can potentially be the gold standard upon which other measures can be tested for criterion validity. With further validation and testing of the CHILD-CHII, community inclusion can be regarded as an outcome and construct that are considered for interventions, service-deliveries, expenditures, and policies.

Future research should also aim to address the inclusion of children with disabilities in a context-based and systems-level approach. This would include interventions that are implemented at a larger, systems-level that target the physical, attitudinal, and institutional environment of the child. These studies should utilize frameworks such as the CRPD and CWF to aid in the creation and implementation of the interventions. An outcome measure such as the CHILD-CHII should be used to measure inclusion as an outcome in high-level studies to ensure consistency in literature and allow for better knowledge syntheses and systematic analyses.

10.5 Concluding statement

Community inclusion is an essential outcome to consider and promote when it comes to providing opportunities for participation in the community and enhancing the health of children with disabilities. Furthermore, it is a fundamental human right upheld by the United Nations' CRPD and CRC. Frameworks like the ICF, CRPD and CWF exist to ensure the inclusion of children with disabilities in all aspects of life, including community life. This is done by laying down the important elements that should be considered and should be present in the environment of the child. The CHILD-CHII is a measurement tool that comprehensively identifies and assesses the barriers and facilitators in community facilities and environments that affect the participation of children with disabilities. It was developed, validated, and tested for feasibility with extensive input from stakeholders who will be directly using or who will be impacted by the use of the tool. The CHILD-CHII is a measurement tool that is well-aligned with the aforementioned frameworks. The appropriate and effective measurement of community inclusion using the CHILD-CHII can be used to estimate child's inclusion in the community, and to inform existing organizations and facilities regarding the inclusiveness of their facilities. It can be used to identify areas that can be targeted for interventions with aims to increase inclusion of children with disabilities. Furthermore, the tool can be used as an outcome measure for future studies to explore context-based, systems-level interventions targeting facilities and communities, opening up new avenues for research with inclusion as the outcome.

The CHILD-CHII resulting from this thesis work has generated indicators that can contribute to advancing the implementation of the CRPD in support of community inclusion for all, regardless of age and disability. More broadly, the CHILD-CHII can be used to inform future health promotion research and initiatives that target outcomes beyond individuals, to communities, to transform systems and societies.

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