Developing and Validating a Self-reported Measure to Comprehensively Capture the Participation Patterns of Transition-aged Youth and young-adults with a Disability Across Different Environmental settings

A thesis submitted to McGill University to the Faculty of Graduate Studies and Research in partial fulfillment of the requirement for the degree of Doctor of Philosophy

by

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Abbreviations	
ASD	Autism Spectrum Disorder
CAPE	Children's Assessment of Participation and Enjoyment
FUNDES-Child	Functioning Scale of the Disability Evaluation System—Child version
ICF	International Classification of Functioning Disability and Health
INCOME	Imagining, iNforming, Choosing, Obtaining, Maintaining, and Exiting
LHCD	Life Course Health development
Life-H	Assessment of Life-Habit
PAC	Preference for Activity of Children
PEM-CY	Participation and Environment Measure for Children and Youth
POPS	Participation Objective, Participation subjective
PROMs	Patient-Reported Outcome Measures
QYPP	Questionnaire of Young People's Participation
Y-PEM	Youth, young-adult Participation and Environment Measure

Abstract

Introduction: Young people with disabilities face many participation restrictions, which can adversely affect their quality of life and transition to adulthood. The environment is key in facilitating participation and in promoting successful transitioning. Thus, outcome measures that identify participation patterns and the impact of the environment on participation during this challenging transition phase are needed. **Objective**: This study aimed to: 1) develop a self-reported measure, Youth, young-adult Participation and Environment Measure (Y-PEM), that comprehensively captures participation of individuals aged 12-30 across different settings: home, school, community, and workplace; and 2) examine its measurement properties in terms of reliability, validity, and utility. **Methods**: Inspired by the Participation and Environment Measure for Children and Youth, items were developed, and content validity was examined. Specifically, a multi-phase sequential design involving five consecutive rounds of in-depth cognitive interviews with 24 youth aged 12-33 ($\bar{x}$ = 20.9; n = 19 with physical disabilities) combined with expert consultation (n = 15) were conducted. To evaluate Y-PEM's initial measurement properties and aspects of utility (perceived value and burden), 113 participants (n = 56 with physical disabilities) aged 12-31 ($\bar{x}$ = 23) completed the Y-PEM and QQ-10 to evaluate utility using an online survey during COVID-19. To establish construct validity, differences in participation levels and environmental barriers/supports between those with (n = 56) and without (n = 57) physical disabilities, matched by age and sex, were examined via t-test. Internal consistency was computed using Cronbach's alpha. To examine test-retest reliability, a sub-sample of 70 youth completed the Y-PEM a second time, 2 to 4 weeks apart, and Interclass correlation was computed. To further explore the Y-PEM utility, especially of the newly developed workplace participation domain, four focus groups with stakeholders (n = 11) were

conducted. Thematic analysis was performed. **Results**: Based on cognitive interviews with youth, age-appropriate activities including dating, caregiving, preparing meals, driving, and a work participation domain, were added. Internal consistency ranged from 0.71- 0.82 across all scales except for workplace (0.61) and home (0.52) frequency. Test-retest reliability ranged from 0.70 - 0.85 across all scales except for school environmental supports (0.66) and workplace frequency (0.43). Descriptively, Y-PEM showed lower levels of frequency and involvement across all four settings among youth with disabilities with significant differences in all scales at the home and fewer scales in the community and workplace. With respect to utility, assessed by the QQ-10, youth (n = 113) perceived the Y-PEM as a valuable tool with relatively low burden. Thematic analysis describing stakeholders' views on the utility of Y-PEM workplace participation in different contexts, revealed three themes: (a) it captures *multiple factors in employment transition;* generating insights and sparking conversations to better appreciate and support transitioning to employment (b) it meets the *need for tools to guide services of transitioning to employment* as it comprehensively assesses participation and the environment, and provides a "snapshot" of the youth in their transition and (c) it *provides a piece of the pie* within this complex process and can be used in conjunction with other tools. **Conclusions:** The Y-PEM is a broad and practical self-reported tool capturing participation and environmental barriers/supports to participation in a range of activities that tap into the transitioning phase and across different settings. Findings provide initial support for Y-PEM measurement properties, especially its reliability and potential ability to guide transition-focused practices. Further testing of Y-PEM among other populations and during non-adverse times is needed.

Résumé

Introduction: Les jeunes avec incapacités font face à des limitations à la participation, ce qui nuit à leur qualité de vie et transition à la vie adulte. L'environnement de ces jeunes est essentiel pour encourager leur participation et faciliter cette transition. Or, des méthodes d'évaluations mesurant l'impact de l'environnement sur la participation sont nécessaires. **Objectif**: Cette étude vise à: 1) développer un questionnaire autodéclarée nommée, Mesure de la participation et de l'environnement des adolescents et des jeunes-adultes (Y-PEM), qui évalue la participation des jeunes de 12 à 30 ans dans différents contextes (maison, école, communauté et lieu de travail) et 2) évaluer sa fiabilité, validité et utilité. **Méthodes**: Inspirés de la Mesure de la Participation et de l'Environnement pour les Enfants et les Jeunes, des questions ont été créées et leur validité ont été examinée. Cinq séries d'entrevues cognitifs avec 24 jeunes (12-33 ans) ($\bar{x}$ = 20,9; n = 19 avec incapacité physique), combinées avec une consultation d'experts (n = 15) ont été menée. Pour évaluer les propriétés de mesure initiales du Y-PEM et ses aspects d'utilité (valeur perçue et fardeau), 113 participants (n = 56 avec incapacité physique) de 12-31 ans ($\bar{x}$ = 23) ont rempli le Y-PEM et QQ-10 en ligne durant la COVID-19. Pour établir la validité conceptuelle, les différences dans les niveaux de participation et les barrières/soutiens environnementaux entre les personnes avec (n = 56) et sans (n = 57) incapacités physiques, appariées selon l'âge et le sexe, ont été évaluées avec un t-test. La cohérence interne a été calculée avec de l'α de Cronbach. Pour examiner la répétabilité, un sous-échantillon de 70 jeunes ont complété le Y-PEM une deuxième fois, 2-4 semaines d'intervalle, et la corrélation interclasse a été calculée. Afin d'explorer l'utilité du Y-PEM, quatre groupes de discussion avec des parties prenantes (n= 11) ont été menés. Une analyse thématique a été effectuée. **Résultats**: Sur la base d'entrevues cognitives avec des jeunes, des activités adaptées à l'âge, notamment les fréquentations, les soins, la préparation des repas, la

conduite, ainsi qu'un domaine de participation au travail, ont été ajoutées. La cohérence interne variait de 0,71-0,82 sur toutes les échelles, sauf à la fréquence de la participation au travail (0,61) et à la maison (0,52). La répétabilité variait de 0,70-0,85 sur toutes les échelles, sauf sur les soutiens environnementaux scolaires (0,66) et la fréquence de la participation au travail (0,43). Le Y-PEM a montré des niveaux de fréquence et d'implication plus faibles dans les quatre contextes chez les jeunes avec incapacités avec des différences significatives à la maison. En ce qui concerne l'utilité, évaluée par le QQ-10, les jeunes (n =113) ont perçu le Y-PEM comme un outil précieux avec un faible fardeau. L'analyse thématique décrivant les opinions des parties prenantes sur l'utilité de la participation au travail dans différents contextes a révélé trois thèmes: (a) *il saisit de multiples facteurs dans la transition vers l'emploi*; génère des idées et suscite des conversations pour mieux apprécier et soutenir la transition des individus vers l'emploi (b) *il répond au besoin d'outils pour guider les services de transition vers l'emploi,* car il évalue la participation et l'environnement et (c) *il fournit une « part du gâteau »* dans ce processus complexe et peut être utilisé en conjonction avec d'autres outils. **Conclusions**: Le Y-PEM est un outil autodéclarée pratique qui saisit la participation et les obstacles/soutiens environnementaux à la participation à une gamme d'activités qui visent la période de transition à la vie d'adulte et dans différents contextes. Les résultats montrent que la fiabilité et la capacité potentielle du Y-PEM sont acceptables pour les pratiques axées sur la transition à la vie d'adulte. D'autres études parmi d'autres populations et pendant des périodes plus favorables sont nécessaires.

Preface

Thesis Organization and Overview

This PhD includes four manuscripts with the overall objective of enhancing an existing proxy-reported participation and environment measure intended for children aged 5 to 17, the PEM-CY, as a self-reported comprehensive measure for older individuals, i.e., youth and young adults aged 12-30, labelled the Y-PEM, comprising an additional new domain of work participation. This thesis also focuses on evaluating the measurement properties of the Y-PEM in terms of reliability, validity, and utility. In this thesis, manuscript 1 synthesizes existing evidence on the impact of the environment on competitive work participation of youth and young adults with disabilities through a scoping review methodology. Manuscript 2 describes the process and methodology of developing and validating the content of the Y-PEM for youth and young adults aged 12-30, including a newly developed workplace participation domain. Manuscript 3 illustrates aspects of the utility (in terms of value and burden) of the Y-PEM from the perspectives of the target population and provides initial evidence on the measurement properties of the Y-PEM (with respect to reliability and validity) for use by youth and young adults. Manuscript 4 details the utility and usefulness of the newly developed workplace participation domain in informing practice among employment-related service providers.

Chapter 1 presents the introduction and comprehensive review on relevant literature regarding the main concepts of this thesis. Notably, these include the definition of youth and young adults, transitioning to adulthood for people with disabilities, and participation. Additionally, current evidence on the perspectives of youth with disabilities and their parents on the process of transitioning to adulthood and its challenges, impact of participation on transition outcomes, and factors that impact participation is presented. The challenges of evaluating

participation, and factors to consider when evaluating participation are further explored with a special focus on the impact of the environment. Finally, the unique features of the PEM-CY in the context of existing measures are explored.

Chapter 2 presents the rationale and objectives of this thesis.

Chapter 3 presents the first manuscript titled "Environmental Factors that Impact Workplace Participation of Transition-Aged Young Adults with Brain-Based Disabilities: A Scoping Review" which is published in the *International Journal of Environmental Research and Public Health (IJERPH)*.

Chapter 4 bridges manuscripts 1& 2.

Chapter 5 presents the second manuscript titled "Development and Content Validity of the Youth and young-adult Participation and Environment Measure (Y-PEM)" which is published in *Disability and Rehabilitation.*

Chapter 6 bridges manuscripts 2 & 3.

Chapter 7 presents the third manuscript titled "Reliability and Validity of the Youth and young-adult Participation and Environment Measure (Y-PEM): An Initial Evaluation" which has been submitted to *Physical & Occupational Therapy in Pediatrics.*

Chapter 8 presents additional post-hoc analysis of data that provides further support to the construct validity of the Y-PEM not published in manuscript 3.

Chapter 9 bridges manuscripts 3 & 4.

Chapter 10 presents the fourth manuscript titled "Utility of the Workplace Participation domain of the Youth and young-adult Participation and Environment Measure (Y-PEM): Stakeholder's Perspectives" which has been accepted for publication in the Journal of Vocational Rehabilitation.

Chapter 11 presents the summary and a comprehensive discussion of all the findings.

Chapter 12 presents the conclusion of this project.

Contribution of Authors

The doctoral candidate serves as the first author of all four manuscripts presented here. Specifically, Ms. Saeideh Shahin conducted the write up for the initial drafts of all the manuscripts and integrated feedback from all members of the advisory committee, Drs. Anaby, Ahmed and Di Rezze, in the final drafts. Data collection and analysis (i.e., both statistical and thematic analysis) were led by the doctoral candidate under the supervision of Dr. Dana Anaby.

With respect to the first manuscript of this thesis, i.e., scoping review, Ms. Shahin co-developed the search strategy and co-executed it, synthesized the data, and drafted all sections of the manuscript. Ms. Meagan Reitzel took part in screening the literature for the inclusion of articles, assisted with coding and categorizing the information, and edited the final version. Drs. Ahmed and Di Rezze reviewed the manuscript and provided feedback. Dr. Anaby critically reviewed the paper and provided extensive feedback to improve the quality of the article for publication. The second and third manuscripts were co-authored by all members of the supervisory committee. Dr. Ahmed and Dr. Di Rezze advised on the methodology used and our approach to data analysis, reviewed the manuscripts, and gave constructive feedback to prepare the manuscripts for publication. Dr. Anaby's guidance and ongoing feedback throughout the process ensured that the manuscripts were of quality and ready for publication. In the fourth manuscript, Drs. Ahmed, Di Rezze and Anaby advised on the methodology used and provided feedback. Ms. Mallory Ryan assisted in co-facilitating some of the focus groups, coding the transcripts, and refining the themes.

Statement of Originality

I declare that this thesis is an original report of my research, has been written by me and has not been submitted for any previous degree. All the assistance received in preparing this thesis has been acknowledged.

This project is a direct extension of the work done at the ASPIRE lab, led by Dr. Anaby, focusing on studying the concept of participation and the development of participation-based measures and interventions. The products of this project are the result of my own work with the support of my supervisor Dr. Dana Anaby, co-supervisor Dr. Sara Ahmed and academic advisor Dr. Briano Di Rezze. The contents of chapters 3, 5, 7, and 10 are original and provide an important contribution to the field of rehabilitation. This work yielded a new tool called the Y-PEM, a self-reported outcome measure modeled after the PEM-CY (with permission), which uniquely targets individuals aged 12-30 years old. Furthermore, the Y-PEM, particularly its addition of a workplace participation domain, is innovative and has significant implications to practice and to transition-related services for youth and young adults with physical disabilities.

The Y-PEM has direct application for researchers, clinicians and community service providers working with youth and young adults during their transitioning phase. This tool not only allows for a firsthand evaluation but also for a comprehensive assessment of youth and young adults' participation patterns and the impact of the environment in four settings: home, school/educational setting, community, and the workplace. With initial evidence for its reliability, validity, and aspects of utility, as illustrated in this thesis, the Y-PEM can be used in research to gather information about young person's participation patterns, their transition needs and goals, as well as the strategies they use to promote their participation in each setting. Clinicians and transition-related service providers can also use the Y-PEM to identify

participation areas that require attention, as well as environmental barriers that affect participation. Such detailed information can guide decision-making and client-centered intervention planning. In addition, the Y-PEM allows for a broad evaluation of youth and young adult's participation in the workplace, from work preparation activities to actual work activities, while considering the environmental barriers/supports to participation in this important domain. As such, this tool affords a structured method to evaluate participation at work with the purpose of supporting young people in the process of pursuing their career aspirations.

Chapter 1: Comprehensive review of the relevant literature

Youth and Young Adults

According to the United Nations, the term 'youth' refers to individuals who are in a period of transition between their childhood to adulthood's independence [1]. It is during this period that youth go through physical and psychological maturation and are expected to develop the necessary skills for successful transitioning to adulthood. The age range of 15-24 years old is often used to categorize the youth population [2]; yet, this age range has been broadened due to factors such as a rise in unemployment and high living costs that prolong the dependency of youth on their families. These factors depend on the country, culture, region, and socioeconomic status of the individual [3]. The lower age-band has also been extended since children enter their teenage years and start gradually acquiring rights and responsibilities as early as the age of 12 [4]. In fact, in Canada, youth and young adult refer to individuals aged between 12-29 years old to capture this important developmental stage [5].

Transitioning to Adulthood and Disability

The period of transitioning to adulthood is complex, and can become even more challenging for individuals with disabilities, adversely affecting their participation patterns [6,7] and, consequently, their quality of life [8]. Prevalence of disability among youth and young adults in Canada is more than 13% and this rate increases with age [9]. The most recent data collected on people with disabilities in Canada show that adults with disabilities are only half as likely to continue to postsecondary education and to obtain a university degree compared to adults without disability [10]. Among the working-age population (25-65 years old), only 59% of those with a disability are employed, compared to 80% of those without a disability [9]. Additionally, more Canadians with disabilities live in poverty (14.4%) compared to those without disability

(10.5%) [11]. As such, difficulties in transitioning to adulthood is one of the most pressing issues (and a priority) among young people with disabilities that requires special attention [12].

The literature reveals a shift from the traditional view of transition from the pediatric to the adult healthcare system to a more holistic and multi-dimensional understanding of this concept [6,13]. Transitioning to adulthood is now marked by a gradual change in status and the acquirement of new responsibilities across a range of participation domains such as employment, postsecondary education, independent living, community engagement, and satisfactory personal and social relationships [1,14,15]. The International Classification of Functioning Disability and Health (ICF) also includes the participation domain of "recreation and leisure, religion and political life" in the list of typical roles that adults acquire [16]. From the perspectives of youth with disabilities and their parents, successful transition to adulthood further involves developing skills required for participation and daily functioning such as managing finances, cooking, communicating socially, navigating the community, and having the necessary strategies and knowledge to maintain a job [17,18]. In other words, for youth with disabilities and their families, gaining autonomy while using available supports, and participating to their full potential in age-related and meaningful activities is indicative of success in adulthood [17,19].

Acquiring and maintaining employment is a key indicator of successful transitioning and one of the most important goals for youth as young as 15 years old [20]. In a study among people with intellectual disabilities, the most frequently reported successful outcome of transition by youth and their parents (65.2%) was having an occupation or a functional role in society [17]. Similar results were found for youth with Duchenne muscular dystrophy [21], physical disabilities [22] and other complex disabilities [23]. Despite work participation being defined as engaging in competitive employment [24,25], for youth and their families, any paid, unpaid,

volunteering and/or supported employment opportunities is considered having a vocation [17]. Beyond having an employment, youth and their parents recognize that finding a job, applying for a job and attaining job-specific skills and training are important aspects of transitioning to employment [17]. This view is reflected and endorsed by the INCOME (Imagining, iNforming, Choosing, Obtaining, Maintaining, and Exiting) career development framework [26]. In this framework that is specifically designed for people with disabilities, the sequence of steps (i.e., imagining, informing and choosing) that lead to obtaining employment is highlighted. However, despite the known benefits of early work exposure and volunteering [27], youth and young adults with disabilities lack opportunities that allow them to develop the necessary skills for acquiring employment [22,28]. Particularly, compared to their typically developing peers, youth with disabilities need help to address barriers in seeking employment and develop skills that prepare them for work (e.g., job interviews) [29].

Transitioning to Adulthood: A Person-Environment Fit

Transitioning occurs within numerous systems and environments (e.g., healthcare, school, home, and the community) and involves youth themselves, their family, peers, organization and community members, services, governments, and the society [12,13,15,30]. Researchers have attempted to capture this multi-dimensional and complex concept through contemporary models such as the Multifaceted Role Engagement model [31], and the Life Course Health development (LHCD) model [32]. These models emphasize the importance of the environment and the person-environment fit on transition outcomes [31,32]. It is without say that youth's personal factors; physical and mental abilities, motivation, values, and interests play a role in their transitioning [33]. However, it is the interaction between personal and environmental factors that regulates successful participation in adult roles [18,34]. This multi-layered level of

influence from systems, that are most often out of the spectrum of intervention by rehabilitation professionals or pediatricians, greatly affect the outcomes of transitioning to adulthood. Therefore, the support of and collaboration between diverse stakeholders (i.e., pediatrician, rehabilitation specialist, employment-related service providers and employers in the community, families of youth, etc.) across different settings (i.e., home, educational, community, workplace) is needed to ensure that youth's transition needs are met across the lifespan [35].

Transitioning to adulthood is a long lasting process that needs to begin early in childhood and should continue into adulthood [15,36]. Many of the transition issues that youth with disabilities face are rooted in their early childhood [37]. Children must be involved in their own daily activities as much as they are able to be as it is during this period that they learn the essential basic skills needed to perform different activities [38]. Reducing activity limitations and participation restrictions in children and youth with disabilities is particularly important as this has a mediating impact on acquiring adult social roles later in adulthood [38]. In fact, participation in different activities during childhood sets the stage for the child to find their interests, strengths, and occupational self-concept [39]. In their review of the transition process of youth with Autism Spectrum Disorder (ASD) from school to adult life, Hendrick & Wehman (2009) denoted that students must begin this process between the ages of 10 and 13. On a similar note, the LCHD approach promotes the development of health capacity, during early childhood through early adulthood [12,32,40]. The importance of early intervention has also been demonstrated in the Life Needs Model in which relevant services and programs are proposed to be offered continuously from the moment the child is born to their adulthood [39]. In that regard, early, integrated, and comprehensive services that span multiple settings, are more likely to lead to better transition outcomes among children and youth with disabilities [31]. To that end,

outcome measures intended for transition-aged individuals must be applicable and consider the different environmental contexts in which participation occurs to facilitate collaboration and communication between different stakeholders.

The Importance of Participation to Transitioning

Participation is defined by the ICF as "involvement in different life situations" [16]. Recent studies suggest that interventions that are focused on participation may improve mental health including emotional, social and psychosocial well-being [41]. Despite the known benefits of participation, children and youth with disabilities experience greater participation limitation when compared to their typically developing peers [42-44]. More specifically, youth with disabilities engage in less diverse and more passive activities when compared to their peers without disabilities [43,45]. Additionally, the participation patterns of youth with disabilities declines as they age. To illustrate, a longitudinal study among individuals with cerebral palsy [48], aged 16 to 34, indicated that their participation deteriorated as they move into their late 20s in the following major life areas determined by the ICF: Education and employment, recreation, community life, interpersonal relationships, and housing. Similar trends were found among young people with autism during the transition to adulthood [46,47]. In that regard, capturing participation patterns in settings that are most pertinent for transition-aged youth such as the home, educational setting, community, and the workplace is paramount to understanding youth's experiences and needs in this complex process.

Participation in meaningful activities has significant implications for transitioning to adulthood [23,32]. Participation restriction in important life areas among children and youth with disabilities translate into significant limitations in acquiring desired roles in adulthood [32]. For example, involvement in community activities during adolescent years increases the likelihood

of volunteering and acquiring employment later in life [47,48]. Subsequently, real-life experiences in the community and gradual integration into the adult world through volunteering in different institutions (i.e., church, clubs and political organizations) facilitate transition to adult roles and increases youth's likelihood to be a more active member of the society [34]. In fact, one of the strongest predictors for competitive employment in adulthood is gaining real-life experiences by participating in extracurricular and community activities, and engaging in career awareness training when still in high school [49]. Furthermore, for many, engaging in secondary education is an important means in securing employment which in itself is a critical step to gaining financial and social independence [50].

Given the importance of participation in the development and growth of children and youth with disabilities, participation has become one of the main rehabilitation goals for this population [45]. Participation needs of youth and young adults in age-related and meaningful activities must be addressed to improve transition outcomes. Indeed, a study that explored the viewpoints of parents of youth with ASD, revealed that transition outcomes are mostly affected by the participation and activity element of the ICF, in addition to the environmental factors [51]. To that end, psychometrically sound outcome measures that evaluate participation and the environment are needed [52]. Such measures must accurately assess and guide transition-related goal setting across different contexts [53], inform intervention planning, and evaluate the effectiveness of such interventions [18]. Participation is a complex and multi-dimensional construct that is affected by multiple factors, making its evaluation challenging. The next few sections attempt to explain what needs to be considered when evaluating the construct of participation.

What Factors Affect Participation

Participation is a complex concept that is affected by several personal factors. Sex, age, severity of impairment, youth's preferences, motivation, and interests are characteristics that impact participation in different activities [45,54]. For example, with respect to recreational participation, female-youths participate more frequently in social, and skill-based activities when compared to male-youths who spend more time in physical activities [42]. Additionally, participation declines at around 12 years of age as children move to their teenage years [45,46]. Youth's participation is also influenced by their physical abilities and severity of injury [55]. In general, youth with greater physical and cognitive limitations experience more challenges to participate in important life areas such as in leisure activities, domestic life, personal care and relationships [56]. Thus, to capture the participation profile of youth and young adults, participation-based outcome measures must contain appropriate domains and activities that are related to a wide age-range to account for the temporal factor associated with youth's participation pattern [57].

The environment plays a vital role in either facilitating or hindering participation [44,58,59]. Despite the presence of limiting personal factors (i.e., physical impairments, low expectation of self, and lack of adequate communication skill), the negative impact of environmental barriers on transitioning is often more pronounced [6]. In fact, previous research indicates that the environment can intensify or alleviate the impact of severity of disability on participation [44]. In a qualitative study done in Canada, 34 people with physical disabilities between the ages of 18-30 were asked to reflect on their adolescent years to identify the barriers and facilitators that they faced in their journey to adulthood [6]. In this study, participants described that transition occurred within the physical, social, cultural, and institutional contexts.

They listed physical inaccessibility, others' attitudes, lack of real-life opportunities and experiences, lack of peer support, and lack of adequate programs and services among the many environmental obstacles that they faced in their transitioning. The importance of the environment, particularly the person-environment fit was highlighted in another study capturing youth and parents' views on transitioning [17]. Similar results were found with regards to the complex process of transitioning to employment [25]. Considering environmental factors are therefore essential for promoting participation [6] and successful transitioning [12]. In fact, current research has demonstrated that modifying aspects of the environment have positive outcomes on the participation of youth and young adults with physical [60-62] and developmental disabilities [63]. As such, the environment must be evaluated when assessing participation as in many cases it is an easier target for intervention than personal factors [44].

Participation – A Challenging Concept to Define and Operationalize

Participation is a difficult concept to measure as it is complex and multidimensional; and it is affected by many different personal (values, interests, gender, age, etc.) and environmental factors (accessibility, social support, attitudes, availability of resources) [58,64]. To add to this complexity, researchers do not agree on a standardized definition of participation [65]. As a result, there is a lack of consensus on how participation should be evaluated [66]. Most researchers critique the way participation is introduced in the ICF. They argue that presenting "participation" and the "activity" constructs in the same chapter creates confusion about the difference between the two concepts and suggests a lack of an explicit explanation of participation [65,67]. Moreover, there are no clear guidelines in the ICF, nor norms, to describe what is meant by "life situations" when describing participation [57]. A distinct "participation" definition is particularly important to develop valid measurement tools which contain items that

reflect all the unique aspects of the participation construct. This clarification will also allow researchers to operationalize and choose adequate scales to measure this construct [66].

To address the lack of an adequate participation conceptual framework, researchers proposed different alternatives to the definition offered by the ICF. In an editorial written about the ICF, Wade and Halligan [68] depicted that participation is the performance of roles in the societal context. Similarly, Whiteneck & Dijkers [69] specified that activities are performed in isolation, while participation occurs in the presence of others. Consequently, the authors proposed to divide the list of the nine domains/chapters presented in the ICF into two distinct lists, with the following 3 domains pertaining to specifically the participation construct; these included: 1) interpersonal interactions and relationships, 2) major life areas including social roles of homemaking for others, parenting of children and caregiving for others, and 3) community, social and civic life. However, defining participation from a sociological lens in terms of one's social roles is not the ultimate solution to the standardization of this term as social roles are not independent from one's context, beliefs, and culture [52]. Additionally, young people often function within their families [66,70]. Hence, conceptualizing participation as a social construct cannot be sustained as it is expected that children and youth, especially in their early years, will inevitably be involved in life situations with the presence of others [66].

In conjunction with the studies presented previously, the term community integration was argued to reflect the meaning of participation as defined by the ICF [71]. Community integration was used by many researchers interchangeably when referring to participation. This term implied being part of a network, belonging to a group, and performing roles that were culturally acceptable [52]. Brown et al. [71] claimed that measures of community integration that focus on age-related roles at home, school and the community can be used to evaluate participation.

Despite the importance of personal preferences on participation outcomes, such measures did not take the individual's values and goals into account [71]. This was not in line with evidence showing that participation was greatly affected by the individual's subjective experience; namely their motivation, preferences, desire, values, interests and satisfaction [54,70]. In fact, optimal or successful participation was more closely linked to the level of satisfaction and enjoyment rather than the intensity and diversity of participation [66]. Therefore, measures of community integration may not accurately capture the essence of participation.

To advance our understanding of this complex construct, some suggested that youth with disabilities and their parents should be involved in describing what optimal participation means for them [52,70]. Youth with disabilities might have different perspectives from social norms and their non-disabled peers [70]. In a qualitative study, children and youth with brain-based disabilities and their parents reported that successful participation involved experiencing fun, and a sense of accomplishment either in the presence of others or independently [72]. This perception of successful or optimal participation was distant from the objective or quantity aspect of participation that most researchers and clinicians often focused on. In other words, it seemed that the number of activities and the intensity of engagement in the activity did not reveal much about the level of participation [66]. It was indeed the feeling of satisfaction and enjoyment during the activity that gave meaning to this concept. As such, gaining insight on the perspectives of youth with disabilities, can contribute to the development of standard and more accurate frameworks of participation for this population. This can further guide the content of participation-based assessment tools, which most often do not reflect theoretical definitions of participation [65].

Certainly, involving youth with disabilities and their parents in the development of participation-based measurement tools can greatly help bridge the gap between such tools and

theoretical definition of participation. The content of the PEM-CY, which has gained international popularity, translated to over 20 languages, has been developed through in-depth interviews with parents of children and youth with and without disabilities [73]. This tool captures participation in activities that were deemed pertinent, using scales that were relevant for parents of children and youth with and without disabilities [59]. Such a method can be especially useful in identifying meaningful areas of participation from the perspective of youth with disabilities. This knowledge can guide researchers to develop measures that reflect the perception of people with disabilities, and further guide practitioners' interventions in participation areas that are meaningful as reported by this population.

One of the most recent frameworks that attempted to conceptualize participation is the family of Participation-Related Constructs (fPRC) [65]. This framework was developed based on a systematic review conducted by Imms et al. [65] that examined 25 participation-related studies. The fPRC identified *attendance* and *involvement* as the two essential components of participation. According to their work, attendance (or 'being there') quantifies participation and can be evaluated objectively through an observation of the frequency, range or the diversity of the activities that youth participate in. Involvement (or 'being in-the-moment') is the qualitative component of participation and must be evaluated subjectively in terms of the individual's "motivation, persistence, social connection, and level of affect" [65]. The systematic review by Imms et al. [65] identified 4 additional constructs that were not synonymous, but closely related to participation in the literature: activity competence, sense of self, preference, and context/environment. In this framework, it is shown that participation occurs within an environmental context and is affected by the activity competence (i.e., skills required to participate), sense of self (i.e., self-esteem, confidence), and preference (i.e., choosing

meaningful activities to participate in) of the individual. The individual's context incorporates elements that affect their ability to participate such as the affordability, accessibility, and availability of services, adequate accommodations, as well as accepting and feeling accepted in that setting [65].

A systematic review that mapped existing participation-based measures for children and youth based on the fRPC, revealed that most participation-based outcome measures do not directly assess participation [74]. Nearly half of participation-based measures that are frequently used in research (e.g., the Assessment of Life-Habit [Life-H]) predominantly evaluate the activity competence construct rather than participation. Other measures such as the Questionnaire of Young People's Participation (QYPP) intended for youth aged 14-21 years capture solely one aspect of participation, in this case "attendance," measured through a frequency scale documenting how often an activity is done [75]. The Participation and Environment Measure for Children and Youth (PEM-CY) [59] is one of the rare examples of an outcome measure that evaluates the essence of participation through both the frequency and involvement scales while taking the environment/context or setting into account. However, one of the limitations of this tool is that involvement is rated through a proxy and therefore does not necessarily reflect the subjective experience of the youth themselves [74].

How to Measure the Concept of Participation Focusing on the Setting and the Environment

Despite the lack of consensus in the conceptualization of participation, many attempted to provide a comprehensive list of domains that pertain to this concept to facilitate the application and evaluation of participation in clinical and real-life situations. A recent content analysis of studies examining the theoretical concept of participation, in addition to patient and expert interviews, listed the following 14 characteristics and domains of participation covering the

transition-age period: (1) Assisting others, (2) Interpersonal relationship and communication, (3) Education, (4) Work and employment, (5) Economic life, 6) Religion and spirituality, (7) Political life and citizenship, (8) Role, (9) Others: participation cannot be done alone, (10) Domestic life, self-care, looking after one's health, (11) Leisure and recreation, (12) Subjective participation, (13) Environment: social, cultural, and temporal, and (14) Community life [76]. Notably, most of the proposed domains are congruent with those suggested by the World Health Organization in the ICF [16,70]. Accordingly, most participation-based measurement tools (e.g., Life-H, QYPP) are somewhat in line with the participation and activity chapters of the ICF [16,52]. While these domains are important areas for examination, most participation-based measures do not comprehensively evaluate the environment, despite its importance when capturing participation [74,76,77].

Participation occurs within an environmental context. Research has shown that environmental factors can either facilitate or hinder opportunities to participate in everyday life [44,58]. For example, youth with physical disabilities may be able to participate in supportive settings but face many restrictions to participate in the same activity in an unsupportive setting [73]. To capture the contextual factors that impact participation, the PEM-CY is structured by setting rather than by participation domains [59]. That is, the PEM-C Y evaluates typical activities that are specific to the home, school, and the community settings. The PEM-CY is unique in its ability to effectively capture the specific features of the environment, including aspects of the social, cultural, physical and institutional environment pertaining to each setting [59]. This approach facilitates the assessment of participation areas that need attention while identifying environmental barriers/supports. Such knowledge promotes interventions that occur in real-life settings and that target aspects of the environment that improve participation [31,59].

The Importance and Current Emphasis on Patient-Reported Outcome Measures

According to a recent scoping review done in 2020 [78], most of what is known about young people's participation is about their attendance, rather than their involvement and experience. This could be explained by an underuse of Patient-Reported Outcome Measures (PROMs) that capture the first-hand experience of service users in outpatient rehabilitation [79]. While youth as young as 12 are reliable self-responders [8], in many cases participation-based measures for children and youth with brain-based disabilities are rated through observations and proxy ratings [74]. Although the objective component of participation (i.e., attendance) can be evaluated through such methods [70], its subjective component (i.e., involvement) must be reported by the youth themselves. In fact, direct observation or proxy ratings may not be fully reliable when evaluating intrinsic factors such as one's level of enjoyment, involvement, or satisfaction [80]. Hence, it is important to ask the youth/young adult whenever possible, as they are the best person to report on their subjective experience derived from participation [72]. Additionally, self-reported questionnaires, in line with PROMs, significantly contribute to evidence-based practice and improved patient care by strengthening patient involvement through client-centered interventions [81]. Therefore, to further address the current gaps in knowledge and capture the full profile of young people's participation, self-reported measurement tools must be accessible, age-appropriate, comprehensible, and easy to complete by this population [70,82].

Which Scales Should be Used?

Participation is a multi-faceted concept. This makes it difficult to identify one appropriate scale for its evaluation. As previously mentioned, a comprehensive assessment tool must encompass both the subjective and objective components of participation using separate scales [65]. The ICF suggests that participation can be objectively quantified using the performance qualifier which

they define as the “lived experience” of an individual within their natural environment. This qualifier determines the level of difficulty when performing the activity on a scale of 5 points (0 = no difficulty, 1 = mild difficulty, 2 = moderate difficulty, 3 = severe difficulty, 4 = complete difficulty) [16]. It is argued that the subjective experience of the individual during the performance is not captured in this qualifier [52]. Therefore, as aforementioned, it is suggested to include an additional qualifier of “involvement” or “satisfaction” to evaluate the subjective experience of participation [16]. Few assessment tools evaluate both the subjective and objective components of participation. Examples include the PEM-CY (intended for children and youth aged 5-17 years old) [59], Life-H (covering the lifespan from 0-99 years old) [83], Children's Assessment of Participation and Enjoyment (CAPE) and its companion measure Preference for Activity of Children (PAC) (intended for children and youth aged 6-21 years old) [84], and the Participation Objective, Participation subjective (POPS) (intended for those aged 18 years and above) [71].

Different approaches have been used to evaluate the objective component of participation. As proposed by the fPRC, attendance can be evaluated through frequency scales and/or through the range or diversity of the activities in which the child or youth participates [65]. Frequency scales which are widely applied, mostly evaluate the number of times (or how often) the child takes part in an activity. For example, the PEM-CY and CAPE evaluate frequency on a 7-point scale (from daily to never) indicating “how often” the child participates in the activity [59,84]. This scale can yield a diversity score illustrating the number of activities done. The QYPP evaluates frequency of participation with up to seven different response options for each item [75]. The recently developed Functioning Scale of the Disability Evaluation System—Child version (FUNDES-Child) measure which is a parent or proxy-report evaluates

participation frequency (“0= the same with or more than age-expected, 1= somewhat less than age-expected, 2= much less than age-expected, and 3= never does") as well as independence (“0= independent, 1= with supervision/ mild assistance, 2= with moderate assistance, and 3= with full assistance”). This tool is intended for children and youth aged 6-18 years old [85]. Considering that there are no norms or standard scales to evaluate the objective component of participation, scores generated by this scale should be carefully interpreted.

Several scales are available to evaluate the subjective component of participation that is closely related to motivation, satisfaction, preference, interest and choice [52]. The fPRC [65] refers to this as involvement. Involvement is captured by the PEM-CY for instance using a 5-point scale (1= minimally involved, 5=very involved) [73]. The Life-H, on the other hand, evaluates youth and young adults’ satisfaction in relation to their performance on a 5-point scale from “very satisfied” to “very dissatisfied” [83]. The CAPE/PAC, however, inquiries about the youth’s enjoyment on a 5-point scale (1= not at all to 5=love it) and preference “the child’s desire to participate in the activity if he or she could do anything in the whole world” [84]. Clearly, it is challenging for one single measure to evaluate all the subjective components of participation [52]. Thus, youth (together with clinicians) must choose which aspects of the subjective experience is most relevant to them and researchers may want to select scales that best fit with their desired outcomes.

A range of different scales are used in current participation-based measures to capture other relevant information. As previously described, some assessment tools evaluate participation on more than two scales. For example, the CAPE/PAC also evaluates where and with whom the child participates in the activity. The respondent identifies if the child performed the activity alone, with close family, other relatives, friends, or others, at the home, relative’s

home, neighborhood, school, community, and beyond the community settings [84]. The PEM-CY evaluates the child's desire for change (yes/no) and type of change desired (do more/ less often, be more/ less involved, be involved in a broader variety of activities) [59].

Many of the measurement tools claim to evaluate participation, but they do not include scales that underlie the construct of participation as identified by the fPRC [65,74]. For example, while the Life-H generates important information regarding the activities that youth and young adults engage in, it fails to adequately portray the level and pattern of participation as suggested in the literature. More specifically, gaining knowledge about the level of difficulty and assistance that a child needs to perform an activity and their satisfaction closely speaks to the *activity competence* related construct of participation rather than the core participation constructs identified by the fPRC [65]. As such, youth and clinicians must carefully choose which tools to complete or administer, as some measures solely evaluate participation-related constructs, rather than the essence of participation [74].

The Unique Features of the PEM-CY in the Context of Existing Measures

Existing participation-based measures mainly cover the age range of 0-18 (e.g., YC-PEM and PEM-CY) and 18-90 (e.g., POPS) years old, without much attention to the participation profile of youth in their transitioning phase, currently defined as 12 to 30 years old. Other participation measures targeting the transition period (or at least part of it) such as the Life-H [83], the QYPP [75], and the CAPE/ PAC [84] do not directly assess environmental barriers and facilitators that impact participation [86]. This observation was further supported through a scoping review on participation measures in rehabilitation [87]. Furthermore, despite employment being one of the main outcomes of transitioning among people with disabilities and known to be influenced by the environment [64], participation-based measures that cover the transition phase, do not

comprehensively evaluate work participation nor include the multitude aspects of the environment pertinent to work. For example, the range of work-related items in the Life-H includes seeking a small job, performing small paid or unpaid jobs, and doing volunteer work [83]. The QYPP contains items related to formal and informal jobs as well as spending breaks with colleagues and attending work-related social events [75]. Similarly, among participation-based measures aimed for adults, work participation is often included in measures of community integration and is not captured comprehensively [25,77]. Additionally, although people with various disabilities often face similar challenges in work, work participation is not evaluated in a consistent way [25,77]. Such measures, as aforementioned, are also limited in their ability to evaluate environmental barriers and facilitators that impact work participation [77].

The PEM-CY addresses many of the challenges in the evaluation of the concept of Participation. According to *A comparative content review of children's participation measures* by Chien et al. [88], the PEM-CY is the only comprehensive assessment tool with the highest percentage (88%) of the items assessing the concept of participation. This psychometrically sound [89] outcome measure was developed based on extensive conceptual analysis from focus groups [73] and tested on more than 500 parents of children and youth with and without disabilities [89]. While its content is congruent with the participation domains suggested by the ICF, the PEM-CY is uniquely structured by settings. It evaluates relevant and age-appropriate activity sets (or clusters) in three different settings: home, school, and the community. Twenty-five items (or activity sets) in the PEM-CY cover the range of activities that pertain to each specific setting. For example, "personal care management," "getting together with other people," "household chores," "arts, crafts, music, and hobbies" reflect some of the activities that children typically do at the home setting. Similarly, "classroom activities," "field trips and school events,"

"getting together with peers outside of class," "and "special roles at school" are among activities usually done in the school setting. As for the community, participating in "neighborhood outings," "community events," "organized physical activities," "unstructured physical activities," and "classes and lessons" are listed activities that pertain to this setting. Each item contains a range of examples pertaining to that category or 'activity set' [59]. This outcome measure not only covers the full breadth of the participation domains as introduced by the ICF, it also assesses environmental factors such as the physical layout and accessibility, attitudes, social support and the resources available to the child and the family in each setting. Specifically, the home setting contains 12 environmental items, the school/educational setting contains 17 environmental items, and the community setting has 16 environmental items [16,88].

Another advantage of the PEM-CY is that it directly assesses the underpinning constructs of participation through the frequency and involvement scales as outlined by the fRPC. To capture the frequency of participation, parents are asked to rate "how often" their child participates in an activity in the last 4 months. Frequency is scored on a 7-point scale (0 = never, 1 = once in the last 4 months, 2 = a few times in the last 4 months, 3 = once a month, 4 = few times a month, 5 = once a week, 6 = few times a week, 7 = daily). To capture the child's involvement, parents rate how involved their child is in the activity. The PEM-CY defines involvement as engagement in the activity while using whatever supports, assistance, adaptations, or methods that the child needs. The child's initiative, interest and satisfaction also relate to the involvement construct scored on a 5-point scale (1 = minimally involved, 2, 3 = somewhat involved, 4, 5 = very involved). The PEM-CY includes another original scale to capture parents' desire to see change in their child's participation. Desire for change is captured in terms of change desired (yes/no) and type of change desired (more/less often, more/less

involved, or be involved in a broader variety of activities). This scale has significant implications for clinicians and service providers as it is indicative of parents' satisfaction with their child's participation. This scale can further guide family-oriented goal setting and intervention planning. The PEM-CY is also unique in its ability to comprehensively evaluate environmental barriers and supports on a 4-point scale (1 = not an issue / not needed, 2 = usually helps / usually yes, 3 = sometimes helps, sometimes makes harder / sometimes yes, sometimes no, 4 = usually makes harder / usually no) [59].

Despite its advantages, the PEM-CY has some limitations. This population-based outcome measure is a parent-reported questionnaire. Therefore, it may not accurately capture the subjective component of participation that is evaluated in terms of involvement [80]. Moreover, the PEM-CY, which is commonly used in pediatric rehabilitation is intended for children and youth aged 5-17 years old [59]. As such, it does not fully capture activities and settings (i.e., work) that are important for this stage in life. Participation-based measures intended for youth and young adults in their transitioning must assess a wide range of activities (i.e., work, caring for others, dating, etc.) to capture the full profile and changing participation patterns of this population [57]. A psychometrically sound self-reported outcome measure that evaluates the environment and the essence of youth and young adults' participation across different settings will significantly contribute to the field of rehabilitation, particularly transition-related services. Such an outcome measure can contribute to service providers' understanding of the complex process of transitioning. It can further guide specific transition-related goal setting and intervention planning [53], and potentially facilitate communication and collaboration between different stakeholders to promote participation and improve transition outcomes [33].

References

1. (UNDESA), U. N. D. o. E. a. S. A. (n.d). Definition of youth https://www.un.org/esa/socdev/documents/youth/fact-sheets/youth-definition.pdf

2. Orgabization), U. U. N. E. S. C. (2014). Youth. https://unevoc.unesco.org/go.php?q=TVETipedia+Glossary+A-Z&id=9

3. Côté, J., & Bynner, J. M. (2008). Changes in the transition to adulthood in the UK and Canada: The role of structure and agency in emerging adulthood. *Journal of youth studies, 11*(3), 251-268.

4. Gaudet, S. p. (2007). *Emerging Adulthood: A New Stage in the Life Course: Implications for Policy Development*. https://publications.gc.ca/collections/collection_2008/policyresearch/PH4-41-2007E.pdf

5. Canada, G. o. (2011). *Chapter 3: The Chief Public Health Officer's Report on the State of Public Health in Canada 2011 – The health and well-being of Canadian youth and young adults*. https://www.canada.ca/en/public-health/corporate/publications/chief-public-health-officer-reports-state-public-health-canada/chief-public-health-officer-report-on-state-public-health-canada-2011/chapter-3.html

6. Stewart, D. A., Law, M. C., Rosenbaum, P., & Willms, D. G. (2002). A qualitative study of the transition to adulthood for youth with physical disabilities. *Physical & Occupational Therapy in Pediatrics, 21*(4), 3-21.

7. Roebroeck, M. E., Jahnsen, R., Carona, C., Kent, R. M., & Chamberlain, M. A. (2009). Adult outcomes and lifespan issues for people with childhood-onset physical disability [Review]. *Developmental Medicine & Child Neurology, 51*(8), 670-678. https://doi.org/https://doi.org/10.4102/sajpsychiatry.v27i0.1639

8. Shikako-Thomas, K., Lach, L., Majnemer, A., Nimigon, J., Cameron, K., & Shevell, M. (2009). Quality of life from the perspective of adolescents with cerebral palsy:"I just think I'ma normal kid, I just happen to have a disability". *Quality of Life Research, 18*(7), 825.

9. Canada, S. (2021, 2021-12-01). *Canadian Survey on Disability Reports-Age of Disability: From Onset to Limitation*. https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2021003-eng.htm

10. Canada, S. (2017). *A profile of persons with disabilities among Canadians aged 15 years or older, 2012*. https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2015001-eng.htm

11. (PALS), P. a. A. L. S. (2006). *Participation and Activity Limitation Survey 2006: Technical and Methodological Report* https://www150.statcan.gc.ca/n1/pub/89-628-x/89-628-x2007001-eng.htm

12. Gorter, J., Stewart, D., & Woodbury-Smith, M. (2011). Youth in transition: care, health and development. *Child: care, health and development, 37*(6), 757-763.

13. Hamdani, Y., Jetha, A., & Norman, C. (2011). Systems thinking perspectives applied to healthcare transition for youth with disabilities: a paradigm shift for practice, policy and research. *Child: care, health and development, 37*(6), 806-814.

14. Cobb, R. B., & Alwell, M. (2009). Transition Planning/Coordinating Interventions for Youth with Disabilities: A Systematic Review. *Career Development for Exceptional Individuals*. https://doi.org/10.1177/0885728809336655

15. Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on autism and other developmental disabilities, 24*(2), 77-88. https://doi.org/10.1177/1088357608329827

16. WHO. (2001). *International Classification of Functioning, Disability and Health: ICF*. World Health Organization.

17. Henninger, N. A., & Taylor, J. L. (2014). Family perspectives on a successful transition to adulthood for individuals with disabilities. *Mental Retardation, 52*(2), 98-111.

18. Stewart, D., Law, M., Young, N. L., Forhan, M., Healy, H., Burke-Gaffney, J., & Freeman, M. (2014). Complexities during transitions to adulthood for youth with disabilities: person-environment interactions. *Disability and rehabilitation, 36*(23), 1998-2004. https://doi.org/10.3109/09638288.2014.885994

19. Rehm, R. S., Fuentes-Afflick, E., Fisher, L. T., & Chesla, C. A. (2012). Parent and youth priorities during the transition to adulthood for youth with special health care needs and developmental disability. *ANS. Advances in nursing science, 35*(3), 57-72. https://doi.org/10.1097/ANS.0b013e3182626180

20. Lindsay, S., Adams, T., McDougall, C., & Sanford, R. (2012). Skill development in an employment-training program for adolescents with disabilities [Research Support, Non-U.S. Gov't]. *Disability & Rehabilitation, 34*(3), 228-237. https://doi.org/https://doi.org/10.3109/09638288.2011.603015

21. Hamdani, Y., Mistry, B., & Gibson, B. E. (2015). Transitioning to adulthood with a progressive condition: best practice assumptions and individual experiences of young men with Duchenne muscular dystrophy. *Disability and rehabilitation, 37*(13), 1144-1151.

22. Lindsay, S., Cagliostro, E., Leck, J., & Stinson, J. (2021). Career aspirations and workplace expectations among youth with physical disabilities. *Disability and rehabilitation, 43*(12), 1657-1668.

23. Joly, E. (2015). Transition to adulthood for young people with medical complexity: an integrative literature review. *Journal of Pediatric Nursing, 30*(5), e91-e103.

24. Holwerda, A., van der Klink, J. J. L., Groothoff, J. W., & Brouwer, S. (2012). Predictors for Work Participation in Individuals with an Autism Spectrum Disorder: A Systematic Review. *Journal of Occupational Rehabilitation, 22*(3), 333-352. https://doi.org/10.1007/s10926-011-9347-8

25. Kirsh, B., Stergiou-Kita, M., Gewurtz, R., Dawson, D., Krupa, T., Lysaght, R., & Shaw, L. (2009). From margins to mainstream: what do we know about work integration for persons with brain injury, mental illness and intellectual disability? *Work, 32*(4), 391-405.

26. Beveridge, S., Craddock, S. H., Liesener, J., Stapleton, M., & Hershenson, D. (2002). INCOME: A framework for conceptualizing the career development of persons with disabilities. *Rehabilitation Counseling Bulletin, 45*(4), 195-206.

27. Awsumb, J. M., Carter, E. W., Schutz, M. A., & McMillan, E. D. (2020). Perspectives of pre-employment transition services providers on preparing youth with disabilities for employment. *Journal of Vocational Rehabilitation, 53*(2), 205-218. https://doi.org/10.3233/JVR-201097

28. Engelbrecht, M., Shaw, L., & van Niekerk, L. (2017). A literature review on work transitioning of youth with disabilities into competitive employment. *African journal of disability, 6*, 298. https://doi.org/10.4102/ajod.v6i0.298

29. Lindsay, S., McDougall, C., Sanford, R., Menna-Dack, D., Kingsnorth, S., & Adams, T. (2015). Exploring employment readiness through mock job interview and workplace role-play exercises: comparing youth with physical disabilities to their typically developing peers. *Disabil Rehabil, 37*(18), 1651-1663. https://doi.org/10.3109/09638288.2014.973968

30. Powers, L. E., Garner, T., Valnes, B., Squire, P., Turner, A., Couture, T., & Dertinger, R. (2007). Building a successful adult life: Findings from youth-directed research. *Exceptionality, 15*(1), 45-56.

31. King, G. A., Baldwin, P. J., Currie, M., & Evans, J. (2006). The Effectiveness of Transition Strategies for Youth With Disabilities. *Children's Health Care, 35*(2), 155-178.

32. Palisano, R. J., Di Rezze, B., Stewart, D., Rosenbaum, P. L., Hlyva, O., Freeman, M., Nguyen, T., & Gorter, J. W. (2017). Life course health development of individuals with neurodevelopmental conditions. *Developmental medicine and child neurology, 59*(5), 470-476. https://doi.org/10.1111/dmcn.13402

33. Pandey, S., & Agarwal, S. (2013). Transition to adulthood for youth with disability: Issues for the disabled child and family. *IOSR Journal of Humanities and Social Science (IOSR-JHSS), 17*(3), 41-45.

34. Stewart, D., Gorter, J. W., & Freeman, M. (2013). Transitions to adulthood for youth with disabilities: Emerging themes for practice and research. *The Prevention Researcher, 20*(2), 3-7.

35. Shogren, K. A., & Wittenburg, D. (2020). Improving outcomes of transition-age youth with disabilities: A life course perspective. *Career Development and Transition for Exceptional Individuals, 43*(1), 18-28.

36. Stewart, D. (2009). Transition to adult services for young people with disabilities: current evidence to guide future research. *Developmental Medicine & Child Neurology, 51*, 169-173. https://doi.org/10.1111/j.1469-8749.2009.03419.x

37. Black, M. M., Walker, S. P., Fernald, L. C., Andersen, C. T., DiGirolamo, A. M., Lu, C., McCoy, D. C., Fink, G., Shawar, Y. R., & Shiffman, J. (2017). Early childhood development coming of age: science through the life course. *The Lancet, 389*(10064), 77-90.

38. Stewart, D., Stavness, C., King, G., Antle, B., & Law, M. (2006). A Critical Appraisal of Literature Reviews About the Transition to Adulthood for Youth with Disabilities. *Physical & Occupational Therapy in Pediatrics, 26*(4), 5-24. https://doi.org/10.1080/J006v26n04_02

39. King, G., Tucker, M. A., Baldwin, P., Lowry, K., LaPorta, J., & Martens, L. (2002). A life needs model of pediatric service delivery: services to support community participation and quality of life for children and youth with disabilities. *Physical & Occupational Therapy in Pediatrics, 22*(2), 53-77. https://doi.org/10.1080/J006v22n02_04

40. Nguyen, T., Stewart, D., & Gorter, J. (2018). Looking back to move forward: Reflections and lessons learned about transitions to adulthood for youth with disabilities. *Child: care, health and development, 44*(1), 83-88. https://doi.org/10.1111/cch.12534

41. Augustine, L., Lygnegård, F., & Granlund, M. (2022). Trajectories of participation, mental health, and mental health problems in adolescents with self-reported neurodevelopmental disorders. *Disability and rehabilitation, 44*(9), 1595-1608.

42. Engel-Yeger, B., Jarus, T., Anaby, D., & Law, M. (2009). Differences in patterns of participation between youths with cerebral palsy and typically developing peers. *The American Journal of Occupational Therapy, 63*(1), 96-104.

43. Law, M., Anaby, D., Teplicky, R., Khetani, M. A., Coster, W., & Bedell, G. (2013). Participation in the home environment among children and youth with and without disabilities. *British Journal of Occupational Therapy, 76*(2), 58-66.

44. Anaby, D. P., Law, M. P., Coster, W. P., Bedell, G. P., Khetani, M. S., Avery, L. M., & Teplicky, R. M. (2014). The Mediating Role of the Environment in Explaining Participation of Children and Youth With and Without Disabilities Across Home, School, and Community. *Archives of physical medicine and rehabilitation, 95*(5), 908-917. https://doi.org/10.1016/j.apmr.2014.01.005

45. King, G., Law, M., Hurley, P., Petrenchik, T., & Schwellnus, H. (2010). A developmental comparison of the out-of-school recreation and leisure activity participation of boys and girls with and without physical disabilities. *International Journal of Disability, Development and Education, 57*(1), 77-107.

46. van Gorp, M., Van Wely, L., Dallmeijer, A. J., de Groot, V., Ketelaar, M., Roebroeck, M. E., & group, P. D. s. (2019). Long-term course of difficulty in participation of individuals with cerebral palsy aged 16 to 34 years: a prospective cohort study. *Developmental Medicine & Child Neurology, 61*(2), 194-203.

47. Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of autism and developmental disorders, 41*(5), 566-574.

48. Farley, M., Cottle, K. J., Bilder, D., Viskochil, J., Coon, H., & McMahon, W. (2018). Mid-life social outcomes for a population-based sample of adults with ASD. *Autism research : Official Journal of the International Society for Autism Research, 11*(1), 142-152. https://doi.org/https://doi.org/10.1002/aur.1897

49. Wehman, P., Sima, A. P., Ketchum, J., West, M. D., Chan, F., & Luecking, R. (2015). Predictors of successful transition from school to employment for youth with disabilities. *Journal of Occupational Rehabilitation, 25*(2), 323-334.

50. Janus, A. L. (2009). Disability and the Transition to Adulthood. *Social Forces, 88*(1), 99-120.

51. Thompson, C., Bolte, S., Falkmer, T., & Girdler, S. (2018). To be understood: Transitioning to adult life for people with Autism Spectrum Disorder. *PLoS ONE [Electronic Resource], 13*(3), e0194758. https://doi.org/https://dx.doi.org/10.1371/journal.pone.0194758

52. Dijkers, M. P. (2010). Issues in the conceptualization and measurement of participation: an overview. *Archives of physical medicine and rehabilitation, 91*(9), S5-S16.

53. Panyo, K., Lersilp, S., Putthinoi, S., & Hsu, H. Y. (2021). Transition service in the occupational therapy process for students with disabilities: A systematic review. *Journal of Occupational Therapy, Schools, & Early Intervention, 14*(3), 343-355. https://doi.org/10.1080/19411243.2020.1862727

54. Shikako-Thomas, K., Majnemer, A., Law, M., & Lach, L. (2008). Determinants of participation in leisure activities in children and youth with cerebral palsy: systematic review. *Physical & Occupational Therapy in Pediatrics, 28*(2), 155-169.

55. Anaby, D., Law, M., Hanna, S., & Dematteo, C. (2012). Predictors of change in participation rates following acquired brain injury: results of a longitudinal study. *Developmental medicine and child neurology, 54*(4), 339-346. https://doi.org/10.1111/j.1469-8749.2011.04204.x

56. Turnbull, A. P., Turnbull, R., & Wehmeyer, M. (2007). *Exceptional lives: Special education in today's schools—Fifth edition* Upper Saddle River, NJ Pearson-Merrill Prentice Hall.

57. Bedell, G., & Coster, W. (2008). Measuring participation of school-aged children with traumatic brain injuries: Considerations and approaches. *The Journal of head trauma rehabilitation, 23*(4), 220-229.

58. Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A., & Law, M. (2013). The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disability and rehabilitation, 35*(19), 1589-1598. https://doi.org/10.3109/09638288.2012.748840

59. Coster, M., Law, M., Bedell, G., Khetani, M., Anaby, D. . (2013). The Participation and Environment Measure for Children and Youth (PEM-CY): An innovative measure for home, school and community. *CanChild*. https://canchild.ca/en/resources/228-the-participation-and-environment-measure-for-children-and-youth-pem-cy-an-innovative-measure-for-home-school-and-community

60. Law, M. C., Darrah, J., Pollock, N., Wilson, B., Russell, D. J., Walter, S. D., Rosenbaum, P., & Galuppi, B. (2011). Focus on function: a cluster, randomized controlled trial comparing child-versus context-focused intervention for young children with cerebral palsy. *Developmental Medicine & Child Neurology, 53*(7), 621-629.

61. Dana, R. A., Mary, C. L., Annette, M., & Debbie, F. (2016). Opening doors to participation of youth with physical disabilities: An intervention study : Favoriser la participation des adolescents ayant des handicaps physiques : …tude dintervention. *Canadian Journal of Occupational Therapy, 83*(2), 83-90.

62. Adair, B., Ullenhag, A., Keen, D., Granlund, M., & Imms, C. (2015). The effect of interventions aimed at improving participation outcomes for children with disabilities: a systematic review. *Developmental Medicine & Child Neurology, 57*(12), 1093-1104.

63. Kramer, J. M., Helfrich, C., Levin, M., Hwang, I. T., Samuel, P. S., Carrellas, A., Schwartz, A. E., Goeva, A., & Kolaczyk, E. D. (2018). Initial evaluation of the effects of an environmental-focused problem-solving intervention for transition-age young people with developmental disabilities: Project TEAM. *Developmental Medicine & Child Neurology, 60*(8), 801-809.

64. Shahin, S., Reitzel, M., Di Rezze, B., Ahmed, S., & Anaby, D. (2020). Environmental factors that impact the workplace participation of transition-aged young adults with brain-based disabilities: a scoping review. *International journal of environmental research and public health, 17*(7), 2378. https://doi.org/10.3390/ijerph17072378

65. Imms, C., Adair, B., Keen, D., Ullenhag, A., Rosenbaum, P., & Granlund, M. (2016). 'Participation': a systematic review of language, definitions, and constructs used in intervention research with children with disabilities. *Developmental Medicine & Child Neurology, 58*(1), 29-38.

66. Coster, W., & Khetani, M. A. (2008). Measuring participation of children with disabilities: issues and challenges. *Disability and rehabilitation, 30*(8), 639-648.

67. Maxwell, G., Alves, I., & Granlund, M. (2012). Participation and environmental aspects in education and the ICF and the ICF-CY: Findings from a systematic literature review. *Developmental neurorehabilitation, 15*(1), 63-78.

68. Wade, D. T., & Halligan, P. (2003). New wine in old bottles: the WHO ICF as an explanatory model of human behaviour. *Clinical Rehabilitation, 17*(4), 349-354. https://doi.org/10.1191/0269215503cr619ed

69. Whiteneck, G., & Dijkers, M. P. (2009). Difficult to measure constructs: conceptual and methodological issues concerning participation and environmental factors. *Archives of physical medicine and rehabilitation, 90*(11), S22-S35.

70. McConachie, H., Colver, A., Forsyth, R., Jarvis, S., & Parkinson, K. (2006). Participation of disabled children: how should it be characterised and measured? *Disability and rehabilitation, 28*(18), 1157-1164.

71. Brown, M., Dijkers, M. P., Gordon, W. A., Ashman, T., Charatz, H., & Cheng, Z. (2004). Participation objective, participation subjective: a measure of participation combining outsider and insider perspectives. *The Journal of head trauma rehabilitation, 19*(6), 459-481.

72. Heah, T., Case, T., McGuire, B., & Law, M. (2007). Successful participation: The lived experience among children with disabilities. *Canadian Journal of Occupational Therapy, 74*(1), 38-47.

73. Coster, W., Law, M., Bedell, G., Khetani, M., Cousins, M., & Teplicky, R. (2012). Development of the participation and environment measure for children and youth: conceptual basis. *Disability and rehabilitation, 34*(3), 238-246.

74. Adair, B., Ullenhag, A., Rosenbaum, P., Granlund, M., Keen, D., & Imms, C. (2018). Measures used to quantify participation in childhood disability and their alignment with

the family of participation-related constructs: a systematic review. *Developmental Medicine & Child Neurology, 60*(11), 1101-1116. https://doi.org/10.1111/dmcn.13959

75. Tuffrey, C., Bateman, B., & Colver, A. (2013). The Q uestionnaire of Y oung P eople's P articipation (QYPP): a new measure of participation frequency for disabled young people. *Child: care, health and development, 39*(4), 500-511. https://doi.org/10.1111/cch.12060

76. Farzad, M., Layeghi, F., Hosseini, A., Whiteneck, G., & Asgari, A. (2017). Using the Rasch Model to Develop a Measure of Participation Capturing the Full Range of Participation Characteristics for the Patients with Hand Injuries. *Journal of Hand and Microsurgery, 09*(02), 084-091. https://doi.org/10.1055/s-0037-1604060

77. Di Rezze, B., Viveiros, H., Pop, R., & Rampton, G. (2018). A review of employment outcome measures in vocational research involving adults with neurodevelopmental disabilities. *Journal of Vocational Rehabilitation, 49*(1), 79-96. https://doi.org/10.3233/JVR-180956

78. Schlebusch, L., Huus, K., Samuels, A., Granlund, M., & Dada, S. (2020). Participation of young people with disabilities and/or chronic conditions in low-and middle-income countries: a scoping review. *Developmental Medicine & Child Neurology, 62*(11), 1259-1265.

79. Briggs, M. S., Rethman, K. K., Crookes, J., Cheek, F., Pottkotter, K., McGrath, S., DeWitt, J., Harmon-Matthews, L. E., & Quatman-Yates, C. C. (2020). Implementing patient-reported outcome measures in outpatient rehabilitation settings: a systematic review of facilitators and barriers using the consolidated framework for implementation research. *Archives of physical medicine and rehabilitation, 101*(10), 1796-1812.

80. Willis, C., Girdler, S., Thompson, M., Rosenberg, M., Reid, S., & Elliott, C. (2017). Elements contributing to meaningful participation for children and youth with disabilities: a scoping review. *Disability and rehabilitation, 39*(17), 1771-1784.

81. Meadows, K. A. F., & Director. (2011). Patient-reported outcome measures: an overview. *British Journal of Community Nursing, 16*(3), 146-151.

82. [Record #1594 is using a reference type undefined in this output style.]

83. Noreau, L., Fougeyrollas, P., & Vincent, C. (2002). The LIFE-H: Assessment of the quality of social participation. *TECHNOLOGY AND DISABILITY, 14*(Part 3), 113-118.

84. King, G. A., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., Rosenbaum, P., & Young, N. (2004). *Children's assessment of participation and enjoyment (CAPE) and preferences for activities of children (PAC)*. PsychCorp.

85. Hwang, A.-W., Yen, C.-F., Liou, T.-H., Bedell, G., Granlund, M., Teng, S.-W., Chang, K.-H., Chi, W.-C., & Liao, H.-F. (2015). Development and validation of the icf-cy-based functioning scale of the disability evaluation system—Child version in Taiwan. *Journal of the Formosan Medical Association, 114*(12), 1170-1180.

86. Perenboom, R. J., & Chorus, A. M. (2003). Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). *Disability and rehabilitation, 25*(11-12), 577-587.

87. Seekins, T., Shunkamolah, W., Bertsche, M., Cowart, C., Summers, J. A., Reichard, A., & White, G. (2012). A systematic scoping review of measures of participation in disability and rehabilitation research: A preliminary report of findings. *Disability and health journal, 5*(4), 224-232.

88. Chien, C.-W. P., Rodger, S. P., Copley, J. P., & Skorka, K. (2014). Comparative Content Review of Children's Participation Measures Using the International Classification of Functioning, Disability and Health-Children and Youth. *Archives of physical medicine and rehabilitation, 95*(1), 141-152. https://doi.org/10.1016/j.apmr.2013.06.027

89. Coster, W., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Liljenquist, K., Gleason, K., & KAO, Y. C. (2011). Psychometric evaluation of the Participation and Environment Measure for Children and Youth. *Developmental Medicine & Child Neurology, 53*(11), 1030-1037. https://doi.org/10.1111/j.1469-8749.2011.04094.x

Chapter 2: Rationale and Objectives of the Thesis Project

Overall Objective

The overall objective of this PhD project is to develop and validate the content of a self-reported measure, named the Y-PEM (see appendix 1), to comprehensively assess participation and the environment across different settings; home, school/educational setting, community, and the workplace, and to evaluate aspects of its measurement properties in terms of reliability, validity, and utility.

Rationale

Youth and young adults face many participation limitations making the transitioning phase to adulthood even more complex [1]. As defined by the UN, youth and young adults include individuals aged 15 to the recently extended age of 30 [2]. However, considering that participation patterns change at the age of 12, it is also important to consider youth in their early adolescence [3]. It is crucial to assess participation levels in this transitioning age as it can be expected that participation patterns decrease, as children become older [4]. Participation is known to be heavily influenced by the environment [5,6]. It is established that the participation patterns of individuals with disabilities is distinct and needs attention to specific environmental factors such as parental and peer support, and supportive services and programs at the societal level [5,7]. Therefore, to fully capture this construct, participation and the environment must be evaluated together. To date, none of the existing participation-based measurement tools comprehensively and specifically look at the participation of transition-aged youth and young adults with a special link to the environment.

The PEM-CY is an example of a psychometrically sound outcome measure that evaluates both participation and the environment. However, the PEM-CY is a parent-report measure

intended for children and youth aged 5-17 years old. This tool lacks the first-hand subjective experience of youth and young adults themselves [6]. Evidence suggests that parental or proxy reports do not always mirror youth's perspective, thus, youth reports should be obtained whenever possible [8]. Additionally, the PEM-CY does not cover the challenging transition phase to adulthood, including activities such as preparation for meaningful employment [9]. These limitations outline the importance of a participation measure exploring participation in transition-aged youth with and without disabilities as a reference for guiding appropriate intervention plans in relevant and appropriate life areas. Therefore, the development of a self-report measure, titled the Y-PEM and modelled on the PEM-CY but intended for youth and young adults aged 12-30, is proposed. The Y-PEM will include a work environment section, aiming to capture participation profiles during this transitioning phase. The Y-PEM is designed to identify environmental supports and barriers which are a promising target for intervention as they are often amenable to change [5,10]. This study thus aimed to develop a self-reported measurement tool to comprehensively capture the participation patterns of transition-aged individuals, 12- 30 years old, living with a disability across four different environmental settings: home, school/educational setting, community, and the workplace.

Objectives

This study had two objectives as follows:

1) Our first objective was to develop a self-reported measure, Y-PEM, that comprehensively captures participation of individuals aged 12-30 years old across different settings: home, school, community, and workplace. To do so, we first aimed to:

   a. synthesize existing evidence on the impact of the environment on the workplace. participation among youth and young adults with disabilities (manuscript 1; chapter 3).
   b. adapt the current content of the PEM-CY for youth and young adults with physical disabilities aged 12-30 years old as a self-report measure and develop and validate items for a new participation domain related to work including the features of the environment that impact work (manuscript 2; chapter 5).

2) Our second objective was to examine measurement properties of the Y-PEM in terms of reliability, validity, and utility. More specifically, we aimed to:
   a. contribute initial evidence towards internal consistency, short-term test-retest reliability, and construct validity of the Y-PEM, and estimate aspects of utility in terms of burden and value of the Y-PEM among the target population (manuscript 3; chapter 7).
   b. Explore the practical utility of the "workplace participation" domain of the Y-PEM among stakeholders providing employment-related services (manuscript 4; chapter 10).

To address the objectives of this project, four peer-reviewed manuscripts were developed; two of which have been published (manuscripts 1 & 2), one of which has been accepted for publication (manuscript 4), and another which has been submitted for publication (manuscript 3). The specific objectives of each manuscript are presented below.

The first manuscript (chapter 3) aimed to synthesize relevant and existing literature on the impact of the environment on the competitive workplace participation of young people with disabilities. Previous research demonstrated the importance of the environment among children

and youth with disabilities on participation outcomes at home, school, and the community [3,5,11]. To develop the workplace setting of the Y-PEM, we needed to know whether the environment continued to play an imperative role in participation outcomes of people with disabilities as they enter the job market. In addition, we wanted to know which specific aspects of the environment were pertinent to the workplace participation of transition-aged youth and young adults with disabilities using the ICF classification system. As such, this literature review was an important component of my PhD project, as it confirmed and supported the need to evaluate the environment when capturing work participation. Results of the scoping review on specific environmental barriers and supports informed the development of examples of environmental features that are important to work participation.

The second manuscript (chapter 5) aimed to describe the process, methodology and results of the study on developing and validating the content of the Y-PEM for youth and young adults aged 12-30, including a newly developed workplace participation domain. This study drew on elements of the COnsensus for Standard Measurements INstrument (COSMIN) methodology for patient-reported outcome measures.

The third manuscript (chapter 7) aimed to evaluate initial psychometric properties of the Y-PEM in terms of its construct validity, internal consistency, and test-retest reliability. In addition, this manuscript explored aspects of the utility in terms of burden and value using the QQ-10 questionnaire from the perspective of youth and young adults. Results of this study generated initial evidence towards the reliability and validity of this tool which are important properties of measurement tools for uptake in practice and research.

Finally, the fourth manuscript (chapter 10) aimed to explore the utility and usefulness of the newly developed workplace participation domain of the Y-PEM from the perspectives of

stakeholders providing/receiving employment-related services to youth and young adults with disabilities. More specifically, this study investigated how the workplace participation domain of the Y-PEM could be used in practice in clinical and non-clinical settings to promote inclusion and participation of people with disabilities in the workplace.

References

1. Palisano, R. J., Di Rezze, B., Stewart, D., Rosenbaum, P. L., Hlyva, O., Freeman, M., Nguyen, T., & Gorter, J. W. (2017). Life course health development of individuals with neurodevelopmental conditions. *Developmental medicine and child neurology, 59*(5), 470-476. https://doi.org/10.1111/dmcn.13402

2. Orgabization, U. N. E. S. a. C. (2014). Youth. https://unevoc.unesco.org/go.php?q=TVETipedia+Glossary+A-Z&id=9

3. Anaby, D., Law, M., Hanna, S., & Dematteo, C. (2012). Predictors of change in participation rates following acquired brain injury: results of a longitudinal study. *Developmental medicine and child neurology, 54*(4), 339-346. https://doi.org/10.1111/j.1469-8749.2011.04204.x

4. van Gorp, M., Van Wely, L., Dallmeijer, A. J., de Groot, V., Ketelaar, M., Roebroeck, M. E., & group, P. D. s. (2019). Long-term course of difficulty in participation of individuals with cerebral palsy aged 16 to 34 years: a prospective cohort study. *Developmental Medicine & Child Neurology, 61*(2), 194-203.

5. Anaby, D. P., Law, M. P., Coster, W. P., Bedell, G. P., Khetani, M. S., Avery, L. M., & Teplicky, R. M. (2014). The Mediating Role of the Environment in Explaining Participation of Children and Youth With and Without Disabilities Across Home, School, and Community. *Archives of physical medicine and rehabilitation, 95*(5), 908-917. https://doi.org/10.1016/j.apmr.2014.01.005

6. Coster, W., Law, M., Bedell, G., Khetani, M., Cousins, M., & Teplicky, R. (2012). Development of the participation and environment measure for children and youth: conceptual basis. *Disability and rehabilitation, 34*(3), 238-246.

7. Killeen, H., Shahin, S., Bedell, G. M., & Anaby, D. R. (2019). Supporting the participation of youth with physical disabilities: Parents' strategies. *British Journal of Occupational Therapy, 82*(3), 153-161.

8. Heah, T., Case, T., McGuire, B., & Law, M. (2007). Successful participation: The lived experience among children with disabilities. *Canadian Journal of Occupational Therapy, 74*(1), 38-47.

9. Stewart, D. A., Law, M. C., Rosenbaum, P., & Willms, D. G. (2002). A qualitative study of the transition to adulthood for youth with physical disabilities. *Physical & Occupational Therapy in Pediatrics, 21*(4), 3-21.

10. Anaby, D., Mercerat, C., Tremblay, S., Wingo, B. C., & Rimmer, J. H. (2017). Enhancing Youth Participation Using the PREP Intervention: Parents' Perspectives. *International journal of environmental research and public health, 14*(9). https://doi.org/10.3390/ijerph14091005

11. Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A., & Law, M. (2013). The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disability and rehabilitation, 35*(19), 1589-1598. https://doi.org/10.3109/09638288.2012.748840

Chapter 3: Manuscript 1

Title: Environmental Factors that Impact the Workplace Participation of Transition-aged Young adults with Brain-based Disabilities: A Scoping Review

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Review

Environmental Factors that Impact the Workplace Participation of Transition-Aged Young Adults with Brain-Based Disabilities: A Scoping Review

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Abstract: Workplace participation of individuals with disabilities continues to be a challenge. The International Classification of Functioning, Disability and Health (ICF) places importance on the environment in explaining participation in different life domains, including work. A scoping review was conducted to investigate environmental facilitators and barriers relevant to workplace participation for transition-aged young adults aged 18–35 with brain-based disabilities. Studies published between 1995 and 2018 were screened by two reviewers. Findings were categorized into the ICF's environmental domains: Products and technology/Natural environment and human-made changes to environment, Support and relationships, Attitudes, and Services, systems and policies. Out of 11,515 articles screened, 31 were retained. All environmental domains of the ICF influenced workplace participation. The majority of the studies (77%) highlighted factors in the Services, systems and policies domain such as inclusive and flexible systems, and well-defined policies exercised at the organizational level. Social support mainly from family, friends, employers and colleagues was reported as a facilitator (68%), followed by physical accessibility and finally, the availability of assistive technology (55%). Attitudes of colleagues and employers were mostly seen as a barrier to workplace participation (48%). Findings can inform the development of guidelines and processes for implementing and reinforcing policies, regulations and support at the organization level.

Keywords: young adult; employment; workplace; labor force; environmental impacts; social environment

1. Introduction

Participation, defined as "involvement in a life situation" by the International Classification of Functioning, Disability and Health (ICF) [1], is one of the main rehabilitation goals among people with disabilities [2]. Participation in work is particularly important for transition-aged young adults living with a disability which involves transition to many new adulthood roles; however, this group often experiences increased participation limitations over time, in this pertinent life area [3].

Generally, employment is associated with improved physical, psychological and social well-being [4]. Having work experience is important for young adults, especially for those with disabilities, as it increases the likelihood of attaining postsecondary employment later in adulthood [5]. Despite its known benefits, young adults with disabilities in North America [6] and around the

world have the lowest employment rates, between 30%–53% [7]. This group also experiences higher rates of poverty when compared to those without disabilities [8]. Focusing on this vulnerable transition-aged group is critical as it involves transitioning to adulthood roles and requires support to ensure successful experiences in their early stages of employment. Such support is important since open and competitive employment settings do not always have the knowledge and resources to make appropriate accommodations [9].

Environmental factors, referring to the physical, social, attitudinal and institutional facets of the environment, are known to affect participation outcomes [10]. These factors can either act as facilitators and enhance one's functioning and participation, and/or serve as barriers impeding one's engagement in meaningful activities [1]. Hence, the environment may explain some of the discrepancies in employment rates among young adults with disabilities [11,12]. Research suggests that the environment can serve as a promising target for interventions to improve participation. Additionally, in many cases, change at the level of the environment is a more practical target rather than at the level of the individual [10]. Understanding the challenges that the environment poses for participation in the workplace among this population can inform such interventions. Recent knowledge syntheses have illustrated the impact of environmental modifications on workplace participation among adults with autism spectrum disorder (ASD) [13] and workplace culture on the participation of people with intellectual disability (ID) [14]. However, to date, no scoping review has been completed to comprehensively synthesize the knowledge-base related to the environmental effects on the workplace participation among the understudied population of transition-aged young adults with various brain-based disabilities [15].

This scoping review aimed to identify and synthesize the existing evidence on the impact of environment on participation in mainstream inclusive work settings among transition-aged young adults with brain-based disabilities. Brain-based disabilities refer to any neurologically based congenital or acquired conditions, as well as neurologically chronic conditions (e.g., cerebral palsy, brain- and spinal-related injuries) including sensory disorders. Such an initiative will also reveal current gaps in knowledge within the field of employment in brain-based disability, informing future research.

2. Materials and Methods

A scoping review methodology was applied, allowing us to map and broadly cover the breadth of current knowledge regarding the environmental factors that impact employment participation of transition-aged individuals [16]. The 5-stage method for scoping reviews by Arksey and O'Mally [16] and advanced by O'Brien, Colquhoun and Levac [17] was used.

2.1. Identifying the Research Question

Typical to scoping reviews, a broad question was identified as follows: What is known about the impact of the environment on the participation in the work setting among transition-aged individuals with brain-based disabilities?

2.2. Identifying Relevant Studies

A systemic search of studies published between 1995 and June 2018 was conducted. Five relevant databases covering a range of research areas including health, social and rehabilitation sciences were consulted: OVID MEDLINE, EMBASE, PsycINFO, PubMed and CINHAL. The input of an expert librarian ensured that all relevant publications were included. The following search terms (see Table 1) were utilized to capture the multi-faceted aspects of the environment combined with OR: physical environment, social environment, cultural environment, institutional environment, built environment, attitudes, workplace, accessibility, services, policy, social support, and relationships. Comprehensive keywords were used to capture the concept of 'work participation', using terms representing 'participation' (e.g., engagement, involvement) combined with terms illustrating 'employment' (e.g., job, productivity). These three categories of terms were combined with the term 'brain-based disability' and related conditions (for further details see Table 1) using AND. Both Medical Subject Headings

(MeSH) and keywords were used. Final searches resulted in 14119 articles, which were organized via EndNote reference manager. The removal of duplicates resulted in 11,515 articles.

Table 1. Search terms used.

Database	Environment [Combined Using OR]	Work Participation [Combined Using OR]	Disability [Combined Using OR]
1. OVID 2. MEDLINE 3. EMBASE 4. PsycINFO 5. PubMed 6. CINHAL	Physical environment Social environment Cultural environment Institutional environment Social support Relationship Attitude Accessibility Architectural accessibility Service Policy Built environment Environmental design Organizational climate	Employment Employment status Participation Involvement Engagement Workplace Work Job Vocational Part time job Productivity Volunteer Part-time work Labor market	Brain-based disabilities Cerebral palsy Brain hemorrhage Traumatic brain injury Cognitive impairment Epilepsy, post-traumatic epilepsy Hydrocephalus Meningitis, bacterial Meningitis, fungal Meningitis, viral Meningoencephalitis Child development disorders, Developmental disabilities Intellectual disability Learning disorders Motor skills disorders Tic disorders Global developmental delay Autism spectrum disorder Asperger syndrome Developmental coordination disorder Sensory integration disorder Sensory system disorder Disorder, Spina bifida Acquired brain injury

2.3. Study Selection

Empirical peer-reviewed studies, regardless of their design, were included if they: (1) explored the relationship between the environment and participation in an open competitive workplace, (2) targeted transition-aged young adults between the ages of 18–35 years old (based on the mean) with acquired or congenital brain-based disabilities, and (3) were published in English. This age range was chosen as it reflects a period of transitioning to adulthood, which involves greater independence, acquiring employment, and maintaining relationships and leisure activities [18]. Full-time employment usually begins at 18 [19], and because dependency on family is prolonged within this population, this transition phase was extended to the mid-30s [20]. Articles were excluded if they had the following characteristics: (1) theoretical, conceptual or opinion papers, (2) studies whose participants' primary diagnosis was a mental health condition, (3) studies that only focused on recommendations to occupational health and safety guidelines in the workplace or included only descriptions of work hardening programs, vocational rehabilitation programs and facility-based programs, or the impact of the environment on these programs. Three researchers independently screened an initial set of 50 articles by title and abstract, attaining a 90% agreement [21]. The remaining articles were equally distributed and screened by title/abstract, resulting in 221 studies retained for full-text screening by two researchers. Any disagreement was resolved through discussions and consultations with the senior investigator. Finally, 25% of the included and excluded articles were randomly selected and validated by a rehabilitation specialist, independent of the study. Consensus was reached through a discussion.

2.4. Extracting and Charting Results

A data extraction sheet containing the reference, year and country of publication, type of study and design, study purpose, number and age of participants, diagnosis, place of employment, aspects of the environment and participation, main findings, and utilized assessment tools was created using Excel. Elo and Kyngäs' [22] coding and categorization process was used to classify data according to the five environmental domains of the ICF framework: Products & technology (e.g., assistive devices,

built environment), Natural environment and human-made changes to environment (e.g., geographic location, climate), Support & relationships (e.g., including family, friends, colleagues, and healthcare professionals), Attitudes (e.g., belief, values and perceptions of others), and Systems, services & policies (e.g., programs, regulations). This comprehensive framework was selected as it accords special attention to the role of the environment on participation [23]. The Products and technology domain was combined with the Natural environment and human-made changes to environment domain into one category as they both relate to the physical environment, resulting in four domains of the environment. Main findings categorized into the ICF environmental domains were jointly validated by two researchers followed by input from the senior researcher [24].

2.5. Collating, Summarizing and Reporting the Results

A descriptive summary of each article is presented with regards to the following elements (see Table 2): author, year, country, aim of the study, study design, population (number, age, diagnostic), ICF environmental domains included, and summary of the main findings. Data was described in terms of the percentage of the articles that explored specific environmental domains of the ICF. Additionally, findings were synthesized to explore the range of identified environmental barriers/facilitators that contribute to young adults' workplace participation. A table (see Table 3) summarizing findings in terms of environmental barriers and facilitators per each ICF environmental domain was also created.

Table 2. The main findings of the individual articles (n = 31).

Author, Year, Country	Aim of the Study	Study Design	Population (Number, Age, Diagnosis)	Environmental Domains				Summary of Main Findings
				Products & Technology & Natural Environment	Support & Relationships	Attitudes	Services, Systems & Policies	
Foley et al. [24] Australia	To present parental descriptions of social participation of young adults with Down syndrome and to explore the levels of social participation with physical and social environment.	Quantitative—Cross-sectional study	n = 197 parents of youth Youth aged * 16–32 Down syndrome	✓	✓	✓		Facilitators: • Positive attitudes of employers and colleagues Barriers: • Negative attitudes of strangers • Lack of support from friends • Unavailability of jobs and public transport
Roessler et al. [25] USA	To demonstrate the application of a contextual assessment of job/person compatibility in four employed college graduates with TBI.	Qualitative—case study	n = 4 Aged 25–32 years TBI	✓		✓	✓	Facilitators: • Flexibility to work from home • Receiving positive reinforcement • Employee assistance programs • Allowing employees to contact doctors during work • Altering work environment (lighting and temperature) as necessary • Having clear employee responsibilities and creating goals for employees Barriers: • Inadequate lighting, temperature and noise in the physical environment • Fast work pace, large variety of duties, performing under pressure, limited feedback on performance, hostile coworkers, inflexible work schedules and unfitting sick/vacation leave policies. • Insufficient time to work alone, little recognitio for the work completed, inadequate training from employer
Foley et al. [26] Australia	To describe the quality of life of families with a young adult with Down Syndrome, recently transitioned from school to post-school and influences of post-school day occupation and personal, environmental factors on family quality of life.	Quantitative—cross –sectional study	n = 150 families of young adults with Down Syndrome Aged * 16–30 years (mean = 22.9)	✓	✓		✓	Barriers: • No suitable open employment jobs available • Employees unable to apply for open jobs while working in sheltered employment • Unreasonable travel distance • Lack of parental support • Policy and funding constraints • Organizations providing inadequate support for employees with disabilities

Table 2. *Cont.*

Author, Year, Country	Aim of the Study	Study Design	Population (Number, Age, Diagnosis)	Environmental Domains				Summary of Main Findings
				Products & Technology & Natural Environment	Support & Relationships	Attitudes	Services, Systems & Policies	
Sung & Connor [27] USA	To investigate career behaviour, self-efficacy, goals, and contextual supports and barriers as predictors of choice actions and work participation among transition-age individuals with epilepsy.	Quantitative—cross-sectional design	*n* = 90 Aged 18–25 Epilepsy		✓			Facilitators: • Work participation was positively associated (moderate) with supports (e.g., having a mentor to guide and encourage) and negatively correlated with barriers (e.g., lack of employer's support) • 58% of the variance in work participation was accounted for by environmental supports from family, friends and processionals (β = 0.238), self-efficacy with making career decisions (β = 0.221), and expectations related to the outcomes of working (β = 0.460)
Butterworth et al. [28] USA	To better understand the relationship between the characteristics of the workplace and the levels of support and social inclusion experienced by employees with a disability.	Qualitative—part of larger study	*n* = 8 young adults Aged * 17–22 Developmental disability		✓		✓	Facilitators: • Managers showing personal interest in employees • Strong sense of teamwork • High levels of support (social opportunities, emphasis on shared job responsibilities, employee trainings for multiple jobs) • Creating multiple in-depth relationships crossing over different life contexts
Barf et al. [29] Netherlands	To examine participation restrictions of a large group of young adults born with SB in relation to disease characteristics, activity limitations and perceived hindrances for participation.	Quantitative—cross-sectional study	*n* = 179 Aged * 16–25 years (mean = 21) SB	✓				Barriers: • Building inaccessibility • General costs • Travel distance to workplace
Greenbaum [30] USA	To obtain information on employment and social status of college alumni (1980–1992) with learning disabilities.	Quantitative—cross-sectional study	*n* = 49 Mean age = 26 Learning disability	✓	✓	✓	✓	Facilitators: • Family support • College education and higher socioeconomic status Barriers: • Only 20% of employees disclosed their diagnosis due to concerns about discrimination • Employee's lack of knowledge or willingness to exercise rights as outlined by the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990
Honey et al. [31] Australia	To investigate the transitions between full-time, part-time and non-employment for young people with and without disabilities.	Retrospective—longitudinal study	n= 766 with disability, n=5008 without disability Aged * 15–29 Disability not specified		✓		✓	Barriers: • Low social support and low education • Current employment status was strongly linked to previous employment status

Table 2. *Cont.*

Author, Year, Country	Aim of the Study	Study Design	Population (Number, Age, Diagnosis)	Environmental Domains				Summary of Main Findings
				Products & Technology & Natural Environment	Support & Relationships	Attitudes	Services, Systems & Policies	
Toldrá & Santosb [32] Brazil	To identify facilitators and barriers faced by people with disabilities in the workforce.	Qualitative—Discourse of the collective subject matter method	*n* = 10 Aged 21–36, SCI, MD, CP, blindness, spinal amiotrophy, multiple arthrogiposis, congenital malformation	✓	✓	✓	✓	Facilitators: • Building social relationships in the workplace • Physically accessible environment Barriers: • Prejudice • Inadequate employee support by companies for workplace accommodations
Solstad & Schreuer [33] USA & Norway	To explore from a cross-national perspective, the complexities of workplace accommodation policies in action.	Qualitative study	*n* = 29 Age *: U.S.A: 22-39 (median 31) Norway: 24-43. (median:33) 2/3 CP, osteogenesis imperfecta, or SB.	✓			✓	Facilitators: • Flexible or reduced work hours • Accessibility to transit, physical work environment, assistive technology, and job coaching • Ability to work from home Barriers: • Timely transportation • Lack of employer's awareness about necessary accommodations • Costs/length of implementing accommodations
Lindsay et al. [34] Holland and Canada	To explore the facilitators, barriers and experiences of employment and post-secondary education among youth and young adults with spina bifida; and their variations between youth and young adults with spina bifida, their parents and health care providers.	Qualitative—secondary analysis from larger study	*n* = 12 youths, 11 parents and 12 health care providers Aged 19–25 SB	✓	✓	✓	✓	Facilitators: • Support from family and peers, participation in internships through school • Having accommodations made through a disability service at the post-secondary educational level Barriers: • Lack of supports and resources, limited options for accessible jobs, transportation, over-protective parents, stigma and discrimination, employer stereotypes, lack of professional support to find employment, and work tasks unfit with the employee's physical skills
Sherer et al. [35] USA	To explore the prognostic value of self-reported traits, problems, strengths and environmental barriers or facilitators for participation outcomes in persons with traumatic brain injury (TBI).	Systematic review	*n* = 63 articles >17 years old TBI	✓	✓		✓	Facilitators: • Access to transportation • Services and social interaction

Table 2. *Cont.*

Author, Year, Country	Aim of the Study	Study Design	Population (Number, Age, Diagnosis)	Environmental Domains				Summary of Main Findings
				Products & Technology & Natural Environment	Support & Relationships	Attitudes	Services, Systems & Policies	
Törnbom et al. [36] Sweden	To compare work participation in 2009 with 1997 in individuals with cerebral palsy and spina bifida.	Longitudinal—descriptive study	*n* = 30 Mean age 24 CP and SB	✓			✓	Facilitators: • Access to personal assistance • Adequate transportation • Implementing necessary accommodations • Continuing education • Wage subsidies to employers Barriers: • 29% of employees used transportation for people with disabilities in 1997 compared to 50% in 2009. This type of transportation was criticized because of frequent late arrivals and long travel times
Lindsay [37] Canada	To explore the characteristics associated with disabled youth who are employed and the types of employment they are engaged in.	Retrospective—cross-sectional study	*n* = 5234 Aged * 15–24 years old mobility, hearing, vision, communication, cognitive impairment	✓	✓		✓	Facilitators: • Access to vehicle • Being in urban setting • Fewer people in a household with a low total household income
De Beer et al. [38] Netherlands	To determine facilitators and barriers associated with participation in work of individuals with developmental disabilities, classified according to the dimensions of the ICF.	Systematic review	*n* = 256 Mean age = 33 Developmental dyslexia and/or learning disability	✓	✓	✓	✓	Facilitators: • Support from employer and colleagues • Access to assistive technology Barriers: • Support and relationships, attitudes of co-workers, working conditions, legal services, systems and policies, social security service systems, policies, SES and education level.
Ripat, & Woodgate [39] Canada	To present experiences and use of assistive technology (AT) from young adults in supporting their productivity.	Qualitative—grounded theory and participatory research study	*n* = 20 Aged * 17–35 SCI, CP, SB, MS, non-verbal disorders, dyslexia, visual impairment, Usher's and Ehlers–Danlos Syndrome	✓		✓	✓	Facilitators: • Access to AT • Active engagement in accommodation duties Barriers: • AT was sometimes seen as unnecessary by co-workers and was viewed as a privilege. • Cost of AT

Table 2. *Cont.*

Author, Year, Country	Aim of the Study	Study Design	Population (Number, Age, Diagnosis)	Environmental Domains				Summary of Main Findings
				Products & Technology & Natural Environment	Support & Relationships	Attitudes	Services, Systems & Policies	
Darrah et al. [40] Canada	To understand the contribution of educational, employment, transportation and assured income service programs to the successful transition of young adults with motor disabilities to adulthood.	Qualitative study	*n* = 76 Aged 20–30 CP and SB	✓			✓	Barriers: • Concerns with having reduced income benefit, lack of accessible transportation, limited post-secondary training opportunities, lack of employment accommodations, and a lack of services available to assist with finding a job.
Morash-Macneil et al. [41] USA	To investigate the efficacy of assistive technology (AT) in improving the ability to complete work tasks independently and efficiently for individuals with intellectual disabilities.	Systematic review	n=29 Aged *: 15–24 ID	✓				Facilitators: • Appropriate assistive technology such as portable electronic devices resulted in improved employment skills like task completion, time management and increased productivity
Holwerda et al. [42] Netherlands	To investigate factors that predict work participation, finding and maintaining employment of young adults with ASD and as ADD.	Longitudinal - cohort study	*n* = 563 Aged * 15–27 (mean = 19.4) ASD and ADHD		✓	✓		Facilitators: • Positive attitude and support from parents and others at work Barriers: • High parental support: overprotective parents might prevent children from finding employment
Tobias & Mukhopadhyay [43] Namibia	To identify the social experiences of individuals with a visual impairment in rural Namibia and to provide suggestions on how to include them in the community.	Qualitative study	*n* = 9 Aged 30 to 90—information was extracted from 3 participants who were in their 30s Vision impairment		✓	✓	✓	Barriers: • Lack of social and family support restricted access to education • The abilities of participants with vision impairment were undermined due to being viewed as dependent. • Policies promoting the employment of people with visual impairments were not enacted.
Hagner et al. [44] USA	To clarify the current implemented strategies to facilitate the involvement of natural support resources in the employment process.	Qualitative study	*n* = 33 vocational specialists/staff Age of participants not specified as study was completed from perspective of vocational support specialists		✓		✓	Facilitators: • Support from family and friends, social interaction among co-workers, and inclusion of company personnel in the training of an employee with a disability Barriers: • Low family involvement: unwillingness to assist in job searching due to lack of time, being overprotective, embarrassment related the youth's disability or not believing that the youth could succeed in a job • Lack of flexibility of company resources and resentment or discrimination toward individuals with disabilities

Table 2. *Cont.*

Author, Year, Country	Aim of the Study	Study Design	Population (Number, Age, Diagnosis)	Environmental Domains				Summary of Main Findings
				Products & Technology & Natural Environment	Support & Relationships	Attitudes	Services, Systems & Policies	
Petner-Arrey et al. [45] Canada	To better understand the experiences of people with intellectual or development disability (IDD) gaining and keeping productivity roles	Qualitative—grounded theory	*n* = 74 (13 persons with IDD, 21 caregivers, 40 pairs of caregivers and people with IDD Aged * 21–54 (mean = 27)		✓			Facilitators: • Parents and social networks facilitated acquiring and sustaining employment providing on the job assistance, helping employees to understand job expectations and providing advocate support
Lindstrom et al. [46] USA	To examine the career development process and postschool employment outcomes for a sample of individuals with disabilities.	Qualitative—case study	*n* = 8 Aged 25–28 learning & emotional disability, orthopedic impairment		✓			Facilitators: • Previous work experience • Positive interactions with colleagues • Completion of higher education and career supports in high school
Lindsay et al. [47] Canada	To explore the extent to which youths with physical disabilities encounter barriers to employment compared to their typically developing peers.	Qualitative—part of larger multi-method study	*n* = 31 youth (16 typ. Dev. And 15 with disability); 9 youth employers, 10 job counselors Aged * 16–19 CP, MD, myoltubularmyopathy, central core myopathy, Guillianbarre, scoliosis	✓	✓	✓	✓	Facilitators: • Peer influence helped motivate youth with disabilities to seek out employment • Financial incentive for employers to hire employees with disabilities Barriers: • Parental overprotection • Inadequate development of social and communication skills needed for the workplace • Inaccessible environments and challenges with advocating for accommodations • Concerns related to disclosing diagnosis, perceived disadvantages as a result of employer stereotypes and potential loss of disability benefits • Employers' lack of knowledge on how to adapt the environment, training procedures and tasks to support employees with disabilities • Lack of funding to support employers' awareness of disability
Reid & Bray [48] New Zealand	To present opinions of workers, supporters and employers and to offer strategies for greater employment rates and better-informed decisions by education, training and support agencies.	Qualitative study	*n* = 17 workers, 3 employers, 7 support people, 2 experts on employment Mean age early 30s (range 24–50) ID		✓		✓	Facilitators: • Engaging in social activities, having flexible work hours, access to services to assist with finding and maintaining employment

Table 2. *Cont.*

Author, Year, Country	Aim of the Study	Study Design	Population (Number, Age, Diagnosis)	Environmental Domains				Summary of Main Findings
				Products & Technology & Natural Environment	Support & Relationships	Attitudes	Services, Systems & Policies	
Scott et al. [49] Australia	To present and contrast the viewpoints of adults with ASD and employers for successful employment and to explore how these viewpoints impact the process of employment.	Qualitative—Q method	*n* = 40 employees *n* = 35 employers Employee: Mean age: 29.1 Median: 26 Employer: Mean age: 44.6 Median: 44 ASD	✓	✓	✓	✓	Facilitators: • Having an inclusive work environment, continued support from an employment support worker after hiring, approachable manager, and investing in inclusion • Workplaces that valued, encouraged and supported the employee
Li EPY [50] China	To look critically at the competitive employment experiences of people with intellectual disability and at their perception of social barriers that could affect their ambition to get a job in the community.	Qualitative study	*n* = 18 Aged * 22–43 (mean = 28.7) Mild ID		✓	✓	✓	Facilitators: • Positive attitudes and support from employers and colleagues • Assistance from professionals for employment, disability education for public and employers, training programs to support the development of work and social skills Barriers: • Stress of the interview and negative attitudes of the employer • Workplace discrimination, poor relationships with co-workers and employer
Roessler et al. [51] USA	To determine whether the nature and scope of workplace discrimination is different for youths with epilepsy as compared to other types of disabilities.	Quantitative—comparison analysis	Epilepsy: *n* = 555; General Disability: *n* = 12,663 allegations Aged 18–25 Epilepsy			✓	✓	Barriers: • Job retention was impacted by allegations of discrimination, stereotypes about epilepsy, and frequently being hired into less secure entry level jobs • Unlawful discharge was higher in youths with epilepsy compared to the general disability grouping
Wilson-Kovacs et al. [52] United Kingdom	To present barriers, problems and potential solutions to challenges that members of marginalized groups encounter in the workplace.	Qualitative study	*n* = 14 Data presented for those 35 years old Polio, hearing loss, MS, dyslexia			✓	✓	Barriers: • Lack of feedback provision and inclusion in decision making, perceptions of employee ability, discrimination, lack of necessary accommodations to support integration into workplace culture

Table 2. *Cont.*

Author, Year, Country	Aim of the Study	Study Design	Population (Number, Age, Diagnosis)	Environmental Domains				Summary of Main Findings
				Products & Technology & Natural Environment	Support & Relationships	Attitudes	Services, Systems & Policies	
Lieketseng & Lorenzo [53] South Africa	To describe the capacity of service providers in facilitating the participation of disabled youth in economic development opportunities	Qualitative—case study	*n* = 5 disabled youth, 4 family members and 6 service providers Age only specified as youth Intellectual or sensory impairment			✓	✓	Facilitators: • Disability grants for young adults with disability who want to start their own business Barriers: • Lack of knowledge about the need for inclusion and how to support it, attitudes, stereotypes about disabled youths' participation in the workplace and lack of enactment of inclusion policies • Disability grants for young adults with disability limit work opportunities
Hagner & Cooney [54] USA	To locate individuals with autism who were successfully employed at jobs in the community and to identify the factors that contributed to their success.	Qualitative study	*n* = 14 Aged * 23–36 ASD		✓		✓	Facilitators: • Job modifications such as maintaining a consistent schedule, flexibility in job training, completing the same set of work duties and providing a checklist of tasks that need to be completed • Supervisors providing information about social cues, rules and direct instructions for work tasks • For employees with ASD: coworkers initiating conversations and providing feedback regarding social conventions
			Total:	**17 (55%)**	**21(68%)**	**15 (48%)**	**24 (77%)**	

ID: Intellectual disability, SB: Spina bifida, SCI: Spinal cord injury, CP: Cerebral palsy, MS: Multiple sclerosis, TBI: Traumatic brain injury, MD: Muscular Dystrophy, ASD: Asperger Spectrum Disorder, ADHD: Attention deficit hyperactivity disorder. * Age: Studies with participants below 18 and above 35 years old are included because the mean age of participants in the study lies within 18–35 years old and/or they provide results for a subset of the participants within the range 18–35 years old.

Table 3. Examples of environmental barriers and facilitators across the ICF domains.

Domains	Facilitators	Barriers
Products & technology/Natural environment	• Physical alterations of the building and/or equipment, accessible path, ramp, door handle, open and lock door system, accessible bathroom, separate office, and adjustable desk [33] • Specialized assistive technology such as voice recognition software, special mouse, or computerized phone [33,38,39,41] • Living in urban cities [37]	• Transportation: lack of access, long distance [29,33,36,40] • Difficulty navigating public transport [34] • Inadequate lighting and temperature in the work setting [25]
Support & relationships	• Support from the employer [38] • Support from colleagues (e.g., proofread work) [30] • Support from family and friends to connect young adult with disability to work opportunities [45] • Support from parents (emotional, help with transportation, finding employment, teaching independence skills) [30,34,44] • Positive interactions with colleagues at work (e.g., lunch, breaks) and during non-work related activities [28,44,46] • Receiving information from colleagues about etiquette and dress code when participating in work-related social conventions [54] • Approachable managers who promote fair workplace setting [28,39,49]	• Poor relationships with employers and co-workers [50] • Overprotective parents [34] • Lack of support from parents in job search [43,44]
Attitudes	• Positive attitude from colleagues towards people with disability [50]	• Employer who does not believe in the abilities of a person with disability [30,32,52] • Employers' attitude, misperceptions and stereotypes [50,51] • Discrimination [30,34,51,52] • Negative reaction upon disclosure of condition [38] • Being alienated by colleagues and co-workers if using assistive technology [39] • Employer's belief that employing people with disability is costly due to their needs for accommodations [52]

Table 3. *Cont.*

Domains	Facilitators	Barriers
Services, systems & policies	• Settings that promote inclusion, fair workplace and high levels of interactions and support [49] • Flexible work demands (schedules, workload) [30] • Workplaces that value and recognize employee's skills and contributions [49] • Availability of support services and training programs for employers as well as employees [44] • Receiving assistance from professionals to find and maintain job [50] • Ongoing support from disability employment service providers when making workplace adjustments [49] • Policies that promote reasonable accommodations based on the employee's needs [33] • Wage subsidies in some countries such as Sweden [36] • Opportunities to continuing education [36]	• Unpreparedness and lack of knowledge from the company on how to accommodate a person with disability [30,32,47] • Lack of available jobs [26] • Lack of knowledge regarding policies and available services [30] • Lack of clear policy implementation guides for workplaces [47,53] • Limited reinforcement of existing policies [43,53] • Certificates or diplomas that are not being recognized by workplaces [40] • Eligibility for accommodations is based solely on medical diagnosis rather than employee's needs or functional levels [33] • Lack of professional support in job search [47] • Slow delivery of services [44] • Inflexible work schedule [25]
Other contextual factors	• Higher family SES [30] • Higher level of education [46,47] • Fewer number of people in the household and lower SES [37] • Participation in internship and co-op programs [47]	• Few opportunities to participate in extracurricular or social activities [47] • Lack of opportunities to volunteer [47] • Low education levels [31]

3. Results

Thirty-one articles met the inclusion criteria (See Figure 1). One hundred and ninety articles were excluded and the reason for exclusion is specified in Figure 1. The validation process, conducted by the rehabilitation specialist, resulted in 100% agreement for included articles and 92% agreement for excluded articles. The initial disagreement on 8% of the excluded articles was resolved, and agreement was reached after a discussion with the senior researcher.

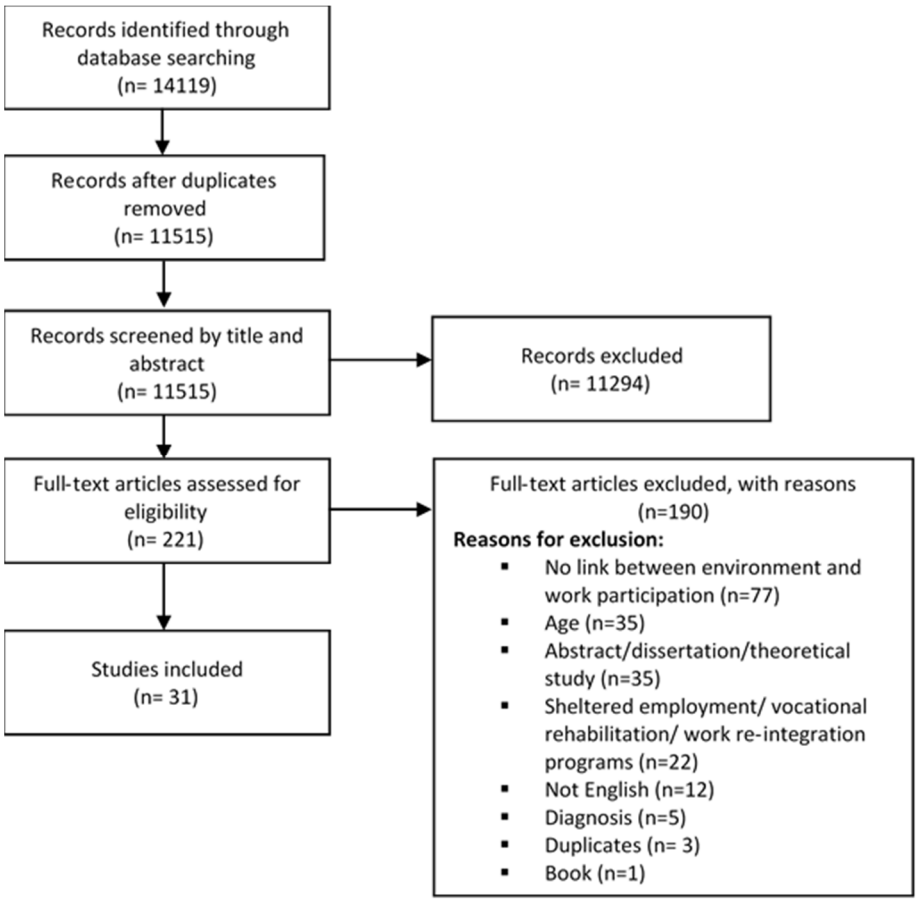

Figure 1. Flow chart of study selection process.

3.1. Descriptive Summary of the Studies

The selected studies were published between the years of 1995 and 2018 with 74% of the studies (n = 23) having been published during or after 2010. The majority of the studies were qualitative (n = 17, 55%), followed by quantitative (n = 11, 35%), and literature reviews (n = 3, 10%). The mean age of the participants was less than 35 years old in 28 of the studies included. The participants in the remaining three studies had a mean age between 35 to 65 years old and were included because data could be extracted specifically to participants aged 35 and younger. Studies were most often completed in the US (n = 10), Canada (n = 5), Australia (n = 4) and the Netherlands (n = 3). Single studies from Brazil, China, Namibia, New Zealand, South Africa, Sweden and the UK were also included. Two studies had representation from more than one country.

Intellectual or developmental disability (n = 9), sensory impairments including vision and hearing loss (n = 7) and cerebral palsy (CP) (n = 6), were the brain-based disabilities most frequently examined in the included studies. Other brain-based disabilities examined include spinal cord injury (SCI) or other spinal conditions, muscular dystrophy (MD), learning disability (LD) or dyslexia, epilepsy, spina bifida (SB), autism spectrum disorder (ASD), multiple sclerosis (MS), attention-deficit hyperactivity disorder (ADHD), traumatic brain injury (TBI) and other neurological conditions. Selected studies

included perspectives of young adults (n = 28), parent or caregivers (n = 5), employers (n = 4), health care providers or unspecified support persons (n = 2) and vocational support specialists (n = 3). Six of the articles reviewed included multiple stakeholder perspectives.

Many of the qualitative studies (n = 17) utilized interviews or focus groups as their primary means of collecting data from participations. Five of the 31 included studies utilizing outcome measures to collect data/information about work participation. These measures included the Assessments of Life Habits [24], the Work Experience Survey [25], the Career Mastery Inventory [25], the Beach Centre Family Quality of Life Scale [26], the Developmental Behaviour Checklist adult version [26], the Index of Social Competence [26], the Stages of Change work Participation Scale [27], and the Vocational Integration Inventory [28]. Only one standardized measure addressed all aspects of the environment; the Measure of the Quality of the Environment [24], while the others focused on a single-domain measure of the environment such as the Family Support questionnaire [26]. Other studies identified environmental factors in the workplace by either relying on data from national surveys or by using their own questionnaires/surveys without any psychometric tests to validate them [27–32].

The majority of the included studies (71%) examined more than one facet of the ICF environmental domains with regards to work participation. The domain of Services, systems and policies (n = 24, 77%) was most frequently examined in the literature followed by the Support and relationships (n = 21, 68%), Products & technology /Natural environment and human-made changes to environment (n = 17, 55%), and Attitudes (n = 15, 48%) (see Figure 2).

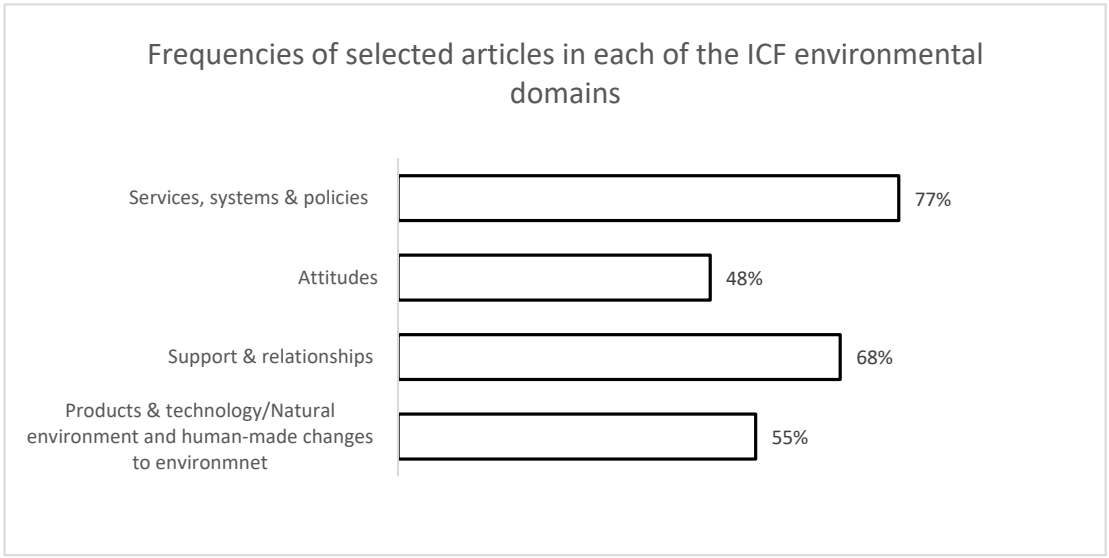

Figure 2. Frequencies of selected articles in each of the International Classification of Functioning, Disability and Health (ICF) environmental domains.

3.2. Main Findings

3.2.1. Products and Technology/Natural Environment and Human-Made Changes to Environment

Among the reviewed articles, 17 (55%) addressed the role of the physical and sensory environments on young adults' participation in the workplace. Identified barriers included the lack of physical accessibility and assistive technology, inflexible and unreliable transportation systems and in some cases, inadequate lighting and temperature of the work setting [30,33–35]. To illustrate, participants with osteogenesis imperfecta, spina bifida or other impairments caused by accidents in the US and in Norway, required workplace accommodations related to the built environment (e.g., accessible paths and bathrooms, ramps, railings, door handles), assistive technology (e.g., voice recognition software), and ergonomic office tools (e.g., a specialized mouse or an adjustable desk) to promote their performance and engagement in the workplace [33]. The sensory environment, including lighting and

temperature, also influenced the employee's ability to effectively perform his/her tasks. For example, the brightness of the environment often caused headaches or impeded computer work due to excessive reflection of light on the desktop among employees with TBI [25].

Studies also discussed the consequences associated with physical environment barriers and the perceived cost of adapting the environment. Failure to provide appropriate accommodations resulted in embarrassing situations and prevented persons with a disability to perform their responsibilities to the best of their abilities [30]. The cost of providing accommodations and adapting the physical environment was reported as a barrier to acquiring a job [29]. In fact, young adults reported that requiring fewer physical adaptations in the workplace increased their chance of acquiring a job [32].

Many studies found that access to adequate transportation is imperative for acquiring and retaining employment [34–36]. Long distance transportation was depicted as a hindrance to working [29]. In fact, transportation was a significant predictor of paid employment amongst young adults with mobility, hearing, vision, communication and/or cognitive impairments [12,37]. Flexible and timely transportation was found to support employment of those with physical disabilities [33]. Additionally, access to a vehicle as either a passenger or driver increased the likelihood of acquiring employment among young adults with various types of disabilities [37]. Lindsay [37] also reported the impact of geographical location on employment rate for individuals in their early years of transitioning who use mobility devices: those living in urban areas were more likely to find a job compared to those living in rural areas. This finding could be explained by other environmental barriers common in these geographical areas, such as a poor economy, scarcity of jobs and lack of services in certain areas that disadvantage people with disabilities [24,26,37].

Environmental supports were also identified; an accessible work environment in which accommodations were made to meet the employee's needs, optimized performance and facilitated engagement in the workplace [30,38]. Many employees reported working from home [25,33,38] and using assistive technology such as Dictaphones, dual monitors, assistive devices for communication and computerized phones and alarms, positively impacted work satisfaction and work maintenance [33,39–41].

3.2.2. Support and Relationships

Twenty-one articles (68%) fell under this category. The main barriers involved young adults' lack of social support or their perception of low support from parents [38]. However, interestingly, those with autism [42] and spina bifida [34] who had high parental support or overprotective parents were even less likely to be employed. Hence, family members, especially parents, played a significant role in finding and maintaining employment [31,43]. The main barriers to employment opportunities for those with autism [44] and intellectual disabilities [26,45] included lack of parental support, time, awareness and knowledge of abilities, parental fatigue and unwillingness to facilitate job search. Family involvement facilitated finding and maintaining employment by guiding career planning and adequate job search, providing support at the workplace, and in some cases, assisting with transportation [27,44,45]. Additionally, having parents with high work-related expectations, who advocated supported employment and provided emotional support, increased the likelihood of being employed and meeting the demands of the job on a daily basis [45] among those with learning disabilities [30] and various types of disabilities [46].

Additional social support from peers and co-workers also emerged as a main facilitator for employment. Sung and Connor [27] demonstrated that in the presence of other important factors (e.g., self-efficacy), 22.5% of the variation in employment among transition-aged individuals with epilepsy was explained by the support they received from parents, friends and professionals. This involved helping them develop specific independence skills required in the workplace [27,34]. Peer support, especially from those already employed, was another facilitator that encouraged and motivated individuals with brain-based disabilities to look for employment [47]. In addition, engagement in work was facilitated in inclusive workplaces in which interaction between co-workers was encouraged [32,44]. In fact, some of the strategies that service agencies used to support

the integration of young adults with disabilities included building relationships and prompting co-workers and supervisors to actively invite employees to socialize during breaks, lunches and while performing the job [44]. Furthermore, a systematic review by De Beer et al. [38] indicated that assistance from colleagues was among the supports that facilitated employment for young adults with developmental dyslexia. To illustrate, having colleagues proofread their work predicted better employment outcomes [30,35], and positive interactions in the workplace led to their career advancement [46]. Participating in work-related social activities such as going to staff functions, eating lunch with other employees and developing interpersonal relationships with co-workers that expanded beyond the workplace, also increased the likelihood of employees with intellectual disabilities to keep their job [28,48].

Management styles within the organization played a role in work experiences of this transitioning population. Approachable managers who created inclusive and fair work environments, as well as those who built relationships and created a strong sense of teamwork, increased engagement in the workplace for those with developmental disabilities [28]. Similarly, managers who had direct contact with their employees, closely collaborated with employment service providers and allowed for work trials rather than interviews, facilitated the employment of young adults with ASD [49]. Moreover, young adults with disabilities were happier in workplaces where they were treated equally [33] and felt that their skills and opinions were valued by the managers [49].

3.2.3. Attitudes

This environmental factor was addressed in 15 (48%) studies in which attitudes of others towards persons with a brain-based disability was mainly seen as a barrier to their employment and participation in the workplace. Young adults with a disability often experienced prejudice and stigma from their employers and co-workers in the workplace. For example, they generally got hired for less skilled occupations as their employers did not believe in their abilities [30,32]. Lindsay et al. [47], illustrated the misconceptions from employers regarding the functional abilities of people with physical disabilities and the negative impact of societal attitudes on their employment. Additionally, many young adults with brain-based disabilities hesitated to disclose their diagnosis (e.g., learning disabilities) to their employer due to fear of discrimination [30]. In their systematic review, De Beer et al. [38] revealed that the reaction of co-workers to this transition-aged population was mostly negative. This negative attitude which usually stems from a lack of knowledge, led to negative experiences for the employee when seeking out a job, i.e., increased stress during the interview, as well as in retaining a position [34,50,51]. In other words, this prejudice created obstacles in young adults' abilities to acquire and enter the labor market or to advance in their careers [30,52]. For example, stereotypes associated with this population such as their inability to work, their need for costly accommodations or their unwillingness to be active members, hindered persons with a disability to exhibit and exercise their skills in the workplace. This was evident in various types of brain-based disabilities, including physical, intellectual and sensory related impairments [39,52,53]. In one study, it was found that this negative perception and discrimination led to higher rates of unlawful discharge of young adults with epilepsy as compared to their colleagues [51]. Overall, approachable employers with positive attitudes and sensitivity to the needs of the employee created positive work experiences and led to better employment satisfaction [30,49,50].

3.2.4. Services, Systems and Policies

The majority of the studies (n = 24, 77%) focused on the impact of services, systems and policies on both acquiring/finding a job and maintaining participation in the workplace. Internal factors, those within the organization/workplace, and external factors, those outside the organization/workplace, were identified.

Internal organization-based barriers and facilitators. Barriers within the organization included complex procedures to obtain and implement accommodations. To illustrate, the organization's lack of flexibility

in allocating resources and its lengthy bureaucratic processes were reported as barriers for obtaining accommodations [25,33,44,52]. The delay in providing necessary services or the lack of support systems in the workplace (e.g., clear guidelines) also created barriers to maintaining employment [33,52]. Unpreparedness of companies and organizations and the lack of awareness of existing policies and resources, as well as limited knowledge on how to implement those policies in their workplace, impeded the successful engagement in employment [53]. Specifically, knowledge on how to select and hire a person with disability, what type of accommodations to provide, and how to handle different situations was limited [30,32,34,47]. This issue was evident in organizations where accommodations were made based on the employers' "recognition" and their "willingness/readiness" to provide services, or in organizations that determined the employee's accommodation needs based on a strictly medical-oriented approach [33]. In such cases, the medical diagnosis rather than the employee's level of function or needs informed the decision of providing accommodations. Limited funding to support awareness of employers and colleagues about disability [49] and insufficient recognition of various types of certificates or diplomas [40] further accentuated this barrier. Additionally, workplaces in which employees were not given constructive feedback, their abilities, skills and contribution were not recognized nor valued, and where they were not involved in the decision-making process, reduced opportunities to advance their careers [25,51,52].

Characteristics of the organization in terms of employment expectations (e.g., task demands, schedules) and availability of support services were reported as facilitators. Work settings that showed flexibility, especially in determining schedules and adapting job demands to the abilities of their employees, facilitated participation [38,44,54]. Flexible organizations that provided adequate accommodations (e.g., allocated more time, allowed work from home, provided breaks as needed, ensured consistent work routine) in a timely manner contributed to the employment of this population [25,33,50]. Those that provided individual-based support to their employees in work (e.g., communicated a change in medication to the employer; broke down or simplified tasks, set work goals, provided personal help to go to the bathroom) and non-work-related areas (e.g., helped adjusting to moving to a new residence) as well as guiding their employees on company policies, protocols and culture (e.g., taking time off for medical reasons), facilitated job sustainability [36,39,49,54]. Offering supervision and appropriate training on work demands and the social cues within the workplace, was another perceived facilitator [28,48–50,54]. The provision of ongoing support combined with clear job descriptions and expectations helped young adults maintain their jobs and progress in their careers [49]. Finally, organizations that promoted disability awareness and provided training for staff increased the likelihood of creating an engaging work environment for this population [25,49,50].

External barriers and facilitators. Factors external to the organization/workplace were also observed and involved both aspects of services and policies. In terms of access to employment supports and services, employees with disability expressed the need for more services to find employment as well as support in the workplace to maintain it. For example, young adults reported that employment services that helped with job applications, but did not assist in job searching that fitted their abilities, made finding employment difficult [40]. Additionally, scarcity of accessible employment and lack of professional support further limited their ability to enter the workforce [24,34,35,47,53]. Access to adult service agencies, disability employment services, job coaches, social workers and school staff, that provided training to employers and supported the employee on the job, facilitated transitioning to the workforce [44,48].

Policies addressing laws and regulations external to the organization, to support inclusion and workplace participation, also had an impact on successful employment as evident in a few studies. The availability of policies and their implementation in workplaces were mainly examined. Parents of young adults with developmental disabilities were concerned about the lack of macro-level policies supporting employment [26]. A study done in Namibia [43] revealed that inclusion policies for young adults with visual impairments were not effective in the workplace and were not implemented. Another study completed in both the United States and Norway highlighted that although some policies such

as the Americans with Disability Act (ADA) recognized the rights of people with disability in the workplace and promoted "reasonable accommodations," they were unclear about the extent and the range of assistance that should be provided. This resulted in the provision of inadequate assistance to the employee, impacting their ability to perform their jobs [33]. Different types of government programs had varying impacts on the access to employment of this population. For example, government wage subsidies were found to facilitate employment in some countries such as Sweden [33,36]. On the other hand, sheltered employment programs restricted the ability of the individual to acquire open and competitive employment in Australia [26]. Finally, young adults also expressed that the removal or reduction of government-based income benefits after acquiring well-paid employment prevented them from reaching their full potential at work [33,40,51].

3.2.5. Other Contextual Factors

Contextual factors that did not fit any of the ICF environmental domains yet contributed to the employment of young adults with brain-based disabilities emerged and are grouped under personal factors. Examples include financial advantages, educational opportunities, and opportunities to participate in extracurricular activities and in the community (e.g., volunteering) [30,47]. Studies found that lack of previous work experience and lower levels of education contributed to fewer employment opportunities [31]. Similarly, Lindstrom et al. [46] and Lindsay et al. [34] concluded that higher levels of education led to broader qualified jobs with a higher salary within this population. Among the facilitators, Lindsay [37] showed that lower household income and fewer household members were associated with increased probability of having paid employment among individuals with cognitive or communication impairments. Young adults who benefitted from disability services and supports, and those who participated in the Co-op and internship programs offered through their high school and post-secondary schools were also found to have better employment opportunities [34,46].

4. Discussion

This scoping review revealed that all aspects of the environment as described by the ICF have an impact on workplace participation as a barrier and/or as a facilitator, expanding previous research conducted among those with ID [14] and ASD [13], to a broader range of brain-based disabilities. Specifically, a large body of evidence (77% of the studies) focused on the impact of services, systems and policies on both acquiring and maintaining a job. An emphasis was placed on the role of the organizations in creating an inclusive work environment, providing training for and promoting disability awareness of managers and staff, as well as embracing positive attitudes. As such, findings draw attention towards the developing of interventions that reduce the environmental barriers at the organizational level, identified in this review.

None of the studies examined the effectiveness of existing policies that specifically promote employment and workplace participation at the macro-level (i.e., provincial and national policies in the larger societal context). The few studies that mentioned "policies", described the lack of awareness and at times, willingness to implement existing policies in the workplace. The same pattern was seen among older adults with disabilities who face work participation challenges due to either inadequate implementation of policies and regulation or the lack of it all together to support their work participation [55,56]. This further emphasizes the importance of implementing policies at early stages since that is when young people enter the work force. Furthermore, not only are there very few policies to promote the employment of this population but there are no clear guidelines and procedures on how to implement and reinforce them in the workplace. Future research can address this issue by developing adequate policies, proposing and testing effective ways to disseminate information on policies to stakeholders (e.g., managers, supervisors, employers and employees with and without disabilities) as well as finding adequate ways to implement them. This can be achieved by providing educational programs, as well as having clear procedures and processes in place to implement them.

Studies also demonstrated the positive impact of social support while shedding light on the detrimental effect of negative attitudes on workplace inclusion of this population. This finding supports the need for effective interventions by service providers and policymakers to improve attitudes in the work environment. This can be done through educational initiatives, increasing others' knowledge about disability and inclusion as well as providing information on how to make successful accommodations in the workplace. Furthermore, findings highlight the use of assistive technology in enhancing work participation by facilitating the completion of certain work tasks and performance of responsibilities. With rapidly developing technological solutions, putting in place technology-based accommodations (applications, software) has become readily available [41], making the implementation of such accommodations more practical.

Several knowledge gaps were identified. Although the literature described a range of environmental barriers that impacted workplace participation, there is still little that is known on effective strategies to overcome these environmental barriers. Indeed, only seven studies (out of 31) described strategies used to facilitate work participation, without evaluating their impact. The available examples of actions that organizations can take, focused mainly on improving physical accommodations (e.g., providing assistive technology, giving extra time to complete tasks, creating an accessible environment), with little evidence on strategies to remove other important barriers like attitudinal (e.g., discrimination, pre-conceived ideas about disability), organizational (e.g., rigid task demands and schedules), and institutional (e.g., lack of training and support). In addition, the majority of the included studies were qualitative in nature. This can be complemented by quantitative studies using advanced statistical methods to systematically evaluate the environment and the workplace participation. Furthermore, most of the studies employed a cross-sectional design, with only two longitudinal studies, suggesting that available evidence is limited in claiming causal relationship between the environment and participation. Notably, while our approach to synthesize evidence according to the domains of the ICF appeared overall appropriate, only five studies (out of the 31) explicitly used the ICF as a guide. Finally, very few of the quantitative studies administered standardized, comprehensive and psychometrically sound measures to evaluate environmental factors that affect participation in the workplace.

The knowledge synthesized may guide employment-related service providers to identify specific environmental characteristics that are important, need to be evaluated, and are potential areas for intervention. Findings demonstrate that there is a strong promise in shifting focus toward the environment, rather than solely focusing on the skills of transition-aged individuals with brain- based disabilities. Interventions, programs and policies can target support and services at the institutional level (within a broader structural context such as social systems/community agencies) and organizational level (within the immediate workplace environment) as these factors were commonly identified as barriers/supports. This information can be used to develop or strengthen environment-based interventions, such as the Pathways and Resources for Engagement and Participation (PREP), proven effective in improving community participation among transition-aged young people by only changing aspects of their environment [57]. Policymakers can also draw on this knowledge to develop clear and specific guidelines to implement and reinforce policies in the work environment. Transition programs and services based in the community can also benefit from this knowledge by developing programs that address specific environmental barriers, faced by young individuals, and foster their inclusion in open and competitive employment.

A limitation of this study is that grey literature and articles not published in English were excluded, which may have resulted in important information being missed. Additionally, given that the aim of this review was to synthesize literature related to the impact of the environment on open and competitive employment, studies focusing on participation in sheltered employment were excluded. Thus, it is possible that information relevant to the environmental impact on employment participation was omitted. Typical to scoping reviews [21], no quality assessment of the included studies was conducted due to the large number of research designs and variety in methodological approaches of the included studies. Given that this topic is a newly studied area, the intent of this review was to

synthesize all information available without parameters related to study quality. Thereby, no firm conclusions can be made about the effectiveness or the magnitude of the effect of the environment on work participation among young adults with brain-based disabilities.

5. Conclusions

Findings highlight the role of the environment in facilitating and/or hindering employment. Particularly, environmental factors at the organizational level and at the institutional level appear to be critical in fostering workplace participation in this population.

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References

1. World Health Organization. *International Classification of Functioning, Disability and Health*; ICF: Geneva, Switzerland, 2001.
2. Chang, F.-H.; Coster, W.J. Conceptualizing the Construct of Participation in Adults with Disabilities. *Arch. Phys. Med. Rehabil.* **2014**, *95*, 1791–1798. [CrossRef] [PubMed]
3. Van Gorp, M.; Van Wely, L.; Dallmeijer, A.J.; de Groot, V.; Ketelaar, M.; Roebroeck, M.E. Long-Term Course of Difficulty in Participation of Individuals with Cerebral Palsy Aged 16 to 34 Years: A Prospective Cohort Study. *Dev. Med. Child Neurol.* **2019**, *61*, 194–203. [CrossRef] [PubMed]
4. Frey, B.S.; Stutzer, A. *Happiness and Economics: How the Economy and Institutions Affect Human Well-Being*; Princeton University Press: Princeton, NJ, USA, 2002.
5. Luecking, L.G.; Mooney, M. Tapping Employment Opportunities for Youth with Disabilities by Engaging Effectively with Employers. *Res. Pract. Br.* **2002**, *1*, 1–5.
6. Statistics Canada. A Profile of Persons with Disabilities Among Canadians Aged 15 Years or Older. Available online: http://www.statcan.gc.ca/pub/89-654-x/89-654-x2015001-eng.htm#r5 (accessed on 27 March 2020).
7. World Health Organization. *World Report on Disability*; WHO: Geneva, Switzerland, 2011.
8. Palmer, M. Disability and Poverty: A Conceptual Review. *J. Disabil. Policy Stud.* **2011**, *21*, 210–218. [CrossRef]
9. Wehman, P.; Taylor, J.; Brooke, V.; Avellone, L.; Whittenburg, H.; Ham, W.; Brooke, A.M.; Carr, S. Toward Competitive Employment for Persons with Intellectual and Developmental Disabilities: What Progress Have We Made and Where Do We Need to Go. *Res. Pract. Pers. Sev. Disabil.* **2018**, *43*, 131–144. [CrossRef]
10. Anaby, D.; Law, M.; Coster, W.; Bedell, G.; Khetani, M.; Avery, L.; Teplicky, R. The Mediating Role of the Environment in Explaining Participation of Children and Youth with and without Disabilities across Home, School, and Community. *Arch. Phys. Med. Rehabil.* **2014**, *95*, 908–917. [CrossRef]
11. Unger, D.D. Employers' Attitudes toward Persons with Disabilities in the Workforce: Myths or Realities? *Focus Autism Dev. Disabl.* **2002**, *17*, 2–10. [CrossRef]
12. Lindsay, S. Discrimination and Other Barriers to Employment for Teens and Young Adults with Disabilities. *Disabil. Rehabil.* **2011**, *33*, 1340–1350. [CrossRef]
13. Khalifa, G.; Sharif, Z.; Sultan, M.; Di Rezze, B. Workplace Accommodations for Adults with Autism Spectrum Disorder: A Scoping Review. *Disabil. Rehabil.* **2019**, 1–16. [CrossRef]
14. Ellenkamp, J.J.H.; Brouwers, E.P.M.; Embregts, P.J.C.M.; Joosen, M.C.W.; van Weeghel, J. Work Environment-Related Factors in Obtaining and Maintaining Work in a Competitive Employment Setting for Employees with Intellectual Disabilities: A Systematic Review. *J. Occup. Rehabil.* **2016**, *26*, 56–69. [CrossRef]

15. Wolf-Branigin, M.; Schuyler, V.; White, P. Improving Quality of Life and Career Attitudes of Youth With Disabilities: Experiences From the Adolescent Employment Readiness Center. *Res. Soc. Work Pract.* **2007**, *17*, 324–333. [CrossRef]
16. Arksey, H.; O'Malley, L. Scoping Studies: Towards a Methodological Framework. *Int. J. Soc. Res. Methodol.* **2005**, *8*, 19–32. [CrossRef]
17. Levac, D.; Colquhoun, H.; O'Brien, K.K. Scoping Studies: Advancing the Methodology. *Implement. Sci.* **2010**, *5*, 1–9. [CrossRef] [PubMed]
18. Di Rezze, B.; Nguyen, T.; Mulvale, G.; Barr, N.; Longo, C.; Randall, G. A Scoping Review of Evaluated Interventions Addressing Developmental Transitions for Youth with Mental Health Disorders. *Child Care Health Dev.* **2016**, *42*, 176–187. [CrossRef] [PubMed]
19. (UNICEF). Age-Related Barriers to Service Access and the Realisation of Rights for Children, Adolescents and Youth. Available online: https://agemattersnow.org/downloads/YPL_Age_Matters_Final_Report_Oct2016.pdf (accessed on 27 March 2020).
20. World Health Organization. Adolescence: A Period Needing Special Attention. Available online: http://apps.who.int/adolescent/second-decade/section2/page1/recognizing-adolescence.html (accessed on 27 March 2020).
21. Pham, M.; Rajić, A.; Greig, J.; Sargeant, J.; Papadopoulos, A.; McEwen, S. A Scoping Review of Scoping Reviews: Advancing the Approach and Enhancing the Consistency. *Res. Synth. Methods* **2014**, *5*, 371–385. [CrossRef] [PubMed]
22. Elo, S.; Kyngas, H. The Qualitative Content Analysis Process. *J. Adv. Nurs.* **2008**, *62*, 107–115. [CrossRef]
23. Kastner, M.; Tricco, A.C.; Soobiah, C.; Lillie, E.; Perrier, L.; Horsley, T.; Welch, V.; Cogo, E.; Antony, J.; Straus, S.E. What Is the Most Appropriate Knowledge Synthesis Method to Conduct a Review? Protocol for a Scoping Review. *BMC Med. Res. Methodol.* **2012**, *12*, 114. [CrossRef]
24. Foley, K.-R.; Girdler, S.; Bourke, J.; Jacoby, P.; Llewellyn, G.; Einfeld, S.; Tonge, B.; Parmenter, T.R.; Leonard, H. Influence of the Environment on Participation in Social Roles for Young Adults with down Syndrome. *PLoS ONE* **2014**, *9*, 1–11. [CrossRef]
25. Roessler, R.T.; Rumrill, P.D.J.; Rumrill, S.P.; Minton, D.L.; Hendricks, D.J.; Sampson, E.; Stauffer, C.; Scherer, M.J.; Nardone, A.; Leopold, A.; et al. Qualitative Case Studies of Professional-Level Workers with Traumatic Brain Injuries: A Contextual Approach to Job Accommodation and Retention. *Work* **2017**, *58*, 3–14. [CrossRef]
26. Foley, K.-R.; Girdler, S.; Downs, J.; Jacoby, P.; Bourke, J.; Lennox, N.; Einfeld, S.; Llewellyn, G.; Parmenter, T.R.; Leonard, H. Relationship between Family Quality of Life and Day Occupations of Young People with Down Syndrome. *Soc. Psychiatry Psychiatr. Epidemiol.* **2014**, *49*, 1455–1465. [CrossRef]
27. Sung, C.; Connor, A. Social-Cognitive Predictors of Vocational Outcomes in Transition Youth with Epilepsy: Application of Social Cognitive Career Theory. *Rehabil. Psychol.* **2017**, *62*, 276–289. [CrossRef] [PubMed]
28. Butterworth, J.; Hagner, D.; Helm, D.T.; Whelley, T.A. Workplace Culture, Social Interactions, and Supports for Transition-Age Young Adults. *Ment. Retard.* **2000**, *38*, 342–353. [CrossRef]
29. Barf, H.A.; Post, M.W.M.; Verhoef, M.; Jennekens-Schinkel, A.; Gooskens, R.H.J.M.; Prevo, A.J.H. Restrictions in Social Participation of Young Adults with Spina Bifida. *Disabil. Rehabil.* **2009**, *31*, 921–927. [CrossRef]
30. Greenbaum, B.; Granham, S.; Scales, W. Occupational and Social Status after College. *J. Learn. Disabil.* **1996**, *29*, 167–173. [CrossRef] [PubMed]
31. Honey, A.; Kariuki, M.; Emerson, E.; Llewellyn, G. Employment Status Transitions among Young Adults, with and without Disability. *Aust. J. Soc. Issues* **2014**, *49*, 151–170. [CrossRef]
32. Toldrá, R.C.; Santosb, M.C. People with Disabilities in the Labor Market: Facilitators and Barriers. *Work* **2013**, *45*, 553–563. [CrossRef] [PubMed]
33. Solstad, V.J.; Schreuer, N. Policy in Action: Stories on the Workplace Accommodation Process. *J. Disabil. Policy Stud.* **2011**, *22*, 95–105. [CrossRef]
34. Lindsay, S.; McPherson, A.C.; Maxwell, J. Perspectives of School-Work Transitions among Youth with Spina Bifida, Their Parents and Health Care Providers. *Disabil. Rehabil.* **2017**, *39*, 641–652. [CrossRef]
35. Sherer, M.; Davis, L.C.; Sander, A.M.; Caroselli, J.S.; Clark, A.N.; Pastorek, N.J. Prognostic Importance of Self-Reported Traits/Problems/Strengths and Environmental Barriers/Facilitators for Predicting Participation Outcomes in Persons with Traumatic Brain Injury: A Systematic Review. *Arch. Phys. Med. Rehabil.* **2014**, *95*, 1162–1173. [CrossRef]

36. Törnbom, M.; Jonsson, U.; Sunnerhagen, K.S. Work Participation among Middle-Aged Persons with Cerebral Palsy or Spina Bifida–a Longitudinal Study. *Disabil. Health J.* **2014**, *7*, 251–255. [CrossRef]
37. Lindsay, S. Employment Status and Work Characteristics among Adolescents with Disabilities. *Disabil. Rehabil.* **2011**, *33*, 843–854. [CrossRef] [PubMed]
38. De Beer, J.; Engels, J.; Heerkens, Y.; van der Klink, J. Factors Influencing Work Participation of Adults with Developmental Dyslexia: A Systematic Review. *BMC Public Health* **2014**, *14*, 1–22. [CrossRef] [PubMed]
39. Ripat, J.D.; Woodgate, R.L. The Importance of Assistive Technology in the Productivity Pursuits of Young Adults with Disabilities. *Work* **2017**, *57*, 455–468. [CrossRef] [PubMed]
40. Darrah, J.; Magill-Evans, J.; Galambos, N.L. Community Services for Young Adults with Motor Disabilities—A Paradox. *Disabil. Rehabil.* **2010**, *32*, 223–229. [CrossRef]
41. Morash-Macneil, V.; Johnson, F.; Ryan, J.B. A Systematic Review of Assistive Technology for Individuals with Intellectual Disability in the Workplace. *J. Spec. Educ. Technol.* **2018**, *33*, 15–26. [CrossRef]
42. Holwerda, A.; van der Klink, J.J.L.; de Boer, M.R.; Groothoff, J.W.; Brouwer, S. Predictors of Sustainable Work Participation of Young Adults with Developmental Disorders. *Res. Dev. Disabil.* **2013**, *34*, 2753–2763. [CrossRef]
43. Tobias, E.I.; Mukhopadhyay, S. Disability and Social Exclusion: Experiences of Individuals with Visual Impairments in the Oshikoto and Oshana Regions of Namibia. *Psychol. Dev. Soc. J.* **2017**, *29*, 22–43. [CrossRef]
44. Hagner, D.; Butterworth, J.; Keith, G. Strategies and Barriers in Facilitating Natural Supports for Employment of Adults with Severe Disabilities. *J. Assoc. Pers. Sev. Handicap.* **1995**, *20*, 110–120. [CrossRef]
45. Petner-Arrey, J.; Howell-Moneta, A.; Lysaght, R. Facilitating Employment Opportunities for Adults with Intellectual and Developmental Disability through Parents and Social Networks. *Disabil. Rehabil.* **2016**, *38*, 789–795. [CrossRef]
46. Lindstrom, L.; Doren, B.; Miesch, J. Waging a Living: Career Development and Long-Term Employment Outcomes for Young Adults with Disabilities. *Except Child.* **2011**, *77*, 423–434. [CrossRef]
47. Lindsay, S.; McDougall, C.; Menna-Dack, D.; Sanford, R.; Adams, T. An Ecological Approach to Understanding Barriers to Employment for Youth with Disabilities Compared to Their Typically Developing Peers: Views of Youth, Employers, and Job Counselors. *Disabil. Rehabil.* **2015**, *37*, 701–711. [CrossRef] [PubMed]
48. Reid, P.M.; Bray, A. Paid Work and Intellectual Disability. *J. Intellect. Dev. Disabil.* **1997**, *22*, 87–96. [CrossRef]
49. Scott, M.; Falkmer, M.; Girdler, S.; Falkmer, T. Viewpoints on Factors for Successful Employment for Adults with Autism Spectrum Disorder. *PLoS ONE* **2015**, *10*, 1–15.
50. Li, E.P.Y. Self-Perceived Equal Opportunities for People with Intellectual Disability. *Int. J. Rehabil. Res.* **2004**, *27*, 241–245. [CrossRef]
51. Roessler, R.T.; Hawley, C.E.; McMahon, B.T. Employment Discrimination Experiences of Youth with Epilepsy: A Comparative Analysis. *J. Vocat. Rehabil.* **2012**, *36*, 149–158. [CrossRef]
52. Wilson-Kovacs, D.; Ryan, M.K.; Haslam, S.A.; Rabinovich, A. 'Just Because You Can Get a Wheelchair in the Building Doesn't Necessarily Mean That You Can Still Participate': Barriers to the Career Advancement of Disabled Professionals. *Disabil. Soc.* **2008**, *23*, 705–717. [CrossRef]
53. Lieketseng, N.; Lorenzo, T. Enhancing the Public Sector's Capacity for Inclusive Economic Participation of Disabled Youth in Rural Communities. *Afr. J. Disabil.* **2016**, *5*, 1–9.
54. Hagner, D.; Cooney, B.F. I Do That for Everybody: Supervising Employees with Autism. *Focus Autism Dev. Disabl.* **2005**, *20*, 91–97. [CrossRef]
55. Prodinger, B.; Weise, A.; Shaw, L.; Stamm, T. A Delphi Study on Environmental Factors That Impact Work and Social Life Participation of Individuals with Multiple Sclerosis in Austria and Switzerland. *Disabil. Rehabil.* **2010**, *32*, 183–195. [CrossRef]
56. Coelho, C.M.; Sampaio, R.F.; Luz, M.T.; Mancini, M.C. Work Reality Perceived by Individuals with Impairments: A Biopsychosocial Experience. *Work* **2013**, *45*, 537–551. [CrossRef]
57. Anaby, D.; Law, M.; Feldman, D.; Majnemer, A.; Avery, L. The effectiveness of the Pathways and Resources for Engagement and Participation (PREP) intervention: Improving participation of adolescents with physical disabilities. *Dev. Med. Child Neurol.* **2018**, *60*, 513–519. [CrossRef] [PubMed]

Chapter 4: Bridging Manuscripts 1 and 2

Research Questions

Manuscript 1

Research question: What is known about the impact of the environment on the participation in the work setting among transition-aged individuals with brain-based disabilities?

Objective: To identify and synthesize existing evidence on the impact of the environment on participation in mainstream inclusive work settings among transition-aged young adults.

Manuscript 2

Research question: How to comprehensively evaluate participation among transition-aged youth and young adults aged 12-30 years old across different settings: home, school/educational setting, community, and the workplace?

Objective: This manuscript had two objectives:

1. To adapt and examine the content validity of the home, school, and community sections of the PEM-CY as a self-reported measure in terms of its clarity and relevancy for a population of young people aged 12-30 years old.
2. To develop and examine the initial content validity of items for a new section on work participation designed for use by young people aged 12-30 years old and adapt the environmental items to capture environmental barriers/facilitators that impact work participation in this age group.

Integration of Manuscripts 1 & 2

Previous research on participation and the impact of the environment on participation for children and youth suggested that participation-based measures should also consider the

environment [1-3]. In fact, one of the unique features and strengths of the PEM-CY is its ability to comprehensively capture environmental barriers and supports in three settings: home, school, and the community [4]. In order to develop a new domain related to work, it was important to investigate what aspects of the environment influence participation in the workplace for youth and young adults with disabilities. To inform content development, we wanted to know what the top components of the environment that affect participation in the mainstream workplace were.

The scoping review synthesized current evidence on the impact of the environment on participation of young individuals with brain-based disabilities (i.e., cerebral palsy, visual impairments, brain and spinal-related injuries) in the workplace. Findings revealed that all environmental components of the ICF impact workplace participation among this population. Examples included support from peers, families, colleagues and employers; an accessible workplace; assistive technologies; flexible work schedules; adequate accommodations; accessible transportation. The results of this scoping review were integral in shaping the environmental items of the newly developed workplace participation domain of the Y-PEM that were inspired by the community setting of the PEM-CY. This review elicited specific and relevant environmental factors that impact work participation. This knowledge informed and added to the specific examples underpinning the items of environmental barriers and supports that tapped into the context of work. Therefore, the scoping review ensured that the examples of the environmental items were grounded in evidence. Results of this synthesis of knowledge supported the need for a measure that looks at both participation and the environment when assessing work and informed the content development of the workplace environmental items. In manuscript 2, the relevancy of these workplace environmental items and examples were further investigated during the initial content validity of Y-PEM's workplace domain by young adults.

References

1. Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A., & Law, M. (2013). The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disability and rehabilitation, 35*(19), 1589-1598. https://doi.org/10.3109/09638288.2012.748840

2. Anaby, D. P., Law, M. P., Coster, W. P., Bedell, G. P., Khetani, M. S., Avery, L. M., & Teplicky, R. M. (2014). The Mediating Role of the Environment in Explaining Participation of Children and Youth With and Without Disabilities Across Home, School, and Community. *Archives of physical medicine and rehabilitation, 95*(5), 908-917. https://doi.org/10.1016/j.apmr.2014.01.005

3. Anaby, D., Law, M., Hanna, S., & Dematteo, C. (2012). Predictors of change in participation rates following acquired brain injury: results of a longitudinal study. *Developmental medicine and child neurology, 54*(4), 339-346. https://doi.org/10.1111/j.1469-8749.2011.04204.x

4. Coster, M., Law, M., Bedell, G., Khetani, M., Anaby, D. . (2013). The Participation and Environment Measure for Children and Youth (PEM-CY): An innovative measure for home, school and community. *CanChild*. https://canchild.ca/en/resources/228-the-participation-and-environment-measure-for-children-and-youth-pem-cy-an-innovative-measure-for-home-school-and-community

Chapter 5: Manuscript 2

Title: Development and Content Validity of the Youth and young-adult Participation and Environment Measure (Y-PEM)

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Development and content validity of the youth and young-adult participation and environment measure (Y-PEM)

Saeideh Shahin, Briano DiRezze, Sara Ahmed & Dana Anaby

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ORIGINAL ARTICLE

Development and content validity of the youth and young-adult participation and environment measure (Y-PEM)

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ABSTRACT

Purpose: To develop and evaluate the content of a self-reported measure of participation and environment, named Youth, Young-adult Participation and Environment Measure (Y-PEM), capturing participation at home, school, community, and the workplace among individuals with physical disabilities aged 12–30.

Materials and methods: A multi-phase sequential design based on elements of COnsensus for Standard Measurements INstrument was employed. Five consecutive rounds of cognitive interviews with 24 participants aged 12–33 years ($\bar{X} = 20.9$; $n = 19$ with a physical disability) and consultation with experts ($n = 15$) were conducted for item development and validation. Relevancy and clarity of items in each setting were assessed using the 10-cm Visual Analogue Scales (VASs).

Results: Participants recommended adding activities specific to this age group (i.e., dating, caregiving, preparing meals, employment). On a 4-point Likert scale, work-related items were perceived important by experts ($\bar{X} = 3.4$) and young adults ($\bar{X} = 3.1$) with average clarity of 8.8 and relevancy of 8.4 out of 10, on the VASs. Similarly, the average clarity of items across settings (home, school, community) ranged from 6.9 to 8.7 and relevancy from 7.4 to 8.1. No modifications were required in environmental items.

Conclusions: Results suggest that Y-PEM is clear, relevant, comprehensive, and can be completed by individuals aged 12–30 with physical disabilities.

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Participation measure; transition-aged; environment; assessment; workplace participation

➤ IMPLICATIONS FOR REHABILITATION

- The Y-PEM can provide a standardized and systematic method to assess the first-hand subjective experience of youth and young adults with disabilities aged 12–30 in their participation at home, school, community, and the workplace.
- The Y-PEM can provide information regarding participation in activities that prepare youth or young adults for the job market as well as their perspective on the environmental barriers or supports that they may face in their employment.
- Clinicians can use the Y-PEM to identify environmental barriers and facilitators that impact participation across different settings and address them to further promote participation in meaningful and age-related activities.

Introduction

Participation, defined by the International Classification of Functioning, Disability, and Health (ICF) and the Child and Youth version (ICF-CY) as "involvement in life situations" [1,2], contributes to improved quality of life among children, adolescents, and young adults with disabilities [3,4]. Despite its known benefits, youth and young adults with physical disabilities engage in less diverse and more passive activities during their transition to adulthood than their typically developing peers [5–7]. Specifically, their level of participation begins to decline as they move to their teenage years, around the of age 12 [8]. Participation in adult roles decreases in their mid and late 20 s in a range of life areas including employment, which is a pertinent domain for this transition-aged group [8,9]. For youth with disabilities, transitioning to adulthood is a complex process that should be supported as early as possible, preferably as individuals enter adolescence, to improve participation outcomes in adulthood [6,10]. This highlights the importance of capturing participation during this critical transition phase—a stage in which life-long habits can be established through positive experiences and opportunities for participation [11]. The transitioned-aged period, defined broadly here, includes individuals aged 12–30 [12].

Assessing the environment is imperative in understanding the challenges that people with disability face in participating in meaningful activities across different settings. Recent scoping reviews indicate that the environment plays a key role in both supporting and hindering the participation of young people in many settings and life domains and across disabilities [13,14]. Among children and youth with various disabilities, aged 5–17, factors referring to the physical, social, attitudinal, and institutional facets of the environment, were significantly linked to participation outcomes at home, school, and the community [13].

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This association continues to persist amongst young adults aged 18–35 years old, expanding to other age-appropriate settings, such as the workplace [15,16]. In fact, the environment explains many of the employment challenges that young adults with disability face. To illustrate, a scoping review by Shahin et al. [16] revealed that all aspects of the environment, as depicted by the ICF, had an impact on the workplace participation of this transition-aged group. Examples of common environmental supports included inclusive and flexible regulations and policies at the organization level as well as social support from family, friends, colleagues, and employers; whereases environmental barriers involved unsupportive attitudes at the workplace among others. It is important, therefore, to have outcome measures that can identify participation patterns and environmental supports/barriers to participation, particularly those that capture the first-hand experience of young people. Such tools, known as Patient-Reported Outcome Measures (PROMs), align well with the current emphasis on individual's perspective in assessing health.

A systematic review of participation-based measurement tools [17] revealed a few measures targeting the transition age range. However, available measures do not comprehensively assess the range of activities that are specific to the transition-aged population nor do they include the environmental factors that directly impact participation [18]. In addition, some measures focus solely on one dimension of participation, i.e., frequency or attendance [19]. Such measures do not capture the subjective component of participation (i.e., level of enjoyment and involvement) which are more closely associated with optimal or successful participation [20]. The Participation and Environment Measure-Children and Youth (PEM-CY) is an example of a measure that assesses participation in a wide range of 25 activity sets typically done at home (e.g., computer and video games; arts, crafts, music and hobbies), school (e.g., classroom activities, special roles at school), and the community (e.g., neighbourhood outings, organized physical activities) using both dimensions of participation, attendance/frequency (using 8-point scale, from never = 0 to daily = 7), and involvement (5-point scale, from minimally involved = 1 to very involved = 5). It also assesses if parents wish to see a change in their child or in youth participation, and if yes, the PEM-CY desire for change scale provides options to indicate the type(s) of change desired (e.g., be more or less involved) [21,22]. In addition, the PEM-CY evaluates aspects of the environment (e.g., physical, social, attitudinal) that support or hinder participation as well as the availability of and access to resources (programs, equipment, supplies, information) that facilitate participation. This outcome measure was developed based on extensive conceptual work with parents of children and youth with and without disabilities [23], with supporting evidence for its psychometric properties [24–26]. However, the PEM-CY is a parent-reported tool intended for children and youth aged 5–17 and does not originally emphasize activities known to be pertinent for those transitioning into adulthood, e.g., independent living, post-secondary education, and employment. This study, therefore, aimed to adapt, develop and examine the content of a self-reported participation measure, modelled after the PEM-CY, called the Youth and Young-adult Participation and Environment Measure (Y-PEM), that comprehensively captures participation patterns and environmental factors affecting participation across a range of settings, including the workplace. Specifically, through a multi-phase sequential process, guided by elements of the COnsensus for Standard Measurements INstrument (COSMIN) [27] and the Benson and Clark model [28], we aimed to:

1. Adapt and examine the content validity of the home, school, and community sections of the PEM-CY as a self-report measure in terms of its clarity and relevancy for a population of young people aged 12–30 years old.
2. Develop and examine the initial content validity of items for a new work section designed for use by young people aged 12–30 years old and adapt the environmental items to capture environmental barriers/facilitators that impact work participation in this age group.

Methods

A multi-phase sequential study was used to develop, refine, and validate the Y-PEM to comprehensively capture participation in the home, school, community, and workplace for transition-aged youth aged 12–30 years old. This age range was selected as it corresponds with the United Nations definition of youth [12] and follows Lindsey et al.'s [29] recommendation to expand the age range for youth with physical disabilities especially within the context of employment, allowing them more time to prepare for complex adults roles. Guided by elements of the COSMIN for establishing content validity [27], a three-phase sequential study with a qualitative focus was employed. Specifically, five consecutive rounds of 1-h cognitive interviews (CIs) were conducted and relevancy and clarity of items using VASs were concurrently collected. Findings of each phase informed the subsequent phase (see Figure 1). The cognitive interviews, using a semi-structured interview guide, involved debriefing techniques and cognitive probes to elicit in-depth information about the participant's impression of the questionnaire, relevancy, clarity, and the comprehensiveness of the items and scales [30].

Twenty-four youth and young adults participated in the study: phase 1 ($n = 10$), phase 2 ($n = 6$), and phase 3 ($n = 8$). They were recruited from rehabilitation centers across the Greater Montreal area using purposeful sampling. Each phase included 6–10 participants which meet the requirement of COSMIN guidelines for establishing/assessing content validity for PROMs [27]. Youth participants were included if they were aged 12–40 years old with adequate cognitive abilities, based on therapists' input, to reflect, and communication skills to report on their participation [31]. Specific to phase 3, participants were included if they had current or previous work or volunteering experience. All CIs were conducted in-person by interviewers with a background in Occupational Therapy (OT) and a similar understanding of participation, at a convenient location for participants (i.e., rehabilitation centre or their home). Fifteen experts in the field of employment were purposefully selected and were included if they had at least 1 year of experience in providing employment-related services. Experts were recruited from research centers and other community organizations across Quebec and Ontario. A range of experts were included, such as researchers, clinicians, directors from community organizations that provide employment services, youth with physical disabilities, and parents.

The specific methods and procedures used in each phase are described below and illustrated in Figure 1. This manuscript provides a detailed report on phases 2 and 3, as phase 1 of the study has been completed and published elsewhere [32] and hence will only be briefly described. The study was approved by Centre de recherche interdisciplinaire en readaptation du Montréal métropolitain (CRIR) ethics committee and all participants have completed an informed consent.

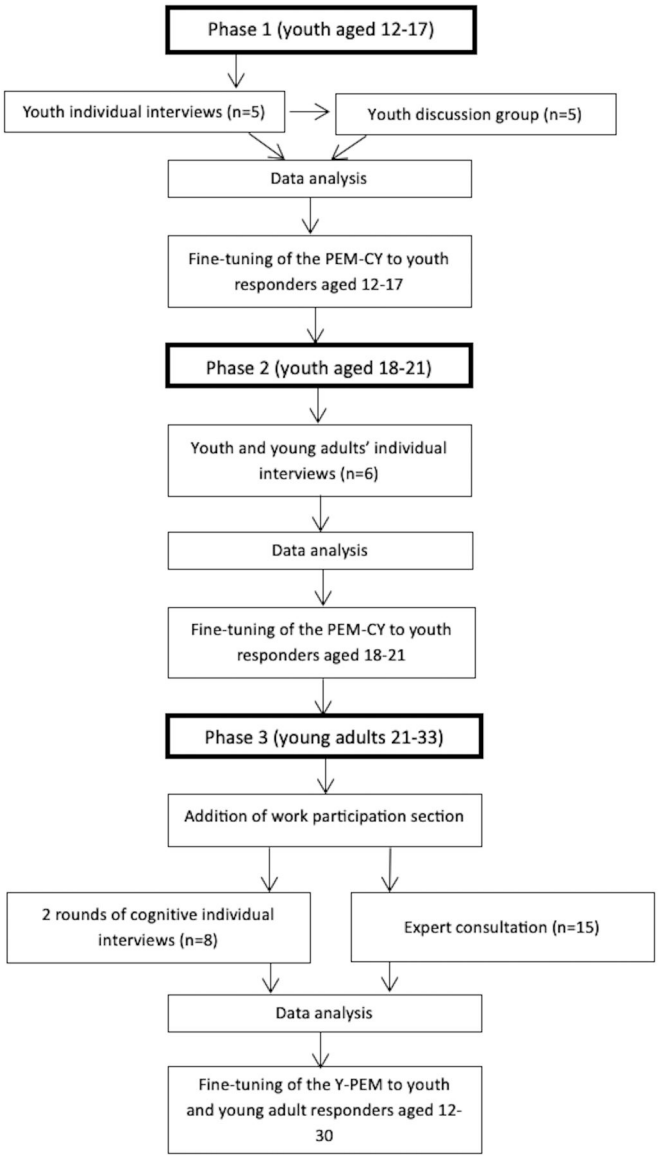

Figure 1. The three interrelated phases of the study.

Phase 1: examining the content of the youth-report version of the PEM-CY to a youth population aged 12–17 years old

In phase 1, the content of the PEM-CY was examined for transition-aged youth aged 12–17 years old ($n = 10$) and adapted based on their recommendations [32]. It involved two rounds of feedback; in the first round youth ($n = 5$) completed the PEM-CY and rated the clarity of items and the relevancy of examples in each setting using two separated 10 cm Visual Analogue Scales (VASs; 0 = "Strongly Disagree" and 10 = "Strongly agree") [33]. Six VASs (2 VASs X 3 settings) were completed; two scales to evaluate the clarity and relevancy of items across each of the three settings (home, school, community). Participants then took part in individual cognitive interviews, conducted by professional master OT students in their final year, to elaborate on the comprehensiveness of the assessment, the clarity of the instructions and the scales, and the relevancy of the items and examples. Data was analysed and suggested modifications were compiled. In the second round, modifications were presented to an additional group of youth ($n = 5$) in a focus group for further validation and revision.

Phase 2: adapting the items pertaining to participation in the home, school, and community for youth and young adults aged 18–21 years old

In phase 2, the revised version of the PEM-CY, based on phase 1 recommendations, was adapted and examined with older youth aged 18–21 ($n = 6$) through one round of feedback. Similar to phase 1, participants completed the participation questionnaire including the VAS scales (total of 6) and took part in individual CIs conducted by an OT. Qualitative and quantitative (VASs) information from this phase was synthesized and integrated to inform the modifications made to the PEM-CY for a population of responders aged 18–21. At the end of this process, the measure was named Youth and Young Adult Participation and Environment Measure (Y-PEM).

Phase 3: (a) developing a new set of items to capture "workplace participation" and (b) examining the initial content validity of the entire Y-PEM (home, school, community, and the workplace) for young adults aged 21–30 years old

In phase 3, a new section to evaluate workplace participation and environmental factors impacting participation was (a) developed and (b) validated for young people aged 21–30 ($n = 8$). It involved two rounds of cognitive interviews (conducted by an OT) each comprised of four young adult participants, as well as expert consultation ($n = 15$), resulting in the Y-PEM involving four settings (home, school, community, workplace). To do so, a team of professionals including two scholars in the field of participation and employment, and three occupational therapists with clinical expertise across the range of transition-aged individuals with various disabilities, one of which a post-doctoral trainee, developed a pool of items to evaluate workplace participation. This process was guided by the first three stages of Benson and Clark's [28] Flowchart for Instrument Development: (1) planning, (2) construction, and (3) evaluation as described below:

- In the *planning stage*, a working definition of "work participation" was developed with reference to the literature, and through a conceptual analysis drawing on three recognized models: the ICF [34], Occupational Therapy Practice Framework [35], and the Disability Creation Process [36]. Existing measures of work synthesized in Chang et al. [37] systematic review (e.g., Life-H, Keele Assessment of Participation) were also reviewed to examine how this concept was defined and operationalized previously, ensuring that existing measures do not serve the same purpose. New items were then developed to evaluate and address the 6 domains of the "workplace participation" definition. To define and operationalize the concept of "environment" and "work environment" we adopted the approach used in the original PEM-CY; especially, the environmental items (16 in total) pertaining to the community setting. Previous research indicated that the PEM-CY fits well, both conceptually and empirically [23,24,38,39], with the five elements of the environment as depicted by the ICF and, therefore, its environmental factors are comprehensive and salient to capture the essence of the environment. Hence, these environmental features were retained yet adapted to the work context of youth and young adult population as described in the construction stage.
- In the *construction stage*, a pool of nine work-related items was devolved to match the domains underpinning the concept of work participation as defined in the planning phase.

This process involved on-going team discussions. Concurrently, 16 environmental items and examples derived from the community setting of the PEM-CY were adapted for a workplace context. This was done by drawing on systematic reviews of environmental factors that impact work participation among young adults with brain-based disabilities [16], adults with developmental dyslexia [39], and intellectual disability [40], in addition to a Delphi study on workplace environmental influencers among those with multiple sclerosis [41].

- In the *evaluation stage*, the content validity of the newly developed work-related items was examined through the input of experts and young adults. Fifteen experts, external to the team, rated the importance of each of the work-related items using a 4-point Likert scale (1 = not important, 2 = slightly important, 3 = somewhat important, 4 = very important) through an online survey, set in REDCap. They were also asked to comment on each item and suggest activities that they believe should be included when evaluating work participation. In addition, two consecutive rounds of cognitive interviews, similar to phases 1 and 2, were conducted with eight young adults with a physical disability aged 21–40 with past or current work experience. The upper age bound was extended to 40 based on the assumption that older people may have gained more work experience allowing for broader reflections. Individuals younger than 21 were not included in this phase given their limited breath of experience on which to draw and lack of employment readiness [29]. To complement information generated by experts, young adult participants were also asked to rate the importance of each of the work-related items using a 4-point Likert scale ranging from 1 (not important) to 4 (very important). Specifically, the suggestions proposed by experts and the first round of interviews by young adults were incorporated in the new version before being presented to young adults in the second round of cognitive interviews ($n = 4$).

Data analysis

Youth and young adults (phases 1–3)

Quantitative data was analysed using descriptive statistics (i.e., mean) for VAS scores. Clarity of items and relevancy of examples were considered acceptable for each setting if they were rated on average at least 7 (out of 10) by participants, especially in the last round of cognitive interviews. Frequencies of Y-PEM scores were also examined to determine if there were activities in which none of the participants took part and environmental characteristics reported as "not an issue"/"not needed" by all participants. Such an analysis further examined the relevancy of the items for this group.

The qualitative data, generated by the cognitive interviews, were coded using the Constant Comparison Method (CCM) in all phases [42]. Specifically, all interviews were recorded and transcribed verbatim by the research assistant. The transcribed data were coded once in phases 1 and 2 whereas in phase 3 data were coded twice and separately: once by the interviewer and once by a second member of the research team. Information was compared and coded within a single interview as well as between participants within each phase to summarize the core of the content for each participant [43]. The coded information was then categorized and organized based on the four elements of the Applied Cultural Equivalence framework adapted to the study context. These four elements include: (1) conceptualization (i.e., changes related to the elements underpinning the concepts of participation and environment as perceived by youth and young adults), (2) item (i.e., changes to improve the relevancy and clarity of activity sets or an environmental feature/item), (3) semantic (i.e., replacing a specific word with a synonym for better relevancy to the context of the target population), and (4) operational (i.e., changes to the layout of the questionnaire) [44]. Data samples of suggested modifications were paired with each element of equivalence by the researcher. This data informed modifications to items and examples to improve the clarity of items and the relevancy of examples, which were further evaluated in subsequent ratings on the VASs.

Experts' consultation (phase 3)

In phase 3, experts' written comments for each work-related item obtained from the online survey were also analysed and summarized descriptively (QUAL). An average mean score (ranging from 1 to 4 on a 4-point Likert scale) for each of the proposed work-related items was calculated to describe the extent to which items were important to include in the Y-PEM (QUAN). The importance ratings of each proposed item were explored with qualitative data. Content analysis of the qualitative data further informed modifications to the "Workplace participation" section of the Y-PEM.

Integrated data analysis across all phases

Qualitative and quantitative data were analysed at the end of each phase. Each round of data analysis, resulted in revisions including adding/removing of examples and/or items, clarifying instructions/items and scales, and revising the design/layout/format of the questionnaire. This was done through an iterative process. Consequently, data gathered in subsequent rounds of interviews were analysed, categorized, and further informed, validated, and extended on the modifications of the Y-PEM for participants aged 12–30 years old. At the final stage, the recommended changes were audited. Specifically, information gathered from all three phases of this study was integrated and further discussed among the research team through a series of meetings. Revisions to the Y-PEM were made according to the suggested changes by both young participants and experts. This process involved re-reading youth's suggestions by going back to the original data extracts by the research team. The revised Y-PEM was then reviewed by a research partner who is an expert in the field of youth employment and a clinician working with transition-aged groups. Revisions were finalized and the content of the Y-PEM was adapted to a population of youth and young adults.

Results

Sample description

Youth and young adults

A total of 24 youth and young adults aged 12–33 years old, of whom 19 had a physical disability, were recruited to develop and validate the content of the Y-PEM. Table 1 provides information on the characteristics of the participants in each of the three phases. Orthopaedic impairment was the primary disability reported by the majority of the participants ($n = 15$), yet other developmental delays and intellectual disability or specific learning disability were also reported. Among those with disability, most participants indicated having difficulty moving around (78%), using hands to do activities (53%), paying attention (42%),

Table 1. Sample characteristics.

	Phase 1* ($n = 10$)	Phase 2 ($n = 6$)	Phase 3 ($n = 8$)	Total sample ($n = 24$)
Age (years)				
Range	12–17	17–20	24–33	12–33
Mean (*SD*)	14.6 (2.1)	18.6 (1.02)	29 (3.2)	20.9 (6.8)
Median	14.5	19	28	19
Gender				
Female	4	3	5	12
Male	6	1	3	10
Other	0	2	0	2
Physical disability				
Yes	6	5	8	19
No	4	1	0	5
Type of community				
Major urban	4	3	3	10
Suburban	3	3	5	11
Small town	1	0	0	1
Missing	2	0	0	2
Language spoken at home				
English	7	5	3	15
French	0	0	3	3
Bilingual	1	1	2	4
Other	0	0	2	2
Missing	2	0	0	2
Youth's education				
High school or less	10	1	0	11
Some college/university or technical training	0	5	2	7
Graduated college/university	0	0	6	6
Living with				
Both parents	0	NA	2	2
Mother	5	NA	1	6
Male legal guardian	3	NA	1	4
Alone	0	NA	2	2
Spouse	0	NA	1	1
Missing	2	NA	0	2
Work status				
Going to school	10	4	0	14
Recovering from illness and looking for work	0	2	0	2
Working full time	0	0	3	3
Working part-time/seasonal	0	0	2	2
Progressive Return to work	0	0	2	2
Volunteering and working part-time	0	0	1	1

NA: not available.

Table 2. Average rate on clarity of items and relevancy of examples across the four settings in each phase.

		Clarity of items				Relevancy of examples			
Phases	*N*	Home	School/educational setting	Community	Workplace	Home	School/educational setting	Community	Workplace
1	5	5.8	8.8	8.6	NA	8.7	7.5	7.6	NA
2	6	6.8	8.1	8.7	NA	7.4	8.5	9.1	NA
3 Round 1	4	8.9	8.5	9.3	9.03	4.1	7.8	6.8	9.0
3 Round 2	4	7.4	7.2	8.5	8.2	8.3	8.8	8.3	7.8
Phases 1–3	19	6.9	8.3	8.7	8.8	7.4	8.1	8.1	8.4

Clarity of items and relevancy of examples were rated on a 10 cm Visual Analogue Scale (VAS) for each setting.

remembering information (37%), and managing emotions (32%). In phase 3, 38% of participants were working full-time, 25% were in progressive return to work, 25% were working part-time and volunteering (13%).

Experts' characteristics

Among the 15 experts who completed the survey, six were clinicians/rehabilitation specialists and five were researchers in the field of employment for people with disability in Canada. The remaining sample included a parent of a youth/young adult with a disability, a working young adult with a physical disability, a past employer, and a director of an organization providing employment-related services to people with disability. Experts had between 3 and 37 years of experience in providing employment-related services to young adults with disabilities (median = 10 years) with a range of affiliations including community-based organizations (i.e., youth employment service; $n = 3$), rehabilitation-based organizations, such as the transition to adulthood programs ($n = 5$), educational settings (college and university; $n = 4$), a hospital ($n = 1$) and a local non-governmental organization ($n = 1$). One working young adult participating in the study was not affiliated with any organizations.

Phase 1: examining the content of the measure for youth aged 12–17. Overall, the content of the PEM-CY was rated 7.7 on the clarity scale and 7.9 on the relevancy scale by youth (see Table 2). Content analysis of the individual cognitive interviews ($n = 5$), described in detail by Li et al. [32], resulted in the emergence of

four main categories; two of which, a field of strengths and the wisdom of youth, illustrated a positive and supportive perspective on the applicability of the PEM-CY as a comprehensive measure that can potentially capture self-perceived participation of adolescents. Particularly, participants reported that they would want to and are competent to report on their participation by themselves. The remaining two categories, i.e., conceptual confusion and innovative recommendations, demonstrated content with a lack of clarity (e.g., availability of "services") and novel ideas (e.g., modifications to wording, new technology, etc.) that require special consideration. These were addressed when developing and refining the youth-report version in the subsequent phases. Content analysis of information gathered *via* the focus group ($n = 5$), resulted in a list of suggested modifications mainly at the level of the item. To illustrate, youth suggested to represent age-relevant examples of activities in the home setting (e.g., removing "hide and seek" from the activity set named "indoor play and games"), and to add examples related to common technology for socializing (e.g., cell phone/smartphone, emails, Facebook). Changes at the school and the community settings pertained to adding roles that youth engage in such as student council, grade representative, and camp counsellor. In this phase, one item-level change was made in the environment section modifying "the physical layout or amount of space and furniture in your home" to "the amount of space in your home." Youth also suggested to keep the item related to having money to support their participation.

Phase 2: examining the content of the measure for youth aged 18–21. The gathered information from participants ($n = 6$) aged 18–21 (phase 2) supported the suggestions made by youth aged 12–17 years old (phase 1). The VAS scores (QUAL), as shown in Table 2, indicated that the community setting was rated highest in terms of both clarity of items and relevancy of examples (attached to/paired with each item/activity set), followed by the school and the home settings. None of the participation-related items were rated as "never" performed by all participants.

Qualitative information, derived from the individual interviews, complemented the quantitative information. The highest number of changes ($n = 6$) pertained to the home setting including one conceptual modification and 5 item-level changes (see Table 3). Specifically, participants suggested to capture new responsibilities that emerge as youth enter adulthood. For instance, a new item was added to capture "care for others" to describe more mature roles. Similarly, other changes reflected the involvement of transition-aged youth in more grown-up social and emotional relationships, such as hanging out with boyfriend/girlfriend, dating, and engaging in broader social activities. These examples corresponded with and were incorporated into two activity sets: one in the home setting (i.e., "socializing using technology") and the other in the community setting (i.e., "getting together with other friends"). Youth also suggested to add examples of activities that were more relevant for them, such as "preparing meals." These examples were added under "household chores" item/activity set.

Table 3. Number of changes suggested in each phase by youth and young adult participants.

	Phase 1				Phase 2				Phase 3			
	I	S	C	O	I	S	C	O	I	S	C	O
Home	4	0	0	0	5	0	1	0	5	3	0	0
School	2	0	0	0	2	0	1	1	3	2	0	0
Community	2	0	0	0	3	1	1	0	4	1	0	1
Workplace	NA				NA				2	0	0	0

I: item; S: semantic; C: conceptual; O: operational.

More up-to-date forms of technological devices (e.g., Wii, Nintendo, iPad) were also suggested as examples of the activity set of "playing and watching episodes/videoclips" done at home. Concerning the environmental items, only a few underwent changes (i.e., removing "babysitter and therapists" from the item pertaining to attitudes of others in the home setting) for better relevancy for older responders.

With respect to the community setting, three changes were proposed: one conceptual (i.e., routine appointments and errands), one at the item level (i.e., adding the example "going on dates"), and one semantic change (i.e., adding friends to the item "getting together with other children"). The scope of the concept of community participation was broadened; it included going to the "hair/nail salons, doctor visits, dentist appointments, grocery shopping, bank/post-office, pharmacy." This was captured by adding "routine appointments and errands" as a new activity set in the community setting.

Regarding the school setting, one conceptual change was made to broaden the domain of the "school setting" to "school/educational setting" to include post-secondary education as youth enter higher educational settings (college/university, etc.). In addition, two item-level changes in this setting were suggested. Specifically, changes at the school setting aimed to improve the relevancy of school activities to an older population (i.e., "going on field trips" was reworded to "outings and social events") and adding roles that youth in their transitioning age typically engage in (e.g., student society representative).

Finally, participants in this age group also suggested to expand the overall concept of participation to include an additional life domain, i.e., work. Specifically, they commented that entering the labour force and maintaining employment becomes a pertinent life domain when youth transition to adulthood. Participants aged 18–21 reported mainly engaging in activities related to job search and job application.

Phase 3 (a) developing a new section to evaluate work participation and adapting the environmental items for a work setting. The conceptual analysis conducted during the *planning phase*, drawing on current models of disability and health, resulted in six sub-domains that defined participation at work. These sub-domains included: (1) identifying interest and seeking employment, (2) engaging in the social aspect of the workplace (i.e., social gatherings, staff night out, etc.), (3) performing a paid or unpaid job, (4) engaging in volunteer work, (5) engaging in a training program (i.e., vocational training, education), and (6) engaging in the process of terminating an employment or asking for a leave of absence. This led to the development of a pool of nine potential work-related items that correspond with the work sub-domains as part of the *construction phase* (see Table 4). After a discussion among the research team, only eight items were kept and introduced to the experts in the field of employment for evaluation. The proposed item, "availability of services" was removed as it pertained to the environmental factors that impact work participation and were already captured in the workplace environment section of the Y-PEM (as described in detail below); specifically, in the item related to "programs, services, and regulation."

A list of 16 workplace environmental items and examples to illustrate each environmental feature (originated by the PEM-CY community setting) were adapted to the work context. This included the physical layout, equipment or supplies, social demands of work activities, others' attitudes, access to transportation, parking, programs and services, information, and money (see

Table 4. The evolution of workplace participation items to its final stage.

Construction stage:	Evaluation stage:		Final auditing stage:
Initial pool of 9 work-related items	Items presented to experts and first 4 young adults	Items presented to the last 4 young adults	Final work-related items
1. Choosing an area of work or a profession (e.g., identify work interests, strengths and challenges, Shadowing, consult career guidance counsellor/service)	1. Choosing an area of work or a profession (e.g., identify work interests, strengths and challenges, Shadowing, consult career guidance counsellor/service)	1. Engaging in the process of selecting an area of work or a profession (e.g., engaging in the process of identifying work interest, strengths and challenges, consulting with career guidance counsellor/ employment service)	1. Engaging in the process of selecting an area of work or a profession (e.g., identifying work interest, strengths and challenges, consulting with career guidance counsellor/employment service, attending career fair)
2. Training for a job (e.g., experience in training programs for a specific job, Apprenticeship, vocational training, advocating for myself)	2. Training for a job (e.g., experience in training programs for a specific job, Apprenticeship, vocational training, advocating for myself)	2. Seeking and acquiring employment (e.g., preparing a cv/resume, networking for potential jobs, contacting employers, applying for a job and preparing for interviews, advocating for oneself, discussing terms and conditions of employment, accessing job search websites, placement services or youth-employment services)	2. Seeking and acquiring employment (e.g., preparing a CV/resume, networking for potential jobs, contacting employers, applying for a job and preparing for interviews, advocating for oneself, discussing terms and conditions of employment, accessing job search websites, placement services or youth-employment services)
3. Seeking and acquiring employment [e.g., preparing a CV (resume), networking for potential jobs, contacting employers, applying for a job, and preparing for interviews, advocating for oneself, discussing terms and conditions of employment, Accessing job search websites or placement services, youth-employment services]	3. Seeking and acquiring employment [e.g., preparing a CV (resume), networking for potential jobs, contacting employers, applying for a job, and preparing for interviews, advocating for oneself, discussing terms and conditions of employment, Accessing job search websites or placement services, youth-employment services]	3. Training for a job (e.g., experience in training programs for a specific job, apprenticeship/"stage," vocational training, education, shadowing, improving specific skills)	3. Training for a job (e.g., training programs for a specific job, apprenticeship/"stage," vocational training, education, shadowing, improving specific skills)
4. Working in a paid job (full or part time or self-employment) (e.g., perform job related tasks, attending staff meetings, maintaining a job, following work schedule, proceedings, shifts, Getting promoted, supervising others) (e.g., babysitting, grocery bag packer)	4. Working in a paid job (full or part time or self-employment) (e.g., perform job related tasks, attending staff meetings, maintaining a job, following work schedule, proceedings, shifts, Getting promoted, supervising others) (e.g., babysitting, grocery bag packer)	4. Working in a paid job (full or part time or self-employment) (e.g., perform job related tasks, attending work-related meetings, monitoring one's own performance, following work schedule, proceedings, shifts, getting promoted, supervising workers or being supervised, taking initiative)	4. Volunteering or working in unpaid job (e.g., for public agencies, charity, religious group, non-profit organization)
5. Volunteering, working in unpaid job, advancing for specific skill needs development (e.g., for an organisation, charity, religious group, non-profit organisation)	5. Volunteering, working in unpaid job, advancing for specific skill needs development (e.g., for an organisation, charity, religious group, non-profit organisation)	5. Volunteering or working in unpaid job (e.g., for an organization, charity, religious group, non-profit organization)	5. Working in a paid job (full or part time or self-employment) (e.g., perform job related tasks, attending work-related meetings, monitoring one's own performance, following work schedule/shifts, proceedings, taking initiative, getting promoted, being supervised or supervising workers)
6. Social gatherings in the workplace (e.g., employee lounge, work sponsored activities-lunches, yoga, Birthday or company celebrations, staff night out)	6. Attending social gatherings and events within and outside the workplace (e.g., employee lounge, work sponsored activities, lunches, yoga, birthday or company celebrations, staff night out, interacting with colleagues)	6. Attending social gatherings and work-related events (e.g., employee lounge, work sponsored activities-lunches, yoga, birthday or company celebrations, staff night out, informal interaction with colleagues)	6. Attending work-related events and social gatherings (e.g., employee lounge, work sponsored activities-lunches, yoga, birthday or company celebrations, staff night out, informal interaction with colleagues)
7. Access services/benefits from work (e.g., job coach, mentor, Union, health, and social services)	7. Leaving a job in an appropriate manner (e.g., giving notice, terminating in an appropriate way)	7. Leaving a job in an appropriate manner (e.g., giving notice, terminating in an appropriate way, taking a leave of absence)	
8. Leaving a job in an appropriate manner (e.g., giving notice, terminating in an appropriate way)	8. Getting to and from your job (e.g., using personal or public transport, Car-pooling, Finding the best routes, using company car/shuttle)		
9. Getting to and from your job (e.g., using personal or public transport, Car-pooling, Finding the best routes, using company car/shuttle)			

Table 5). To illustrate, to describe "attitudes and action of others towards you" (item #7), typical work-related personnel were listed, such as co-workers, supervisors, and customers. Other examples were added to describe "availability of relevant programs, services and regulations in the workplace" (item #12), such as terms of employment, job benefits, special accommodations, and mentoring among others. Table 5 lists the 16 adapted environmental items.

In the evaluation phase, qualitative information gathered from experts in the field of employment ($n = 15$) supported that the

Table 5. Final workplace environmental items.

Workplace environmental items
1. The physical layout or amount of space outside and inside buildings (e.g., accessible parking space, availability of ramps or elevators, accessible bathrooms and cafeterias, space to manoeuvre indoors and out, office layout, workstation)
2. The sensory qualities of the work setting (e.g., noise, number of people, lighting, temperature)
3. The physical demands of typical work activities (e.g., strength, endurance, sitting or standing tolerance, moving around, coordination)
4. The cognitive demands of typical work activities (e.g., concentration, attention, organization, problem-solving, multitasking)
5. The social demands of typical work activities (e.g., communication, interacting with colleagues, supervisors, and/or customers in person or by email, telephone, and/or social media)
6. Your relationship with co-workers, supervisors, customers and/or external partners
7. The attitudes and actions of others towards you (e.g., co-workers, supervisors, customers, family members, personal aides, other service providers who assist you at work)
8. Outside weather conditions (e.g., temperature, climate)
9. The safety of the workplace (e.g., air quality, accessibility to protective equipment, emergency procedures, bullying, harassment, and confrontation)
10. Access to personal transportation to get to and from work, including training programs or unpaid work, or to perform job related travel (e.g., personal car, carpool, family car, car sharing program, parking)
11. Access to public transportation to get to and from work, to training programs or to unpaid work, or to perform job related travel (e.g., adapted transport, bus, train, subway, company car/shuttle)
12. Programs, services and regulations (e.g., terms of employment, salary, flexible schedule, on job training, job benefits, union support, personal support worker, special accommodations, mentoring, counselling and employment seeking services, job coaches, availability of jobs)
13. Information (e.g., about services available to employees, job placement/searching services, programs, activities offered at work, employment rights)
14. Equipment or supplies (e.g., specialized software, voice recognition, microphone, adjustable work surface, adapted computer/keyboard, assistive device, visual aids)
15. Do you (and/or your support person) have enough time to support your unpaid work/volunteering or to engage in activities to prepare you for work?
16. Do you (and/or your caregiver) have enough money to support your unpaid work/volunteering, or to engage in activities to prepare you for work?

The highlighted text indicates adaptations made to the community-based items for a work context.

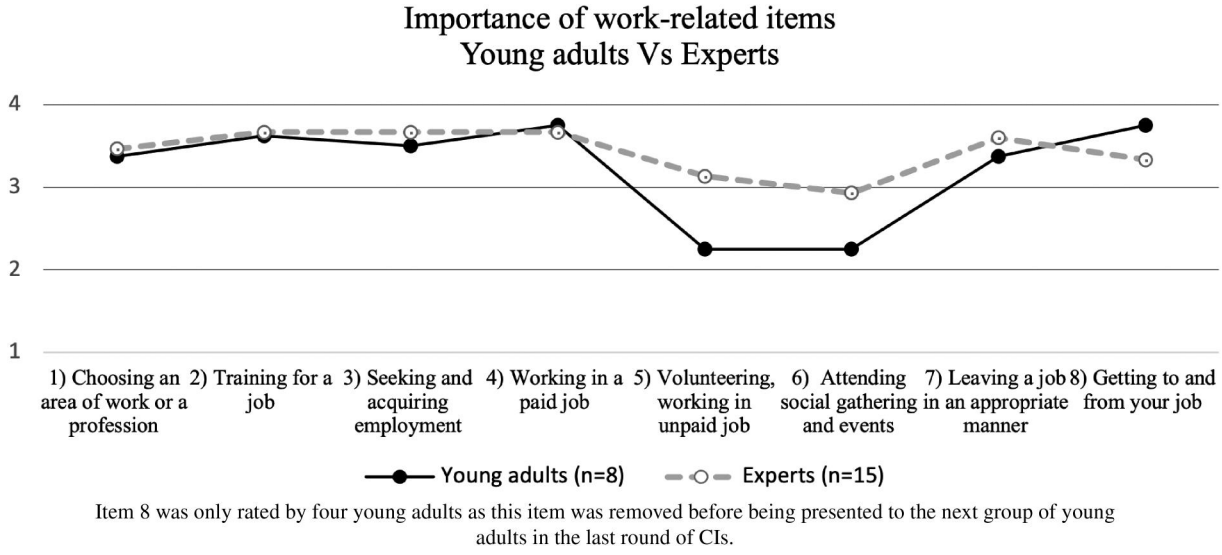

Figure 2. Young adult and experts' average of reported rates on the importance scale.

proposed work-related items capture work participation. Experts' definition of work participation was closely related to the six domains of workplace participation provided to them. Content analysis revealed two elements in the construct of work participation: work preparation activities, such as learning about different jobs, showing interest, training, and advancing skills, as well as work participation, such as volunteering, meeting employer's expectations, engaging in social interactions with other colleagues and in meetings, respecting work procedures and policies, and performing work-related tasks. This was further demonstrated by the quantitative data (see Figure 2) which showed that all items were perceived by experts as quite important. On average, items were ranked at least 3 (somewhat important) on the 4-point importance scale, except for the item capturing social gathering in the workplace that received a slightly lower rating of 2.93 (slightly important). Nonetheless, the median of all 8 items was at least 3 out of 4 (somewhat important) on the importance scale. Among those, seeking and acquiring employment, training for a job, working in a paid job, leaving a job in an appropriate manner, and getting to and from your job were rated as "very important" by 67% of experts. Although few experts reported that participating at work-related social gatherings was "not a priority" or "not always necessary," others believed that it created a "feeling of belonging" and that positive interactions and communications with colleagues could be important in some work settings. Hence, following a discussion, the research team decided to retain this item especially because the social aspect of work was identified as an element of workplace participation in the literature (planning phase).

Concurrently, these 8 work-related items were presented to four young adults who reported overall positive feedback. The workplace participation section was rated on average 9.3/10 on

the clarity VAS scale and 9.03/10 on the relevancy VAS scale. Seventy-five percent of the items (i.e., 6 items) were rated on average 3 or more on the 4-point importance scale. Upon discussion with the research team, the item "going to and from work" was removed as it was already captured by the environmental item "access to personal and public transportation." The remaining seven items were then presented to four young adults in the second round of interviews. In this round, the clarity of items was rated on average 8.2 and relevancy of the examples 7.8 (out of 10). Participants reported that overall, the items reflected the real-life sequential process in which one usually engages in acquiring a job and that this section was easy to complete and relevant to their age group. Participants rated four items related to choosing an area of interest, training, seeking and acquiring employment, and working in a paid job on average more than 3 on the 4-point importance scale. The three remaining items; volunteering, attending social gatherings, and leaving a job were rated on average <3 on the importance scale.

Across the two rounds of interviews, the two items that consistently were rated less important (<3 on the 4-point scale) by young adults were related to volunteering and attending work-related social events (see Figure 2). Young participants believed that attending social gatherings at work did not necessarily reflect their level of engagement, commitment, and dedication to their work. However, as explained earlier this item was retained in the Y-PEM (see Table 4). Furthermore, participants believed that although volunteering could create an advantage and an opportunity to acquire employment, it was not necessarily important, especially as they approached the age of 30. This item was however found to be important by experts and thus retained in the Y-PEM.

During the final auditing stage conducted by the research team, the item "leaving a job in an appropriate manner" was further discussed and then removed (see Table 4) as it was not related to work participation but rather its lack of. Additionally, none of the participants had engaged in this activity and they reported that it was not possible to rate this activity set on the three scales, particularly of the frequency scale. Removing this item was also confirmed through expert input, external to the team, who is the original developer of the PEM-CY. This resulted in a total of 6 participation-based work-related items of the Y-PEM. The research team modified the labels of four activity sets (#1, 4, 5, and 6) throughout this procedure for better clarity (see Table 4). Finally, the team reordered the remaining six work-related items in the Y-PEM for the better chronological flow of work-related activities (i.e., work preparation items presented first followed by work participation items). Please see Table 4 for a detailed description of the final workplace participation items.

In addition, environmental items underwent semantic changes regarding the order of example ($n = 3$) as well changes at the level of the item ($n = 8$) to improve the relevancy of examples. More specifically, examples were modified to illustrate the physical layout (e.g., office layout, accessible bathrooms, and cafeteria), sensory demands (e.g., number of people), physical demands (e.g., sitting or standing tolerance), cognitive demands (e.g., multitasking, organization), and social demands (e.g., communication with colleagues and costumers) specific to the work context. Similarly, items capturing attitudes of others, safety of the workplace (e.g., air quality, harassment, and confrontation), services, programs, and regulations (e.g., terms of employment), information (e.g., employment rights), and equipment or supplies (e.g., adapted computer, visual aids) underwent changes to represent realities at the work setting. Finally, these decisions were further supported by the expert input of the original lead-developer of the PEM-CY. Please see Table 5 for detailed information on the adaptations made to the environmental items.

Phase 3 (b) examining the initial content validity of the entire Y-PEM for youth aged 21–30. Data gathered through the completion of the Y-PEM including the work section, as well as cognitive individual interviews with young adults supported the validity of the Y-PEM for those aged 21–30. This was demonstrated by quantitative results ($n = 8$) where the average clarity and relevancy of items was relatively high in the community (8.9 and 7.5, respectively), workplace (8.8 and 8.4), school/educational setting (7.96 and 8.2), followed by the home (8.1 and 6.2). Correspondingly, during the interviews, the number of changes suggested in each setting was highest at the home setting ($n = 8$; $n = 5$ at the level of the item; $n = 3$ semantic changes), followed by the school setting ($n = 5$; $n = 3$ at the level of the item; $n = 2$ semantic changes), the community ($n = 5$; $n = 4$ at the item level; $n = 1$ semantic change), and the work setting ($n = 1$ conceptual change). Additionally, five changes were made at the operational level before finalizing the Y-PEM for youth and young adults.

Young adults in phase 3, confirmed recommendations made by the younger group aged 18–21 years old (phase 2) and suggested item-level changes to capture activities that young adults engage in their 20 s. For instance, young adults reported to become more independent in their personal care (i.e., "taking medication," and "managing appointments") and having more responsibilities within their family (i.e., "playing with younger family members"). On the other hand, they perceived playing "puzzles and arts and crafts" as juvenile and recommended to remove them from the list of examples of activities under the item "indoor plays and games."

In the school/educational setting, participants suggested more changes at the item level to utilize general terms (e.g., adding career fair) to represent those who attend post-secondary educational institutions (e.g., college, university, vocational training, etc.). Moreover, young adults suggested additional special roles (e.g., student society representative, student tutor, and committee member) that they assumed in the educational setting.

In the community setting, item-level changes were made to include driving courses as an example to the activity set of "classes and lessons" for youth transitioning to adulthood. The items "neighbourhood outings" and "community events" were merged to incorporate activities that can be done in the community (e.g., going to a mall, concert, restaurant, etc.). The activity set "getting together with other children/friends in the community" was made relevant for young adults by removing the word "children." Participants also recommended to modify "working for pay" to "occasional work" to distinguish between activities related to acquiring permanent employment as opposed to working occasionally.

In the workplace setting, young adults were overall satisfied with the relevancy, clarity and range of work participation and environmental items included. They reported that environmental items reflect the type of barriers/facilitators that they face in the workplace and other settings (home, school, community). Additionally, none of the environmental items were rated by young adults as "not an issue" or "not needed." During the final auditing by the research team, minor semantic changes were made in which the order of the examples were changed to increase harmony and create a better flow among the listed examples and activities.

At an operational level, the 4th element of the Applied Cultural Equivalence framework, the majority of participants reported that the questionnaire was easy to complete as all sections follow a similar pattern of questions. However, during the individual interviews, younger participants had difficulty figuring out in which order to answer the first few questions. To address this issue, a separate figure was added to the introduction page to visually demonstrate how to complete the Y-PEM. To ensure adherence to the instructions and facilitate answering the 3 questions about frequency, involvement, and desire for change for each item before moving to the next item, letter grades A, B, and C were added before each scale in each setting. Furthermore, as suggested by young adults, the option of "not applicable (skip to question C)" was added in the frequency scale in the workplace participation setting to acknowledge the experience of those who participated in work preparation activities, but not within the last 4 months. Participants also reported that the involvement scale was difficult to answer for the home participation section as certain activities were done out of necessity and not enjoyment/interest. This difficulty was resolved when the definition of involvement was reminded to them as they were better able to understand the question. Hence, we added a reminder of involvement's definition using a comment box next to the involvement scale in each setting. In addition, during the auditing phase, the research team decided to add a note in the community participation section to inform the responder about a more in-depth evaluation of work participation in the subsequent section. This was to further distinguish between occasional work and permanent work. Finally, operational changes were made to include the newly developed work participation section on the introduction page and to provide a brief definition of work participation in the "workplace participation" setting. In the last round of cognitive interviews (see Table 2), the ratings of clarity and relevancy of items across all settings were acceptable as evidenced by an average >7. Overall, the current version of the Y-PEM included 31 participation items (home =10 items, school/educational = 5 items, community = 10 items, workplace = 6 items), and 61 environmental items (home = 12 items, School/educational = 17 items, community = 16 items, workplace = 16 items).

Discussion

This study contributed a comprehensive assessment of participation and the environment, namely Y-PEM, for a unique transition-aged population. Findings support the content validity of the Y-PEM which is a paramount fist-step in measurement development and one of the key measurement properties of PROMs [27]. Aligned with the COSMIN criteria for establishing content validity, this study employed a rigorous sequential and multi-phase methodology along with the multiple rounds of in-depth cognitive interviews with youth and young adults themselves; thereby, ensured that the content of the Y-PEM captures the real-life experiences of the target population. Indeed, our findings suggest that the Y-PEM is a comprehensive participation-based assessment tool that can be completed as a self-reported questionnaire by youth and young adults with and without physical disabilities. As such, this questionnaire will allow clinicians to follow youth's participation paths early on from the age of 12 until they reach 30, to detect and address the challenges associated with the complex process of transitioning to adulthood.

The Y-PEM specifically includes the typical roles and activities that youth and young adults engage in across different settings as they transition to adulthood. Indeed, participants' input on the content of the Y-PEM coincides with previous studies; especially those that view successful transitioning as a change in status and roles. This change is marked by employment, participation in post-secondary education, independent living, community engagement, and the development of satisfactory personal and social relationships [45,46]. These important adult roles were demonstrated through the suggested addition of activities, incorporated into the Y-PEM. Examples of activities included engaging in more mature relationships (including dating), caring for others, taking driving lessons, going to routine appointments and grocery shopping, preparing meals, and seeking and acquiring employment. One new item of the Y-PEM, i.e., routine appointments and errands, resembles an activity set pertaining to younger children (as shown in the parent-reported Young Children Participation and Environment Measure [47], also modelled after the PEM-CY). In early childhood, children may tend to engage in these activities as part of their parents' routine. In this study, it represented mature roles led by the young person themselves. Such mature roles were also brought up in the home setting of the Y-PEM in the new item of "care for others" which involves caring for young children, and in "indoor play and games" which refers to playing games with younger family members including children and siblings. The resemblance in the type of activities in the PEM (Participation and Environment Measures) series validates the use of the PEM approach more broadly for advancing a life course health development model that has recently been described as being relevant for application in paediatric rehabilitation [48].

Interestingly, the highest number of recommended changes pertained to the home setting across all three phases. This can be explained by the vast variability in responsibilities and roles that are assumed at home across age groups. For example, as youth get older, they get more access to technological devices for socialization and entertainment, partake in more complex household chore activities (e.g., meal prepping), and become more independent in managing personal finances, appointments, and preparing for school/workday [8,49]. Such activities are important for preparing youth for independent living and new adult roles and are well-represented in the Y-PEM.

One of the conceptual considerations in the Y-PEM, recommended by youth, was the addition of a new setting to the questionnaire, work. A few participation-based questionnaires, such as the Life-H [50] and the Questionnaire of Young People's Participation (QYPP) [19] provide valuable information and touch upon work participation among the transition-aged group. However, this pertinent life domain is not captured in a comprehensive manner. To illustrate, the QYPP captures the objective domain of participation only (i.e., frequency) and the Life-H evaluates the level of difficulty, assistance, and satisfaction with the accomplishment of activities that closely relates to the construct of activity competence rather than participation [51]. The Y-PEM can complement these assessment tools by evaluating both the subjective (involvement) and objective (frequency) experiences of youth and young adults in a range of activities including work-related activities (from work preparation to work participation), as well as assessing environmental supports and barriers that impact work participation. The newly generated items, grounded in well-recognized models of disability, capture a range of pertinent work-related activities from the perspectives of employment-based service providers as well as young adults.

Our findings further validate the importance of assessing environmental factors that impact participation as those items were relevant to youth and young adults' experiences throughout the home, school, community, and workplace settings [16,52]. The list

of workplace environmental items was deemed comprehensive and relevant to the experiences of young adults with disabilities as no additional comments were made by this group to add or remove items. This was also observed in other settings where none of the environmental items were scored as "not an issue" or "not needed" by all participants. We are not surprised to see this because types of activities can change with age, yet core elements of the environment (e.g., attitudes of others, relationship with peers, physical layout and amount of space, etc.) remain important across the lifespan. This portrays the rigorous conceptual work that was done to develop the original environmental items of the PEM-CY.

Limitations and future directions

A limitation of this study is that all youth and young adult participants were recruited from the Greater Montreal area, making their experiences and participation specific to an urban context. Although our sample was diverse in terms of their age, education, and occupational experiences to ensure varying perspectives—an important principle for item development—all participants had good communication skills and cognitive ability based on clinical judgement (versus a standardized screening tool). Therefore, findings in this study are only applicable for those with physical disabilities who do not have cognitive and/or communication difficulties, and caution is needed when interpreting results. Furthermore, youth younger than 21 did not contribute to the development of the work-related setting. This was done because previous research indicates that younger individuals with physical disabilities may have limited employment experience on which to draw [29]. To make this tool available for use in practice, its psychometric properties must be examined. Psychometric testing in a larger more representative group of youth and young adults with and without physical disabilities, with age subgroup analysis, is currently underway by our team.

Implication for practice

The Y-PEM is a participation-based outcome measure designed to provide a standardized and systematic method to assess the first-hand subjective experience of youth and young adults in their participation at home, school, community, and the workplace. This tool can be used by clinicians to gain information on the types of barriers and supports that impact youth and young adults' participation in meaningful activities across different settings. A new feature of the Y-PEM is to provide information regarding the youth or young adult's involvement and engagement in activities that prepare them for the job market as well as their perspective on the environmental barriers or supports that they may face in their employment. Such information can potentially guide decision-making in supporting the participation of young people in pertinent and age-related activities, such as employment. Furthermore, the information generated from the Y-PEM can potentially guide the development of services and enhancement of policies to further reduce environmental barriers and build on supports to improve participation among this population. However, further studies are needed to determine the applicability of the Y-PEM among young people with other types of disabilities as well as among their caregivers. As well, its utility, specifically of the newly-developed workplace participation section, can be further examined among clinicians and employment-related service providers to better understand how the Y-PEM can inform clinical practice and decision-making when working with the transition-aged population.

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References

[1] WHO. International classification of functioning, disability and health: ICF. Geneva: World Health Organization; 2001.
[2] WHO. International classification of functioning, disability, and health: children & youth version: ICF-CY. Geneva: World Health Organization; 2007.
[3] Dahan-Oliel N, Shikako-Thomas K, Majnemer A. Quality of life and leisure participation in children with neurodevelopmental disabilities: a thematic analysis of the literature. Qual Life Res. 2012;21(3):427–439.
[4] García-Villamisar DA, Dattilo J. Effects of a leisure programme on quality of life and stress of individuals with ASD. J Intellect Disabil Res. 2010;54(7):611–619.
[5] King G, Law M, Hurley P, et al. A developmental comparison of the out-of-school recreation and leisure activity participation of boys and girls with and without physical disabilities. Int J Disabil Dev Educ. 2010;57(1):77–107.
[6] Stewart D. Transition to adult services for young people with disabilities: current evidence to guide future research. Dev Med Child Neurol. 2009;51:169–173.
[7] Law M, Anaby D, Teplicky R, et al. Participation in the home environment among children and youth with and without disabilities. Br J Occup Ther. 2013;76(2):58–66.
[8] van Gorp M, Van Wely L, Dallmeijer AJ, et al. Long-term course of difficulty in participation of individuals with cerebral palsy aged 16 to 34 years: a prospective cohort study. Dev Med Child Neurol. 2019;61(2):194–203.
[9] Taylor JL, Seltzer MM. Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. J Autism Dev Disord. 2011;41(5):566–574.
[10] King G, Tucker MA, Baldwin P, et al. A life needs model of pediatric service delivery: services to support community participation and quality of life for children and youth with disabilities. Phys Occup Ther Pediatr. 2002;22(2):53–77.
[11] Gorter J, Stewart D, Woodbury-Smith M. Youth in transition: care, health and development. Child Care Health Dev. 2011;37(6):757–763.
[12] (UNDESA) UNDoEaSA. Definition of youth. n.d.

[13] Anaby D, Hand C, Bradley L, et al. The effect of the environment on participation of children and youth with disabilities: a scoping review. Disabil Rehabil. 2013;35(19): 1589–1598.
[14] Krieger B, Piškur B, Schulze C, et al. Supporting and hindering environments for participation of adolescents diagnosed with autism spectrum disorder: a scoping review. PLoS One. 2018;13(8):e0202071.
[15] Lindsay S. Discrimination and other barriers to employment for teens and young adults with disabilities. Disabil Rehabil. 2011;33(15–16):1340–1350.
[16] Shahin S, Reitzel M, Di Rezze B, et al. Environmental factors that impact the workplace participation of transition-aged young adults with brain-based disabilities: a scoping review. IJERPH. 2020;17(7):2378.
[17] Field DA, Miller WC, Ryan SE, et al. Measuring participation for children and youth with power mobility needs: a systematic review of potential health measurement tools. Arch Phys Med Rehabil. 2016;97(3):462–477.e40.
[18] Adair B, Ullenhag A, Rosenbaum P, et al. Measures used to quantify participation in childhood disability and their alignment with the family of participation-related constructs: a systematic review. Dev Med Child Neurol. 2018; 60(11):1101–1116.
[19] Tuffrey C, Bateman B, Colver A. The Questionnaire of Young People's Participation (QYPP): a new measure of participation frequency for disabled young people. Child Care Health Dev. 2013;39(4):500–511.
[20] Coster W, Khetani MA. Measuring participation of children with disabilities: issues and challenges. Disabil Rehabil. 2008;30(8):639–648.
[21] Imms C, Granlund M, Wilson PH, et al. Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. Dev Med Child Neurol. 2017;59(1):16–25.
[22] Coster WL,M, Bedell G, Anaby D, et al. Participation and environment measure for children and youth (PEM-CY) – form & user's guide©. Hamilton (ON): Canchild; 2014.
[23] Coster W, Law M, Bedell G, et al. Development of the participation and environment measure for children and youth: conceptual basis. Disabil Rehabil. 2012;34(3): 238–246.
[24] Coster W, Bedell G, Law M, et al. Psychometric evaluation of the participation and environment measure for children and youth. Dev Med Child Neurol. 2011;53(11):1030–1037.
[25] Jarvis JM, Fayed N, Fink EL, et al. Caregiver dissatisfaction with their child's participation in home activities after pediatric critical illness. BMC Pediatr. 2020;20(1):415.
[26] Kaelin VC, Wallace ER, Werler MM, et al. Caregiver perspectives on school participation among students with craniofacial microsomia. Am J Occup Ther. 2021;75(2): 7502205100p1–7502205100p10.
[27] Terwee CB, Prinsen CAC, Chiarotto A, et al. COSMIN methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study. Qual Life Res. 2018;27(5):1159–1170.
[28] Benson J, Clark F. A guide for instrument development and validation. Am J Occup Ther. 1982;36(12):789–800.
[29] Lindsay S, McDougall C, Sanford R, et al. Exploring employment readiness through mock job interview and workplace role-play exercises: comparing youth with physical disabilities to their typically developing peers. Disabil Rehabil. 2015;37(18):1651–1663.
[30] Irwin DE, Varni JW, Yeatts K, et al. Cognitive interviewing methodology in the development of a pediatric item bank: a patient reported outcomes measurement information system (PROMIS) study. Health Qual Life Outcomes. 2009;7(1): 3–10.
[31] Peterson CH, Peterson NA, Powell KG. Cognitive interviewing for item development: validity evidence based on content and response processes. Meas Eval Counsel Dev. 2017; 50(4):217–223.
[32] Li N, Mazhar S, Messina S, et al. Validating the youth-report version of the participation and environment measure for children and youth (PEM-CY): preliminary findings. Erg-Go Rev Des Ergothér Québec. 2014;3:30–35.
[33] Wewers ME, Lowe NK. A critical review of visual analogue scales in the measurement of clinical phenomena. Res Nurs Health. 1990;13(4):227–236.
[34] Santé Omdl, Organization WH. International classification of functioning, disability and health: ICF. Geneva: World Health Organization; 2001.
[35] American Occupational Therapy Association. Occupational therapy practice framework: domain and process. 4th ed. Am J Occup Ther. 2020;74(Supplement_2):1-7412410010.
[36] Fougeyrollas P, Boucher N, Edwards G, et al. The disability creation process model: a comprehensive explanation of disabling situations as a guide to developing policy and service programs. Scand J Disabil Res. 2019;21(1):25–37.
[37] Chang F-H, Coster WJ, Helfrich CA. Community participation measures for people with disabilities: a systematic review of content from an international classification of functioning, disability and health perspective. Arch Phys Med Rehabil. 2013;94(4):771–781.
[38] Bedell GM, Khetani MA, Cousins MA, et al. Parent perspectives to inform development of measures of children's participation and environment. Arch Phys Med Rehabil. 2011; 92(5):765–773.
[39] de Beer J, Engels J, Heerkens Y, et al. Factors influencing work participation of adults with developmental dyslexia: a systematic review. BMC Public Health. 2014;14:77.
[40] Ellenkamp JJ, Brouwers EP, Embregts PJ, et al. Work environment-related factors in obtaining and maintaining work in a competitive employment setting for employees with intellectual disabilities: a systematic review. J Occup Rehabil. 2016;26(1):56–69.
[41] Prodinger B, Weise AP, Shaw L, et al. A Delphi study on environmental factors that impact work and social life participation of individuals with multiple sclerosis in Austria and Switzerland. Disabil Rehabil. 2010;32(3):183–195.
[42] Glaser BG. The constant comparative method of qualitative analysis. Soc Probl. 1965;12(4):436–445.
[43] Boeije H. A purposeful approach to the constant comparative method in the analysis of qualitative interviews. Qual Quant. 2002;36(4):391–409.
[44] Stevelink SA, van Brakel WH. The cross-cultural equivalence of participation instruments: a systematic review. Disabil Rehabil. 2013;35(15):1256–1268.
[45] Hendricks DR, Wehman P. Transition from school to adulthood for youth with autism spectrum disorders: review and recommendations. Focus Autism Other Dev Disabl. 2009;24(2):77–88.
[46] Cobb RB, Alwell M. Transition planning/coordinating interventions for youth with disabilities: a systematic review. Career Dev Except Individ. 2009;32(2):70–81.

[47] Khetani M, Coster W, Law M, et al. Young children's participation and environment measure (YC-PEM). Fort Collins: Colorado State University (copyright to authors); 2013.

[48] Palisano RJ, Di Rezze B, Stewart D, et al. Life course health development of individuals with neurodevelopmental conditions. Dev Med Child Neurol. 2017;59(5):470–476.

[49] Imms C. Children with cerebral palsy participate: a review of the literature. Disabil Rehabil. 2008;30(24):1867–1884.

[50] Noreau L, Fougeyrollas P, Vincent C. The LIFE-H: assessment of the quality of social participation. TAD. 2002;14(3):113–118.

[51] Imms C, Adair B, Keen D, et al. 'Participation': a systematic review of language, definitions, and constructs used in intervention research with children with disabilities. Dev Med Child Neurol. 2016;58(1):29–38.

[52] Colver A, Group S. Study protocol: SPARCLE-a multi-centre European study of the relationship of environment to participation and quality of life in children with cerebral palsy. BMC Public Health. 2006;6:105.

Chapter 6: Bridging Manuscripts 2 and 3

Research Questions

Manuscript 2

Research question: How to comprehensively evaluate participation among transition-aged youth and young adults aged 12-30 years old across different settings: home, school/educational setting, community, and the workplace?

Objective: This manuscript had 2 objectives:

1. To adapt and examine the content validity of the home, school, and community sections of the PEM-CY as a self-reported measure in terms of its comprehensiveness, clarity and relevancy for a population of young people aged 12-30 years old.
2. To develop and examine the initial content validity of items for a new work domain designed for use by young people aged 12-30 years old and adapt the environmental items to capture environmental barriers/facilitators that impact work participation in this age group.

Manuscript 3

Research question: To what extent is the Y-PEM reliable, valid, and acceptable (in terms of value and burden) to be used by youth and young adults aged 12-30 years old?

Objective: To evaluate aspects of utility (in terms of value and burden) and provide initial evidence towards the construct validity and reliability (in terms of internal consistency and test-retest reliability) of the Y-PEM as a self-reported questionnaire for youth and young adults aged 12-30 years old.

Integration of Manuscripts 2 & 3

The second manuscript which describes the development and initial content validation of the Y-PEM, provided a valuable and original contribution to the field of transition from childhood to adulthood and rehabilitation. This study resulted in a comprehensive self-reported participation measure that captures more matured age-related activities across different settings (i.e., home, school/educational setting, community, and the workplace) among transition-aged young individuals. The strength of the Y-PEM, compared to other existing tools, is its ability to evaluate environmental barriers and facilitators to participation across settings. In this study, the content validity of the Y-PEM was established through a rigorous methodology based on several sources of evidence. Specifically, the content of the PEM-CY was significantly modified and a new domain pertaining to work was added based on suggestions and recommendations from youth and young adults themselves. The content of this self-reported measure underwent important adaptations based on multiple rounds of cognitive interviews involving the target population, with input from experts in the field of employment to ensure relevancy for this group [1]. To further test this measure, its initial measurement properties had to be examined.

An important component of measurement development is indeed the examination of its psychometric properties. In fact, measurement properties have significant implications for the quality of rehabilitation research and clinical evaluation [2]. In particular, reliability and validity are amongst the most important and fundamental aspects of measurement properties that need to be established for any good measurement [3,4]. Reliable and valid instruments produce consistent results under the same conditions and effectively evaluate what they intend to measure [4]. Knowledge about such properties is of utmost importance to researchers and clinicians when choosing measurement tools in their practice [3]. Self-reported measures should also consider

other aspects of measurement properties such as feasibility/acceptability (e.g., ease of application, the time it takes to complete the questionnaire, etc.) and responder burden to encourage its uptake in clinical practice [1]. Therefore, Y-PEM's measurement properties such as its construct validity, internal consistency, test-retest reliability, and utility among the target population had to be examined. Knowledge of the measurement properties of this enhanced self-reported measure is imperative in the adoption of this tool by researchers and clinicians in their practice. Additionally, youth and young adults' perspectives on the utility of this tool in terms of its value and burden provide further insight into the adequacy of the Y-PEM among the target population.

References

1. Kroenke, K., Monahan, P. O., & Kean, J. (2015). Pragmatic characteristics of patient-reported outcome measures are important for use in clinical practice. *Journal of clinical epidemiology, 68*(9), 1085-1092.

2. Gadotti, I., Vieira, E., & Magee, D. (2006). Importance and clarification of measurement properties in rehabilitation. *Brazilian Journal of Physical Therapy, 10*, 137-146.

3. Ahmed, I., & Ishtiaq, S. (2021). Reliability and Validity: Importance in medical research. *Journal of the Pakistan Medical Association, 71*(10), 2401-2406.

4. Mohajan, H. (2017). Two criteria for good measurements in research: Validity and reliability. *Annals of Spiru Haret University Economics Series*(4).

Chapter 7: Manuscript 3

Title: Reliability and validity of the Youth and young-adult Participation and Environment Measure (Y-PEM): An initial evaluation

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Reliability and validity of the Youth and young-adult Participation and Environment Measure (Y-PEM): An initial evaluation

Aim: To examine initial psychometric properties, and aspects of utility of the Youth and Young-adult Participation and Environment Measure (Y-PEM). Methods: Young people with and without physical disabilities (n=113) aged 12 to 31 ($\bar{x}$ = 23; SD= 4.3) completed an online survey containing the Y-PEM and QQ-10 questionnaire. To examine construct validity, differences in participation levels and environmental barriers/facilitators were examined between those with (n=56) and without disabilities (n=57) via t-test. Internal consistency was computed using Cronbach's alpha. To examine test-retest reliability, a sub-sample of 70 participants completed the Y-PEM a second time, 2-4 weeks apart. The Intraclass correlation coefficient (ICC) was calculated. Results: Descriptively, participants with disabilities had lower levels of frequency and involvement across all four settings: home, school/educational, community, workplace. Internal consistency were 0.71 and above (up to 0.82) across all scales with the exception of home (0.52) and workplace frequency (0.61). Test-retest reliability were 0.70 and above (up to 0.85) across all settings except for environmental supports at school (0.66) and workplace frequency (0.43). Y-PEM was perceived as a valuable tool with relatively low burden. Conclusions: Initial psychometric properties are promising. Findings support Y-PEM's use as a feasible self-reported questionnaire for individuals aged 12-30 years old.

Keywords: participation measure; transition-aged; environment; assessment; workplace participation

Introduction

Transitioning to adulthood is a multifactorial and challenging process that becomes even more complex for youth with disabilities, adversely affecting their quality of life. This critical phase is marked by a change in various domains of participation such as employment, post-secondary education, independent living, community engagement, and the development of satisfactory personal and social relationships (Boop et al., 2020; Cobb & Alwell, 2009; Hendricks & Wehman, 2009). Participation, defined by the International Classification of Functioning Disability and Health (ICF) as "involvement in different life situations" (WHO, 2001), is a key rehabilitation outcome (Law, 2002; Lorenzo et al., 2019) essential for successful transitioning to adulthood and improved quality of life (King et al., 2002; Nguyen et al., 2018; Stewart, 2009). Environmental factors such as the physical, social/attitudinal, and institutional can explain participation across different settings: home, school, community (Anaby et al., 2013; Anaby et al., 2014) and the workplace as demonstrated in a recent scoping review (Shahin et al., 2020) where all ICF environmental domains served as barriers and/or supports to participation. Examples of barriers included unsupportive attitudes of colleagues and employers whereas supports involved availability of services and inclusive policies at the organizational level, and access to assistive technology, among others. Therefore, both participation and the environment are important to consider especially when developing transition-focused outcome measures.

Participation is a highly individualized construct. Therefore, patient-reported outcome measures that assess the subjective experiences of youth/young adults are most appropriate (Kingsley & Patel, 2017) to evaluate it. Exploring the first-hand experiences of youth with

disabilities is paramount to better understand the complexity of this transitioning phase (Nguyen et al., 2018). Existing participation-based measures provide valuable information, however, most do not capture both elements of participation, i.e., attendance and involvement (Imms et al., 2016), and do not explicitly cover the unique transition-aged period (from early adolescence to young adulthood) while identifying the impact of the environment on participation across a range of settings, all evaluated in one assessment (Adair et al., 2018; Seekins et al., 2012). Therefore, psychometrically sound transition assessments to guide service providers in this process, particularly in setting transition-specific goals are needed (Panyo et al., 2021). The Youth and young adult Participation and Environment Measure (Y-PEM) is a new self-reported participation-based outcome measure that comprehensively evaluates participation and the environment in four settings: home, school/educational, community and the workplace. The Y-PEM is modelled after the parent-reported PEM-CY (Participation and Environment Measure-Children and Youth) intended for younger individuals aged 5 to 17 (Coster, 2014). Specifically, the Y-PEM, developed with input of young people with disabilities (through multiple rounds of cognitive interviews) and experts' consultation (Shahin et al., 2022), evaluates participation across a range of more mature activities pertinent to transition-aged population. Examples include independent living, caring for others, dating, preparing meals, and going to routine appointments. This newly developed tool also assesses participation at work and environmental factors affecting work (Shahin et al., 2022).

While the content validity of the of Y-PEM was supported (Shahin et al., 2022), other measurement properties have yet to be examined. This study aimed to evaluate aspects of utility (in terms of value and burden) and provide initial evidence towards the construct validity and

reliability (in terms of internal consistency and test-re-test reliability) of the Y-PEM as a self-reported questionnaire for youth and young adults aged 12-30 years old.

Methods:

Design

A cross-sectional study design was employed to explore the utility, construct validity and internal consistency of the Y-PEM among 113 youth and young adults with (n=56) and without (n=57) disabilities, matched by sex and age. This was followed by a test-retest design of a sub-sample of 70 participants, to examine its short-term test-retest reliability of two repeated measures, 2-4 weeks apart. This delay was chosen as it was anticipated, based on previous studies (e.g., Coster et al., 2011), that participation levels at home, school, community, and the work will not change significantly in terms of the frequency, involvement, and desire for change in such a short period of time.

Procedure

Youth and young adults aged 12- to 31 with and without physical disabilities were recruited. Participants with physical disabilities were recruited using convenience sampling through ads posted on social media (i.e., Twitter, Facebook). In addition, youth were approached by local coordinators from nine programs (including transition-based programs) in four Quebec-based rehabilitation centers/hospitals providing services to this population. Other recruitments strategies involved reaching out to six community-based employment services for young people with disabilities, and two Canada-wide disability associations. Participants with physical disabilities were included if they had a mobility restriction, adequate cognitive ability to answer

questions about their participation by themselves and could read and understand English or French. Those with intellectual disability and cognitive impairment, based on therapist's input, were excluded from the study. Participants without disability were mainly recruited from Quebec through purposeful sampling to ensure the two groups are proportionally similar in terms of sex and age. Participants were asked to complete a set of 3 questionnaires, the Y-PEM, the QQ-10 (assessing utility), and a demographic questionnaire using REDCap (Research Electronic data Capture) (n.d., 2004). Automatic emails were sent through REDCap to participants who were interested to complete the Y-PEM a second time. Ethics approval was obtained from the Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR) and McGill University's Research Ethics Board. Informed consent was obtained from all youth via REDCap. This study was conducted during the COVID-19 pandemic and data was collected from January 2020 to October 2021.

Measures

Youth and young adult Participation and Environment measure: The Y-PEM (Shahin et al., 2022) assessed young people's perception of their participation in a broad range of activity sets (overall 31 items) in the last four months across four settings. This included the home (10 items; e.g., socializing using technology, getting together with other people, household chores, personal care management, care for others), school/educational (5 items; e.g., in-class activities, outings and social events, special roles), community (10 items; e.g., neighborhood outings and community events, routine appointments and errands, getting together with friends in the community) and workplace (6 items; e.g., seeking and acquiring employment, training for a job,

working in a paid job, attending work-related events and social gatherings). The Y-PEM provides examples for each activity set.

For each activity set, three dimensions of participation were evaluated: (1) frequency (8-point scale, from never [0] to every day [7]); (2) involvement (5-point scale, from minimally involved [1] to very involved [5]), and (3) desire for change in their participation (yes [1], no [0]); and type of change desired in terms of frequency (i.e., more often or less often), involvement (i.e., more involved or less involved) and/or participation in a broader variety of activities. Three mean scores were generated for each setting: frequency ranging from 0-7, involvement from 1-5, and desire for change by counting number of activities in which change was desired presented in percentages.

Participants were also asked to evaluate the impact of the environment (e.g., physical layout, sensory qualities, physical/social/cognitive demands of activities, services, policies) on their participation in each of the corresponding setting: home (12 items), school/educational setting (17 items), community (16 items) and the workplace (16 items). Environmental items were assessed on a 4-point rating scale (1= Usually makes harder/usually not available, 2= Sometimes helps, sometimes makes harder/ sometimes yes, sometimes not available, 3= Usually helps/ usually yes (available), 4= Not an issue/not needed). Number of environmental supports (i.e., items scored 3 and 4) were calculated in percentages for each item per setting. A mean score percentage for environmental support (i.e., items scored 3 out of 4) was then generated for each setting.

The 80% rule for missing data was applied to scores at the home, school/ educational, and the community settings excluding data from the Y-PEM that had less than 80% valid response (Tabachnick & Fidell, 2013). This rule was not applied to the workplace participation

scores as justified missing data was anticipated for younger participants who were not working or working participants who were not seeking a new job (items 1-3 of the workplace).

The QQ-10 questionnaire: The QQ-10 questionnaire, developed by Moores, Jones and Radley (2012) to assess the perceived burden and value of patient-reported questionnaires in health care was used. This self-reported 10-item questionnaire contained 6 items evaluating the value (i.e., helped communication, relevant, comprehensive) and 4 items examining the burden (i.e., overlong to complete, overcomplicated) of the Y-PEM. All items were rated on a 5-point Likert scale (strongly disagree being 0 to strongly agree being 4). Two mean scores and the frequency of participants rating the level of burden and value were generated ranging from 0-4 where higher scores indicated greater perceived value and lower burden. The QQ-10 was shown to have good internal consistency and item correlation with a Cronbach of >0.70 for both value-related and burden-related items for clinical patients (Moores et al., 2012). This questionnaire was used effectively to assess Participation and Environment measures (Boyd, 2018).

Demographic questionnaire: Participants reported on their personal factors (i.e., age, sex, language, education, type of activity most involved in [i.e., work, study, recovering from illness, volunteering]), family factors and living situation (i.e., household income, with whom they live, type of community they live in). Participant with disabilities also reported their health condition from a list of 15 conditions and functional issues using a checklist of 11 areas of function (no problem [0], little problem [1], big problem [2]). Areas that were scored 1 or 2 were counted as 1 functional issue. Participants also rated the extent to which COVID-19 pandemic affected participation across settings on a 7-point scale from 0 being not at all to 6 being to a very great extent. A mean score ranging from 0-6 was generated where higher scores indicated higher perceived impact of COVID-19 on participation.

Data analysis

Aspects of utility were evaluated across the entire sample (n=113) using the QQ-10 questionnaire. Other elements of utility in terms of feasibility were examined including time (in min) and number of breaks required for the completion of the measure. Descriptive statistics were used to report QQ-10 results, time (min) and number of breaks needed to complete the Y-PEM. We hypothesized that: a) at least 80% of the participants (to meet common agreement levels) (Chaturvedi & Shweta, 2015) will rank the 6 value-related items presented in the QQ-10 questionnaires as "mostly agree" or "strongly agree" b) at least 80% of the participants will rank the 4 burden-related items presented in the QQ-10 questionnaires as "mostly disagree" or "strongly disagree" and c) on average, the Y-PEM will be completed in less than 45min (based on a previous study using PEM measures; (Coster, 2014) and in no more than 2 seating (1 break) (set arbitrarily).

Internal consistency of the participation frequency, involvement, and the environment scales was examined using Cronbach's alpha, across the entire sample (n=113). Internal consistency coefficients were interpreted using Ponterotto & Ruckdeschel's (2007) classification. To assess test-retest reliability (among a sub-sample of 70 participants), the mean scores of each scale of the Y-PEM (frequency, involvement, and the environment across all 4 settings) was computed and compared between the two data points, using the Intraclass correlation coefficient (ICC) (two-way mixed effects model for absolute agreement). Reliability coefficients below 0.50 were considered poor, those between 0.50 and 0.75 were considered moderate, and those above 0.75 were considered good (Portney & Watkins, 2009). We hypothesized that the levels of internal consistency and test-retest reliability would be at least 0.06 ($\alpha \geq 0.60$, ICC ≥ 0.60,

respectively). This value was selected as participation patterns could be impacted by multiple factors in each setting (Coster et al., 2011).

To assess preliminary construct validity, descriptive statistics for each scale (frequency, involvement, desire to change, and number of environmental barriers/supports) in each setting was computed for each group (with and without disabilities). Differences in participation levels between the two groups were analyzed using independent samples t-tests. It was anticipated that individuals with physical disabilities, in comparison to those without disabilities, will have lower levels of participation frequency and involvement across settings, will have a higher number of activities to which they wish to see change, and a higher number of environmental barriers (or lower number of environmental supports) across all 4 settings. With a sample size of 51 per group, we can, with 80% confidence and type I error of 0.05 (G*power) deduce initial data for construct validity of the Y-PEM.

To further explore construct validity, the relationship between environmental support and participation patterns (i.e., frequency, involvement, and desire for change) across settings was examined using Pearson Correlation among the entire sample. Based on previous studies (Anaby et al., 2014), a positive correlation was anticipated between environmental support and frequency of participation and involvement, and a negative correlation with desire for change. Additionally, post-hoc analysis was done among the disability group. Specifically, t-test was used to examine differences in participation outcomes (i.e., frequency, involvement, desire for change) between those with lower (up to 4.5) and higher (4.6 and above) number of functional issues (subgroups were created based on the median). As seen in previous research using PEM (Anaby et al., 2014), it was expected that people with more functional issues participate less frequently, would

be less involved in activities across all settings and wished to see change in a greater number of activities. All analyses were done using SPSS version 27.0. Level of significant was set to 0.05.

Results:

Sample description:

A total of 113 youth and young adults (n=56 with disabilities, n=57 without disabilities) between the ages of 12-31 years old ($\bar{X}$=23; SD=4.3) living in Canada completed the online survey. Participants with and without disabilities were similar in terms of their age, sex and type of community they live in. Participants rated the impact of COVID-19 pandemic on their participation across all settings on average 5.48 out of 6 (SD= 1.57). Participants with disabilities differed from those without disabilities in the language spoken at home, working status (part-time and full-time) and living situation (participants without disabilities were more likely to live with their mother/ legal guardian or other member compared to those with disabilities) (Table 1). Among the disability group (n=56), participants reported up to 6 health conditions (Table 2) among which about 43% reported two or more health problems. In addition, they reported up to 10 functional issues (Table 2) (median= 4.5) with 79% of them having 2 or more functional issues. Among the completed surveys, 95 were done in English and 18 in French as per participants' request. Of the 113 participants, 70 completed the online survey a second time between 2-4 weeks apart; half of them had a disability. The distribution of their demographic characteristics resembles that of the total sample as described above. Two participants with disabilities received assistance of a researcher by phone or Zoom to click the boxes on the survey questionnaires. Please see Table 1 for more details.

Twelve participants (n=10 with disabilities; n=6 male; n=6 female) aged 15-31 ($\bar{X}$=25; SD=4.5) withdrew from the study.

Table 1. Sample characteristics.

Variable	Total sample	Construct validity sample (%)		Test-retest reliability sample (%)
		With disability	Without disability	
Total n	113	56	57	70
Age (y), mean (SD)	23 (4.3)	22.8 (4.19) min 14 max 31	22.9 (4.29) min 12 max 30	22.8 (4.3)
12-15	4 (4%)	3 (5.4%)	1 (1.8%)	4 (6%)
16-19	24 (21%)	12 (21.4%)	12 (21%)	13 (19%)
20-23	34 (30%)	17 (30.4%)	17 (29.8%)	22 (31%)
24-27	32 (28%)	15 (26.8%)	17 (29.9%)	20 (29%)
28-31	19 (17%)	9 (16.1%)	10 (17.5%)	11 (16%)
Sex				
Male	46 (41%)	22 (39%)	24 (42.1%)	28 (40%)
Female	67 (59%)	34 (61%)	33 (57.9%)	42 (60%)
Group				
No Disability	57 (50%)	NA	NA	34 (49%)
Disability	56 (50%)	NA	NA	36 (51%)
Household income				
Below $60 000	44 (39%)	27 (49.1%)	17 (29.8%)	26 (37%)
About $60 000	20 (18%)	13 (23.6%)	7 (12.3%)	14 (20%)
Above $60 000	48 (42%)	15 (27.3%)	33 (57.9%)	30 (43%)
Missing	1 (1%)	1 (1.8%)	0 (0%)	0 (0%)
Type of Community				
Major urban	70 (62%)	32 (58.2%)	38 (66.7%)	43 (61%)
Suburban	32 (28%)	15 (27.3%)	17 (29.8%)	20 (29%)
Small town	8 (7%)	6 (10.9%)	2 (3.5%)	6 (9%)
Rural	2 (2%)	2 (3.6%)	0 (0%)	1 (1%)
Missing	1 (1%)	1 (1.8%)	0 (0%)	0 (0%)
Language spoken at home				

English	51 (45%)	28 (50%)	23 (40.4%)	32 (46%)
French	28 (25%)	24 (42.9%)	4 (7%)	16 (23%)
Other	51 (45.1%)	5 (8.9%)	46 (80.7%)	28 (40%)
Living with				
Mother	82 (72%)	36 (64.3%)	46 (80.7%)	50 (71%)
Father	59 (52%)	23 (41.1%)	36 (63.2%)	38 (54%)
Male legal guardian	1 (1%)	1 (1.8)	0 (0%)	1 (1%)
Female legal guardian	1 (1%)	0 (0%)	1 (1.8%)	1 (1%)
Alone	24 (21%)	15 (26.8)	9 (15.8%)	14 (20%)
Other	21 (19%)	8 (14.3%)	13 (22.8%)	16 (23%)
Highest education level				
High school or less	35 (31%)	22 (39.3%)	13 (22.8%)	19 (27%)
Some college or university or technical training (at least one year)	22 (19%)	9 (16.1%)	13 (22.8%)	14 (20%)
Graduated college/University	44 (39%)	20 (35.7%)	24 (42.1%)	28 (40%)
Graduate degree	10 (9%)	3 (5.4%)	7 (12.3%)	8 (11%)
Vocational training/Diploma	2 (2%)	2 (3.6%)	0 (0%)	1 (1%)
Activities engaged in during the week				
working full time	32 (28%)	12 (21.4%)	20 (35.1%)	21 (30%)
working part-time/ seasonal	33 (29%)	12 (21.4%)	21 (36.8%)	21 (30%)
Looking for work	13 (11%)	6 (10.7%)	7 (12.3%)	8 (11%)
Going to school	62 (55%)	25 (44.6%)	37 (64.9%)	36 (51%)
Recovering from illness	11 (10%)	10 (17.9%)	1 (1.8%)	7 (10%)
Volunteering	15 (13%)	7 (12.5%)	8 (14%)	10 (14%)
Other	6 (5%)	3 (5.4%)	3 (5.3%)	1 (1%)

NA= Not applicable

Table 2. Self-reported health condition and functional issues.

	Validity sample (N=56) (%)	**Reliability sample (N=36) (%)**
Health condition		
Developmental delay	1 (2%)	1 (3%)
Intellectual disability	1 (2%)	1 (3%)
Hearing impairment	4 (7%)	1 (11%)
Speech or language impairment	7 (13%)	3 (8%)
Vision impairment	3 (5%)	1 (3%)

Serious emotional disturbance	1 (2%)	1 (3%)
Orthopedic impairment/ movement impairment (e.g., cerebral palsy, spina bifida, or muscular dystrophy)	22 (39%)	13 (36%)
Autism spectrum disorder	3 (5%)	3 (8%)
Attention deficit disorder	10 (18%)	10 (28%)
Traumatic brain injury	2 (4%)	1 (3%)
Specific learning disability	7 (13%)	3 (8%)
Health impairment (e.g., epilepsy/seizures, asthma, cardiac or heart problems, arthritis)	17 (30%)	8 (22%)
Multiple disabilities	12 (21%)	10 (28%)
Other impairments/problems	14 (25%)	8 (22%)
Functional issues		
Paying attention or concentration	32 (57%)	19 (53%)
Remembering information, e.g., directions	27 (48%)	16 (44%)
Learning new information or new activities	19 (34%)	12 (33%)
Communicating with others	20 (36%)	13 (36%)
Reacting to sensations (e.g., noise, crowds)	26 (46%)	19 (53%)
Moving around	39 (70%)	26 (72%)
Using hands to do activities	33 (60%)	22 (61%)
Managing emotions (e.g., anxiety, depression)	27 (48%)	16 (44%)
Controlling behavior or activity level	15 (27%)	10 (27%)
Seeing	14 (25%)	9 (25%)
Hearing	12 (2%)	10 (27%)

Aspects of utility

Two out of 3 utility criteria were met. Participants required an average of 39min (median=35; SD: 18min; minimum=11min; maximum=120min) with 1 break (median=0.5; SD=1.4; minimum=0; maximum=5) to complete the Y-PEM. Results of the QQ-10 questionnaire indicated a mean score of 2.9 out of 4 (median= 3, SD=0.6) on the value scale with 75% of participants agreeing with the value-related items, approaching our criterion. Mean level of burden was 3 out of 4 (median= 3.25, SD=0.8) with 80% of the participants reporting they disagree with the burden-related items, meeting our set criterion.

Reliability

Internal consistency (n=113):

As shown in Table 3, Cronbach's alpha estimates for the frequency scale ranged from 0.61 to 0.77 (fair to excellent) except for the home setting (0.36), and 0.71 to 0.82 (moderate to excellent) for the Involvement scale across all four settings: home, school/educational, community and the workplace. Item 1 in the home setting (computer games and video games) was negatively correlated with the rest of the home activities (coefficient correlation: -0.14); when isolated, the internal consistency coefficient correlation of the home frequency scale increased to 0.52. With respect to the environment scales, Cronbach's alpha ranged from 0.78 to 0.82 (moderate to good) across all the 4 settings. It should be noted that the school/ educational and the workplace settings each contain 5 and 6 items respectively compared to 10 items in the home and community settings.

Test-retest reliability (n=70):

Test-retest reliability estimates (Table 3) of frequency scale were good for the home (0.78), school/educational setting (0.84), and the community (0.76) settings, and poor for the work setting (0.43). With respect to the involvement scale, ICCs were good for the community (0.85) and home (0.84) settings and moderate for the school/educational (0.77) and workplace (0.74) settings. Similarly, reliability estimates for the environment scale were moderate for the home (0.72), community (0.70), workplace (0.73) and the school/educational (0.66) settings.

Table 3. Reliability of the Y-PEM frequency, involvement, and the environment scales.

Scale	**Settings**	**Internal consistency**		**Test-retest reliability**		
		N	**Alpha.valid**	**N**	**ICC**	**95% CI**
Frequency						

	Home	108	0.36	66	0.78	0.69,0.85
	Home_r*	107	0.52	64	0.76	0.66,0.84
	School/educational	103	0.77	62	0.84	0.76,0.89
	Community	109	0.72	66	0.76	0.66,0.83
	Workplace	101	0.61	64	0.43	0.25,0.59
Involvement						
	Home	107	0.71	59	0.84	0.76,0.89
	Home_r*	104	0.71	50	0.85	0.77,0.91
	School/educational	81	0.72	20	0.77	0.56,0.89
	Community	106	0.82	16	0.85	0.68,0.94
	Workplace	97	0.74	61	0.74	0.81,0.97
Environment						
	Home	110	0.79	65	0.72	0.61,0.81
	School/educational	101	0.81	56	0.66	0.52,0.77
	Community	108	0.78	63	0.70	0.57,0.79
	Workplace	101	0.82	60	0.73	0.62,0.82

*Home_r excludes item 1 (computer games and video games) from the analysis.

Construct Validity

Frequency and involvement mean scores (across all the four settings) and number of environmental supports (across 3 settings) were descriptively lower among those with disabilities compared to the group with no disabilities (Table 4). Statistically significant differences between the groups were found in all scales at the *home* setting: frequency, involvement, desire for change and environmental supports. In the community, youth without disabilities had significantly higher levels of involvement with a large effect size. In the workplace, youth without disabilities desired to see significantly more change in their participation with a small effect size. Youth without disabilities were also significantly ($t(86) = -1.88$, $p = .003$, ES = 0.40) more involved in work participation activities (i.e., volunteering or working in unpaid job, working in a paid job, attending work-related events and social gatherings). Youth with disabilities participated in less variety of activities across all the 4 settings with significant difference at the community ($t(111) = -2.002$, $p = .02$, ES = -0.38) and the workplace ($t(111) = -$

2.068, p = .001, ES = -0.389) settings. Overall effect sizes ranged from small (0.1) to large (1.1). No statistically significant differences between the groups were observed in the school setting on either of the scales.

Table 4. Construct validity of the Y-PEM frequency, involvement, desire for change and environmental supports scales.

Scales	Presence of disability	N	*Mean*	*SD*	*t*	*p*	*ES*
Home							
Frequency	Yes	52	5.40	0.82	0.52	.003	0.10
	No	56	5.47	0.58			
Involvement	Yes	48	3.81	0.68	1.88	.010	0.37
	No	54	4.02	0.44			
Desire for change	Yes	56	4.57	3.31	1.23	.007	0.23
	No	57	5.25	2.45			
Environment	Yes	56	8.48	3.31	0.58	.024	0.11
	No	57	8.81	2.60			
School/ educational							
Frequency	Yes	50	2.39	1.79	1.81	.524	0.36
	No	53	3.03	1.78			
Involvement	Yes	21	3.58	0.88	1.68	.194	0.50
	No	25	3.97	0.70			
Desire for change	Yes	56	2.02	2.00	0.52	.538	0.10
	No	57	2.21	1.92			
Environment	Yes	56	11.55	4.94	-0.15	.532	-0.03
	No	57	11.42	4.65			
Community							
Frequency	Yes	52	2.54	1.13	1.18	.892	0.23
	No	57	2.80	1.15			
Involvement	Yes	16	3.52	0.83	3.37	.005	1.10
	No	23	4.19	0.41			
Desire for change	Yes	56	4.98	3.29	0.28	.135	0.05
	No	57	5.14	2.67			
Environment	Yes	56	10.13	3.79	1.62	.855	0.30
	No	57	11.26	3.69			

Workplace							
Frequency	Yes	46	2.95	1.72	1.34	.313	0.27
	No	55	3.37	1.44			
Involvement	Yes	43	3.76	1.06	1.26	.082	0.26
	No	54	4.00	0.84			
Desire for change	Yes	56	2.59	2.43	0.42	.043	0.08
	No	57	2.77	2.15			
Environment	Yes	56	10.04	5.13	1.38	.069	0.26
	No	57	11.23	4.03			

Table 4. This table demonstrates the mean of participation frequency, involvement, desire for change and the number of environmental supports reported between those with and without disability with the 80% missing rule applied to the home, school/education, and the community settings for the frequency and involvement scales. Difference is statistically significant with a $p<0.05$.

Relationship between perceived environmental support and participation patterns (n=113):

Significant positive correlations were found between overall environmental supportiveness and participation frequency across 3 settings: home, community, and the workplace settings. Similarly, significant positive correlation was found between environmental supportiveness and involvement across 3 settings: the home, school/ educational, and community settings (Table 5). There was a significant negative correlation between environmental supports and desire for change across all the four settings for the sample as a whole, indicating that youth with greater environmental supports had lower number of activities they wanted to see changed. Coefficient correlations ranged between moderately low to moderate.

Table 5. Relationship between overall environmental supportiveness" and participation patterns among the entire sample (n=113).

Scale	**Home**		**School/ educational**		**Community**		**Workplace**	
	r	**p**	**r**	**p**	**r**	**p**	**r**	**p**
Frequency	.36**	.000	-.05	.652	.33**	.000	.25*	.012
Involvement	.26**	.006	.23*	.04	.23*	.016	.13	.201

Desire for change	-.34**	.000	-.25**	.009	-.37**	.000	-.31**	.001

* Correlation is significant at the 0.05 level (2tailed).
** Correlation is significant at the 0.01 level (2-tailed).

Discussion:

Results provide initial evidence to support the psychometric properties of the Y-PEM in terms of reliability, validity and utility. With regards to internal consistency and test re-test reliability, the majority of the Y-PEM scales (10/12) had a coefficient of 0.7 and above indicating moderate to good reliability. Few scales, especially those that pertained to frequency, had lower estimates of internal reliability than anticipated. To illustrate, Cronbach's alpha of the frequency scale at the home setting was 0.52 yet comparable to the reliability coefficient of PEM-CY measure of 0.59 (Coster et al., 2011). This estimate improved after the item "computer games and video games" was removed. This could be because when engaging in video and computer games, participation in other household activities becomes limited therefore high correlation between items may not always be observed. However, to ensure that all pertinent home activities were represented in the Y-PEM, all 10 items including "computer games and video games" were kept in the final version of the questionnaire (Shahin et al., 2022). Another specific frequency scale that demonstrated lower than anticipated test-retest reliability (0.43) was evident in the workplace setting. Unlike other settings, changes in work attendance between the two time points were more likely to occur due to COVID-19 exposure/illness or workplace closures.

With respect to Y-PEM's construct validity, our hypothesis was partially confirmed. As expected, the Y-PEM could descriptively detect differences in participation patterns (frequency and involvement) between the groups across all scales and settings; youth with disabilities had lower levels of participation frequency and involvement. Concurrently, these differences were

not always statistically significant (evident in 5 scores). This is incongruent with pre-COVID-19 research using the PEM assessments (Khetani et al., 2014; Li) and may be explained by the context of the study where data was gathered during the pandemic. During this period, participation patterns were disrupted for all (regardless of presence of disability) especially at the school, community, and the workplace (Balanzá-Martínez et al., 2021; Jackson et al., 2021). Most programs in educational and the community settings were closed, many people worked from home and remained in lockdown at different time intervals depending on their local public health guidelines. This may explain the reason that significant differences were observed between the two groups at the home setting. The small effect size however, compared to another PEM study (Law et al., 2013), could be due to nature of our sample involving youth with higher level of function. In fact, Y-PEM results indicated that both groups of young people with and without disabilities were somewhat unsatisfied with their participation as evident by the desire for change scale; specifically, both groups wanted to see change in nearly half of the activities listed in the home, community, and the workplace. This relatively high rates of desire for change could be unique to the COVID-19 period and could be attributed to the dynamic period of transitioning to adulthood which often brings doubts and uncertainty about current and future participation.

The small differences in participation patterns among young people with and without disabilities, in comparison to previous parent-reported PEM studies, could also be explained by the targeted population of the Y-PEM. As a self-reported questionnaire, the Y-PEM is intended for youth and young adults with adequate cognitive ability and reading skills of a fifth grader. Excluding participants with physical disabilities who had comorbidities impacting their cognition and ability to complete the measure on their own, resulted in a sample population that were

higher functioning compared to participants of other PEM studies (Coster et al., 2011; Khetani, 2013). Indeed, people with more severe disability are less likely to have successful transitions to adulthood and engage in productive activities (i.e., post-secondary education and employment) (Anaby et al., 2014). Our post-hoc analysis, examining the disability group only, further supported this assumption. Specifically, we found that youth with greater number of functional issues (>4.6) tend to have lower levels of participation across all settings and significantly less environmental supports (and more barriers) at home and the workplace. This trend lends further support to the construct validity of the measure, yet larger studies are needed.

Our findings also indicated that youth with greater number of environmental supports tend to have significantly higher levels of participation frequency and involvement and fewer number of activities in which change was desired. This was evident in most of the scales across all the 4 settings. While the correlation coefficients were small to moderate, they were in the expected direction (Anaby et al., 2013; Anaby et al., 2014; Shahin et al., 2020). These findings provide additional support for the Y-PEM construct validity and further demonstrates the important impact of the environment on participation outcomes. In fact, the Y-PEM addresses the need for self-reported participation measures (Adair et al., 2018) with a unique outlook on the environment. Data generated from this tool can be used to guide environment-based interventions such as the PREP (Pathways and Resources for Engagement and Participation) to improve participation in meaningful and age-related activities among youth with disabilities (Anaby et al., 2017; Anaby et al., 2018). Additionally, participation-based interventions which have shown promising results in improving body, cognitive and affective functions, are receiving increasing attention and interest among clinicians (Anaby et al., 2020). The Y-PEM could potentially be used by clinicians to evaluate participation, set goals, identify relevant

environmental barriers/ supports, and guide client-centered intervention planning to improve the quality of life and support transitioning into adulthood (Shahin et al., in press).

This study has some limitations. Data was collected during the 2020-2021 COVID-19 pandemic which had an impact on participation of people with and without disabilities across all settings; particularly, at the school, community, and the workplace. This may have affected the results limiting the ability to detect differences in participation patterns between people with and without disabilities (and hence construct validity) in such challenging times. In addition, this study did not evaluate other aspects of construct validity by looking at the association between Y-PEM constructs, i.e., frequency, and other measures such as the Questionnaire of Young People's Participation (Tuffrey et al., 2013) as well as the association between Y-PEM environmental items and the Craig Hospital Inventory of Environmental Factors (Whiteneck et al., 2001). Finally, most participants resided in Quebec and did not have severe cognitive problems or intellectual disabilities (due to the demands required for completing the Y-PEM) and, thus, caution should be taken in generalizing the findings. Future Canada-wide studies involving a larger sample size are required, allowing the examination of the factorial structure of Y-PEM dimensions (structural validity) in non-adverse times. Making the Y-PEM accessible to those with intellectual and/or communication impairments is also warranted.

Conclusion

Findings provides promising evidence regarding the initial psychometric properties of the Y-PEM, especially its reliability as a self-reported questionnaire for young people aged 12-30 with and without physical disabilities. This new participation-based questionnaire evaluates aspects of participation as well as the environment in activities pertinent for transition-aged youth and young adults (i.e., independent living, social relationship, post-secondary education,

employment), affording a comprehensive evaluation of participation in four settings: home, school/educational, community, and the workplace. Findings also shed light on the utility of this tool- with high perceived value and low burden- by the target population.

References:

Adair, B., Ullenhag, A., Rosenbaum, P., Granlund, M., Keen, D., & Imms, C. (2018). Measures used to quantify participation in childhood disability and their alignment with the family of participation-related constructs: a systematic review. *Developmental Medicine & Child Neurology, 60*(11), 1101-1116. https://doi.org/10.1111/dmcn.13959

Anaby, D., Avery, L., Gorter, J. W., Levin, M. F., Teplicky, R., Turner, L., Cormier, I., & Hanes, J. (2020). Improving body functions through participation in community activities among young people with physical disabilities. *Developmental Medicine & Child Neurology, 62*(5), 640-646. https://doi.org/10.1111/dmcn.14382

Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A., & Law, M. (2013). The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disability and rehabilitation, 35*(19), 1589-1598. https://doi.org/10.3109/09638288.2012.748840

Anaby, D., Mercerat, C., Tremblay, S., Wingo, B. C., & Rimmer, J. H. (2017). Enhancing Youth Participation Using the PREP Intervention: Parents' Perspectives. *International journal of environmental research and public health, 14*(9). https://doi.org/10.3390/ijerph14091005

Anaby, D. P., Law, M. P., Coster, W. P., Bedell, G. P., Khetani, M. S., Avery, L. M., & Teplicky, R. M. (2014). The Mediating Role of the Environment in Explaining Participation of Children and Youth With and Without Disabilities Across Home, School, and Community. *Archives of physical medicine and rehabilitation, 95*(5), 908-917. https://doi.org/10.1016/j.apmr.2014.01.005

Anaby, D. R., Law, M., Feldman, D., Majnemer, A., & Avery, L. (2018). The effectiveness of the Pathways and Resources for Engagement and Participation (PREP) intervention: improving participation of adolescents with physical disabilities. *Developmental medicine and child neurology, 60*(5), 513-519. https://doi.org/10.1111/dmcn.13682

Balanzá-Martínez, V., Kapczinski, F., de Azevedo Cardoso, T., Atienza-Carbonell, B., Rosa, A. R., Mota, J. C., & De Boni, R. B. (2021, Jan-Mar). The assessment of lifestyle changes during the COVID-19 pandemic using a multidimensional scale. *Rev Psiquiatr Salud Ment (Engl Ed), 14*(1), 16-26. https://doi.org/10.1016/j.rpsm.2020.07.003

Boop, C., Cahill, S. M., Davis, C., Dorsey, J., Gibbs, V., Herr, B., Kearney, K., Metzger, L., Miller, J., & Owens, A. (2020). Occupational therapy practice framework: Domain and process fourth edition. *AJOT: American Journal of Occupational Therapy, 74*(S2), 1-85.

Boyd, J. (2018). Face Validity, Internal Consistency and Applicability of The Participation and Environment Measure: Child and Youth (German Translation) in Switzerland: A Mixed Methods Pilot Study. https://dalspace.library.dal.ca//handle/10222/73809

Chaturvedi, S., & Shweta, R. (2015). Evaluation of inter-rater agreement and inter-rater reliability for observational data: an overview of concepts and methods. *Journal of the Indian Academy of Applied Psychology, 41*(3), 20-27.

Cobb, R. B., & Alwell, M. (2009). Transition Planning/Coordinating Interventions for Youth with Disabilities: A Systematic Review. *Career Development for Exceptional Individuals*. https://doi.org/10.1177/0885728809336655

Coster, W., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Liljenquist, K., Gleason, K., & KAO, Y. C. (2011). Psychometric evaluation of the Participation and Environment Measure for Children and Youth. *Developmental Medicine & Child Neurology, 53*(11), 1030-1037. https://doi.org/10.1111/j.1469-8749.2011.04094.x

Coster, W., Law, M., Bedell, G., Anaby, D., Khetani, M Teplicky R. (2014). Participation and Environment Measure for Children and Youth (PEM-CY) – Form & User's Guide ©. https://www.canchild.ca/en/resources/248-participation-and-environment-measure-for-children-and-youth-pem-cy

Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on autism and other developmental disabilities, 24*(2), 77-88. https://doi.org/10.1177/1088357608329827

Imms, C., Adair, B., Keen, D., Ullenhag, A., Rosenbaum, P., & Granlund, M. (2016). 'Participation': a systematic review of language, definitions, and constructs used in intervention research with children with disabilities. *Developmental Medicine & Child Neurology, 58*(1), 29-38.

Jackson, S. B., Stevenson, K. T., Larson, L. R., Peterson, M. N., & Seekamp, E. (2021). Outdoor Activity Participation Improves Adolescents' Mental Health and Well-Being during the COVID-19 Pandemic. *International journal of environmental research and public health, 18*(5), 2506. https://www.mdpi.com/1660-4601/18/5/2506

Khetani, M., Coster W., Law M., Bedell GM. . (2013). Young Children's Participation and Environmnet Measure (YC-PEM). (Fort Collins: Colorado State University (Copyright to authors))

Khetani, M., Marley, J., Baker, M., Albrecht, E., Bedell, G., Coster, W., Anaby, D., & Law, M. (2014). Validity of the Participation and Environment Measure for Children and Youth

(PEM-CY) for Health Impact Assessment (HIA) in sustainable development projects. *Disability and health journal, 7*(2), 226-235. https://doi.org/10.1016/j.dhjo.2013.11.003

King, G., Tucker, M. A., Baldwin, P., Lowry, K., LaPorta, J., & Martens, L. (2002). A life needs model of pediatric service delivery: services to support community participation and quality of life for children and youth with disabilities. *Physical & Occupational Therapy in Pediatrics, 22*(2), 53-77. https://doi.org/10.1080/J006v22n02_04

Kingsley, C., & Patel, S. (2017). Patient-reported outcome measures and patient-reported experience measures. *Bja Education, 17*(4), 137-144. https://doi.org/10.1093/bjaed/mkw060

Law, M. (2002). Participation in the occupations of everyday life. *American journal of occupational therapy, 56*(6), 640-649. https://doi.org/10.5014/ajot.56.6.640

Law, M., Anaby, D., Teplicky, R., Khetani, M. A., Coster, W., & Bedell, G. (2013). Participation in the home environment among children and youth with and without disabilities. *British Journal of Occupational Therapy, 76*(2), 58-66.

Li, N., Mazhar, S., Messina, S., Moyse, J., White, K., Cormier, I. & Anaby, D. Validating the Youth-report version of the Participation and Environment Measure for Children and Youth (PEM-CY): Preliminary findings. *Erg-go: Revue des Ergothérapeutes du Québec, 3*, 30-35.

Lorenzo, T., McKinney, V., Bam, A., Sigenu, V., & Sompeta, S. (2019). Mapping participation of disabled youth in sport and other free-time activities to facilitate their livelihoods development. *British Journal of Occupational Therapy, 82*(2), 80-89. https://doi.org/10.1177/0308022618817281

Moores, K. L., Jones, G. L., & Radley, S. C. (2012). Development of an instrument to measure face validity, feasibility and utility of patient questionnaire use during health care: the QQ-10. *International journal for quality in health care : journal of the International Society for Quality in Health Care, 24*(5), 517-524. https://doi.org/10.1093/intqhc/mzs051

n.d. (2004). *Research Electronic data Capture (11.4.4) [Computer software]*. https://redcap.researchdatabases.ca

Nguyen, T., Stewart, D., & Gorter, J. (2018). Looking back to move forward: Reflections and lessons learned about transitions to adulthood for youth with disabilities. *Child: care, health and development, 44*(1), 83-88. https://doi.org/10.1111/cch.12534

Panyo, K., Lersilp, S., Putthinoi, S., & Hsu, H. Y. (2021). Transition service in the occupational therapy process for students with disabilities: A systematic review. *Journal of Occupational Therapy, Schools, & Early Intervention, 14*(3), 343-355. https://doi.org/10.1080/19411243.2020.1862727

Ponterotto, J. G., & Ruckdeschel, D. E. (2007). An overview of coefficient alpha and a reliability matrix for estimating adequacy of internal consistency coefficients with psychological research measures. *Perceptual and motor skills, 105*(3), 997-1014.

Portney, L. G., & Watkins, M. P. (2009). *Foundations of clinical research: applications to practice* (Vol. 892). Pearson/Prentice Hall Upper Saddle River, NJ.

Seekins, T. P. D., Shunkamolah, W. B. A., Bertsche, M. B. A., Cowart, C. B. A., Summers, J. A. P. D., Reichard, A. P. D., & White, G. P. D. (2012). A systematic scoping review of measures of participation in disability and rehabilitation research: A preliminary report of findings. *Disability and health journal, 5*(4), 224-232. https://doi.org/10.1016/j.dhjo.2012.05.002

Shahin, S., DiRezze, B., Ahmed, S., & Anaby, D. (2022). Development and content validity of the youth and young-adult participation and environment measure (Y-PEM). *Disability and rehabilitation*, 1-13. https://doi.org/10.1080/09638288.2022.2030809

Shahin, S., Reitzel, M., Di Rezze, B., Ahmed, S., & Anaby, D. (2020). Environmental factors that impact the workplace participation of transition-aged young adults with brain-based disabilities: a scoping review. *International journal of environmental research and public health, 17*(7), 2378. https://doi.org/10.3390/ijerph17072378

Shahin, S., Ryan, M., Di Rezze, B., Ahmed, S., & Anaby, D. (in press). Utility of the Workplace Participation Domain of the Youth and Young-adult Participation and Environmnet Measure (Y-PEM): Stakeholder's perspectives. *Journal of Vocational Rehabilitation*.

Stewart, D. (2009). Transition to adult services for young people with disabilities: current evidence to guide future research. *Developmental Medicine & Child Neurology, 51*, 169-173. https://doi.org/10.1111/j.1469-8749.2009.03419.x

Tabachnick, B. G., & Fidell, L. S. (2013). *Using multivariate statistics* (6th ed. ed.). Pearson Education. http://www.pearsonhighered.com/tabachnick/

Tuffrey, C., Bateman, B., & Colver, A. (2013). The Q uestionnaire of Y oung P eople's P articipation (QYPP): a new measure of participation frequency for disabled young people. *Child: care, health and development, 39*(4), 500-511. https://doi.org/10.1111/cch.12060

Whiteneck, G., Harrison-Felix, C., Mellick, D., Brooks, C., Charlifue, S., & Gerhart, K. (2001). Craig Hospital Inventory of Environmental Factors. *PsycTESTS Dataset*.

WHO. (2001). *International Classification of Functioning, Disability and Health: ICF*. World Health Organization.

Chapter 8: Post-hoc Analysis to Further Add to the Construct Validity (Not Published and Will Not be Published):

Relationship Between Number of Self-Reported Functional Issues on Participation Patterns Among the Disability Group (n=56)

Findings indicated that participation mean scores for frequency (except for the school/educational setting), and involvement were descriptively lower and desire for change was higher for those with more functional issues (>4.6. based on median) across all settings (see figure 1). In this population, those with less than 4.5 self-reported functional issues reported more environmental supports across all settings and less environmental barriers at the home and school/educational settings. This difference was found to be statistically significant at the home (barrier: $t(54) = -2.006$, $p = .002$, ES= -0.54; support: $t(54) = 3.946$, $p = .000$, ES = 1.06) and the workplace (barrier: $t(54) = 1.996$, $p = .028$, ES = 0.53; support: $t(54) = 1.096$, $p = .039$, ES = 0.29) settings.

Figure 1. Number of functional issues and participation patterns

Relationship Between Impact of COVID-19 Pandemic on Participation Patterns

Results of Pearson Correlation between self-reported impact of COVID-19 pandemic on "Participation frequency", "Involvement", and "Desire for change" mean scores for the sample as a whole are presented in table 1. A significant positive correlation was found in "desire for change" scores across all settings (home= 0.23; school/ educational= 0.27; community= 0.21; workplace= 0.22) and negative correlation with "Participation frequency" in the community (-0.23).

Table 1. The impact of COVID-19 pandemic on participation patterns

Domain	**Scale**	**N**	**p**	**Pearson Correlation**
Home				
	frequency	102	0.585	-0.055
	involvement	100	0.542	-0.062
	desire for change	102	0.021	.228*
School				
	frequency	95	0.45	0.078
	involvement	71	0.758	-0.037
	desire for change	102	0.005	.274**
Community				
	frequency	101	0.019	-.234*
	involvement	98	0.508	0.068
	desire for change	102	0.034	.211*
Workplace				
	frequency	91	0.601	0.056
	involvement	87	0.52	0.07
	desire for change	102	0.026	.221*

* Correlation is significant at the 0.05 level (2tailed).
** Correlation is significant at the 0.01 level (2-tailed).

Chapter 9: Bridging Manuscripts 3 and 4

Research Questions

Manuscript 3

Research question: To what extent is the Y-PEM reliable, valid, and acceptable to be used by youth and young adults aged 12-30 years old?

Objective: To evaluate aspects of utility (in terms of value and burden) and provide initial evidence towards the construct validity and reliability (in terms of internal consistency and test-retest reliability) of the Y-PEM as a self-reported questionnaire for youth and young adults aged 12-30 years old.

Manuscript 4

Research question: In what ways the information generated by the workplace participation domain of the Y-PEM is relevant in practice among different stakeholders/professionals (i.e., clinicians and community-based employment service providers)?

Objective: To qualitatively explore the utility of the newly developed "workplace participation" domain of the Y-PEM among stakeholders providing employment-related supports and services, and those receiving services (i.e., employees with disabilities).

Integration of Manuscripts 3 & 4

The third manuscript is another significant contribution to the field of transition and rehabilitation as it provides further support for the use of the Y-PEM with transition-aged individuals. This study provided initial evidence to support the construct validity, internal consistency, and short-term test-retest reliability of the Y-PEM. Data on initial measurement properties are in fact necessary for the uptake in practice of newly developed self-reported

outcome measures as evidence supporting aspects of validity and reliability indicate that the scores of the tool are sound, replicable and accurate [1,2]. The findings of this study also shed light on aspects of feasibility (e.g., the average time and number of seating (or breaks) needed to complete the questionnaire) and perceived value and burden from the perspectives of the target population. Youth and young adults perceived the Y-PEM as a valuable tool to evaluate their participation patterns and environmental factors that impact participation. Responder burden was low as demonstrated by the average score on the 4-burden-related items on the QQ-10 questionnaire. Reports on such valuable information allows researchers and clinicians to make an informed decision when choosing appropriate measurement tools in their practice.

One way to facilitate the uptake of newly developed measurement tools is to demonstrate their utility to stakeholders [3]. After evaluating aspects of the utility of the entire Y-PEM in terms of perceived value and burden from the perspectives of youth and young adults, we wanted to further investigate the usefulness of the newly developed workplace participation domain from the perspectives of other stakeholders, including those who provide employment-related services in both the clinical and non-clinical milieu. In other words, we wanted to explore the practical characteristics of this new domain from the viewpoints of those who would be using the tool in their practice. Such an approach not only creates valuable knowledge on the usefulness of this tool, but also paves the way for its uptake in practice. Such an investigation can also provide further evidence for the content validity and relevancy of this new domain for employment-related services. Another implication of this utility study is to explore the potential application of Y-PEM's workplace participation domain, in non-clinical settings. Extending the practical utility of this domain outside of the rehabilitation context could potentially facilitate communication and collaboration between clinicians and other stakeholders in the community. This in turn

promotes intersectional and continuum of care for youth and young adults with disabilities, improving transitioning outcomes [4-6]. The following utility study was therefore a first step towards initiating discussion and generating guidance regarding the implementation of the workplace domain across different contexts.

References

1. Gadotti, I., Vieira, E., & Magee, D. (2006). Importance and clarification of measurement properties in rehabilitation. *Brazilian Journal of Physical Therapy, 10*, 137-146.

2. Ahmed, I., & Ishtiaq, S. (2021). Reliability and Validity: Importance in medical research. *Journal of the Pakistan Medical Association, 71*(10), 2401-2406.

3. Kroenke, K., Monahan, P. O., & Kean, J. (2015). Pragmatic characteristics of patient-reported outcome measures are important for use in clinical practice. *Journal of clinical epidemiology, 68*(9), 1085-1092.

4. King, G. A., Baldwin, P. J., Currie, M., & Evans, J. (2006). The effectiveness of transition strategies for youth with disabilities. *Children's Health Care, 35*(2), 155-178.

5. Palisano, R. J., Di Rezze, B., Stewart, D., Rosenbaum, P. L., Hlyva, O., Freeman, M., Nguyen, T., & Gorter, J. W. (2017). Life course health development of individuals with neurodevelopmental conditions. *Developmental medicine and child neurology, 59*(5), 470-476. https://doi.org/10.1111/dmcn.13402

6. Di Rezze, B., Viveiros, H., Pop, R., & Rampton, G. (2018). A review of employment outcome measures in vocational research involving adults with neurodevelopmental disabilities. *Journal of Vocational Rehabilitation, 49*(1), 79-96. https://doi.org/10.3233/JVR-180956

Chapter 10: Manuscript 4

Title: Utility of the Workplace Participation Domain of the Youth and young-adult Participation and Environment Measure (Y-PEM): Stakeholder's perspectives

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Utility of the Workplace Participation domain of the Youth and Young-adult Participation and Environment Measure (Y-PEM): Stakeholder's perspectives

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Abstract

Background: Assessing workplace participation of people with disability using measures that can inform practice is vital. **Objective:** To investigate the utility of the Youth and Young-adult Participation and Environment Measure's (Y-PEM) Workplace Participation domain. **Methods:** Four focus groups were conducted with 11 stakeholders from different employment-related settings. Open-ended questions regarding Y-PEM's interpretation, meaning and relevance, drawing on elements of clinical utility, were used. Data were analyzed by two investigators using inductive thematic analysis. **Results:** Stakeholders' experience in providing/receiving employment services varied (1-16 years). Three themes emerged. *The Y-PEM* captures *multiple factors in employment transition;* it generates insights and sparks conversations to better appreciate and support individuals' transitioning to employment. Y-PEM meets the *need for tools to guide services of transitioning to employment* as it is comprehensive in assessing participation and the environment, can provide a "snapshot" of where the young person is at in their transition, and serves different purposes. The *tool provides a "piece of the pie"* within this complex process and could be used in conjunction with other tools. **Conclusion:** Y-PEM was perceived as essential, comprehensive, and appropriate for use in clinical and employment-related service contexts to inform practice, and guide stakeholders' decision-making in facilitating transitioning to employment.

Keywords: Workplace participation, outcome measure, transition-aged, employment-related service providers

Introduction:

For individuals with disabilities, transitioning to adulthood remains a pressing issue (WHO, 2011). Successful transition to adulthood involves engaging in domains such as independent living, relationships, and employment (Janus, 2009; Newman et al., 2011). Particularly, employment -an important focus of transition services for youth with disabilities- is considered a central part of many adults' lives in terms of financial benefits, social networks, and being a contributing member of society (Newman et al., 2011). However, this critical period of "emerging adulthood" focusing on the transition from school to work, is often delayed for people with disabilities (Lindsay, McDougall, Sanford, et al., 2015). As such, youth and young adults with disabilities continue to experience lower rates of employment compared to their peers without disabilities (WHO, 2011). This highlights the need for appropriate measures to shed light on the complex process of preparing for and engaging in employment especially during the challenging transitioning to adulthood.

Participation in the workplace is an important outcome of transition services. A recent review of employment outcome measures in vocational rehabilitation of adults with neurodevelopmental disabilities reported that although common employment challenges exist across various diagnoses, a variety of services and tools were used (Di Rezze et al., 2018) with fewer studies that focused on the environment or directly addressed the impact of the environment on participation (Di Rezze et al., 2018). This raises a concern as a recent scoping review (Shahin et al., 2020) revealed that participation in work is significantly influenced by environmental factors. Examples of such factors include: availability of transportation, accessibility of the workplace, relationship with and attitudes of employers and colleagues and flexibility of work schedule among others (Shahin et al., 2020). Hence, outcome measures

should capture both the participation in work-related activities, and environmental factors that impact work functioning (Gorter et al., 2011). Such tools can guide service providers' decision-making and intervention planning to improve youth's participation outcomes in employment and can also inform youth about potential environmental factors that could impact their participation.

The Youth and young-adult Participation and Environment Measure (Y-PEM) is a unique outcome measure that evaluates both participation and environmental factors impacting participation among individuals aged 12-30 years old (Shahin, DiRezze, et al., 2022). It is modelled after the Participation and Environment Measure-Children and Youth (PEM-CY) (Coster et al., 2012), a psychometric sound parent-report assessment intended for children aged 5 to 17 that evaluates participation at home, school, the community (Coster et al., 2011). The Y-PEM, completed by the youth, includes a new domain evaluating workplace participation. This new domain contains 6 work-related participation items (see supplemental material) pertaining to job preparation (i.e., identifying interests and seeking employment), training (i.e., vocational training, education, internships, job shadowing), and engagement (i.e., performing task demands, interacting with colleagues, going to work-related social gatherings) (Shahin, DiRezze, et al., 2022). Each item is rated using three scales: *frequency* (8-point scale ranging from never to daily)*, involvement* (5-point scale ranging from minimally involved to very involved) and *desire for change* (Yes/No; and the type of change desired (e.g., be more/less involved)) in the last 4 months. In this "workplace participation" domain, 16 environmental items (see supplemental material) representing barriers/supports impacting participation at work are also assessed. Examples include the physical layout of the workplace, the cognitive and social demands of the job, and availability of programs and services. These

items are scored on a 4-point scale (1= Usually makes harder/usually not available, 2= Sometimes helps, sometimes makes harder/ sometimes yes, sometimes not available, 3= Usually helps/ usually yes (available) , 4= Not an issue/not needed) where higher scores indicate higher levels of environmental facilitators (Shahin, DiRezze, et al., 2022).

The content of the Y-PEM, developed with input of young people and through expert consultation, was found relevant and clear (Shahin, et al. 2022). In addition, results of the QQ-10 questionnaire (which assesses the feasibility of the tool) among youth with and without disability (n=110) indicated that the Y-PEM was perceived as a fairly valuable measure (mean of 2.9 out of 4) that involved relatively low levels of burden (mean=3 out of 4) (Shahin, Ahmed, et al., 2022). The workplace participation section of the Y-PEM has fairly good internal consistency (0.74 to 0.82) and test-re-test reliability (0.73 to 0.74) for most of the scales (Shahin, Ahmed, et al., 2022). However, the utility of the Y-PEM in practice has not been evaluated by other stakeholders especially among service providers. The concept of measurement utility is often referred to the usefulness of a tool in practice. Clinical utility can be defined as the ease and efficiency of use of an assessment as well as the relevance (and value) of the information it provides (Smart, 2006).This study, therefore, aimed to qualitatively explore the utility of the newly developed "workplace participation" domain of the Y-PEM among stakeholders providing employment-related support and services, and those receiving services (i.e., employees with disabilities). Specifically, we aimed to better understand in what ways the information generated by this domain is relevant and meaningful in practice among different stakeholders/professionals (i.e., clinicians and community-based employment service providers). Such knowledge can set the stage for better integration of this tool in practice within two distinct sectors (health and

social services) that provide services for people with disabilities:
clinical rehabilitation centers and employment-oriented (non-clinical) organizations.

Methodology

A qualitative descriptive study design comprised of four focus groups was employed (Bradshaw et al., 2017) to elicit and describe the perspectives of stakeholders in the field of employment for individuals with disabilities regarding the utility of the Y-PEM in supporting employment of this population. A purposeful maximum variation sampling method (Patton, 2002) was used to ensure variability in stakeholder's role in supporting the targeted population (e.g., clinicians, employment consultants, managers) as well as the context in which they practice (i.e., health, social services). Sampling continued until saturation was reached (no new codes came up during the analysis).

Study procedure

Clinicians (e.g., occupational therapists, vocational specialists, orientation counselor), employment-related community-based service providers (e.g., employment counselors, directors and coordinators of employment programs) who assist youth and young adults with various disabilities in finding and sustaining employment, as well as a working young adult with disability were purposefully recruited. Stakeholder-participants from both the French and English organizations were included if they had more than one year of working experience to ensure that they are familiar with current challenges in securing employment among this population and with relevant participation-based assessment tools in their field.
They were recruited through clinical coordinators from rehabilitation centers offering transition programs, and community-based centers that provide employment services to young adults with

disabilities located in the provinces of Quebec and Ontario through recruitment ads sent to our networks.

Four separate focus groups with 11 stakeholders were conducted based on participants' preferred language; two with clinicians (n=5 in the English-speaking group; n=2 in the French-speaking group) and two with community-based service providers and service users (n=2 in English-speaking group; n=2 in French-speaking group). Having four distinct focus groups minimized potential power imbalance and allowed individuals with a common experience yet from diverse contexts and professions to share their thoughts about the Y-PEM in their respective fields (Ayrton, 2019).

All focus groups were facilitated by the same person, lasted between 1.5-2 hours and were conducted through online video conferencing in stakeholder's preferred location (i.e., home, office). First the Y-PEM questionnaire was introduced, with a special focus on the newly developed workplace participation domain illustrated through a case example. The case example exhibited the completed item-level results of workplace participation domain of Alice, a young woman aged 25 years old with spinal cord injury, who had recently finished her bachelor's degree in Computer Sciences and was looking for assistance to transition to her new employment. Stakeholders were asked to describe what the responses on the workplace participation domain of the Y-PEM meant to them and if (and how) they would use the information in their practice. A focus group guide (see supplemental material) was developed based on elements of clinical utility suggested by Smart (2006). This guide included 4 open-ended and additional prompt questions regarding the interpretation, as well as the meaning and relevance of the information obtained, which are pertinent elements of clinical utility in the field of rehabilitation (Smart, 2006). This approach enabled more comprehensive exploration of the

utility of the Y-PEM in informing practice and decision-making among stakeholders. The focus groups were video- and audio-recorded and transcribed without any identifying information. Inform consent was obtained from all stakeholder-participants.

Data analysis

The audio recordings of the focus groups were transcribed verbatim, and participants were given IDs to preserve anonymity within the transcripts. Transcripts were analyzed following Braun and Clarke's (2006) six phases of inductive thematic analysis. After familiarization with the data, each focus group conducted in English was coded manually and separately by the investigator and a second member of the research team. Both coders were rehabilitation healthcare professionals with similar levels of experience in qualitative research and a common understanding of the concept of participation. Initial 'data-driven' themes and sub-themes were identified independently by the two team members and then compared. Themes were reviewed together by both team members by first reviewing and refining the individual coded extracts within each theme and then reviewing whether the proposed thematic map accurately reflects the meanings of the overall data. The focus groups conducted in French were then coded by the investigator who was bilingual. Codes were matched to the existing thematic map. Through further discussion, themes were then defined and further refined focusing on the 'story' that each theme tells. Given the chosen descriptive methodology, the researchers attempted to stay close to the data by repeatedly going back to the original transcripts to resolve any disagreement and ensure that themes and subthemes accurately describe and summarize findings (Bradshaw et al., 2017). A third member of the research team-the principal investigator-who also acted as the peer debriefer to validate findings (Creswell & Poth, 2017) was involved at

the final stage to provide feedback on the overall narrative and clarifying what each theme entails. All three members discussed how to best name each theme and reached agreement through ongoing discussion. A summary of the main findings was then generated.

Results

Stakeholder participants

A total of 11 stakeholders (9 females, 2 males) participated in this study, among which seven were clinicians (n=5 English-speaking; n=2 French-speaking), three were community-based employment-related service providers (n=1 English-speaking; n=2 French-speaking) and one was a young adult advocate with a disability in the workforce (English-speaking) (see table 1). Stakeholder-participants had between 1-16 years of experience (median= 6.5 years) in providing employment-related services to youth and young adults older than 16 years of age with various disabilities (e.g., spinal cord injury, autism spectrum disorder, developmental disability including intellectual disability (or IQ<70),) in their transitioning phase to adulthood.

Table1

Sample description (n=11)

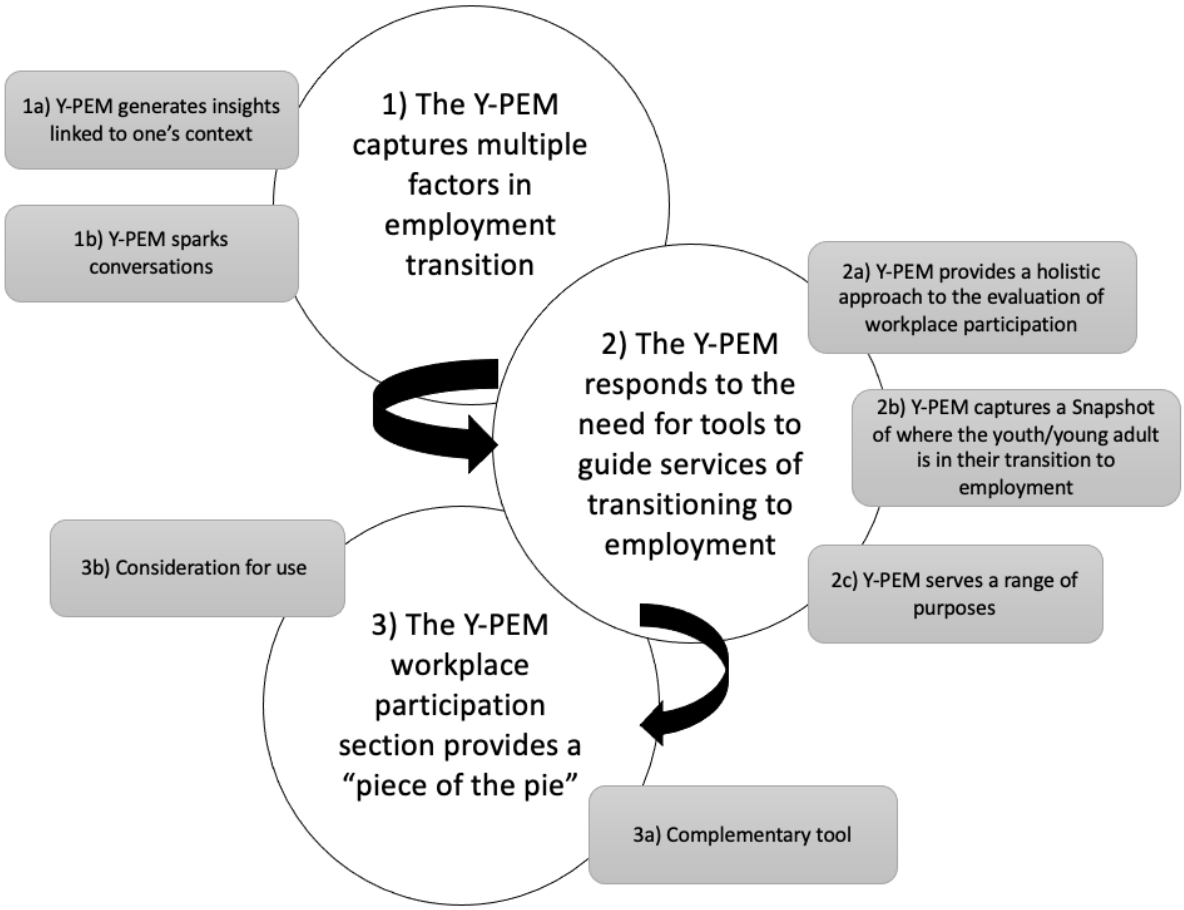
Settings	**Stakeholder participants**	**Role**
Rehabilitation/clinical settings	7 clinicians	1 occupational therapist 2 orientation counselors 1 vocational counselor 1 special care counselor 1 clinical coordinator 1 program manager
Employment-related organizations in the community (non-clinical)	3 stakeholders	2 directors of employment programs 1 coordinator with experience as an employment counselor
Workplace	1 working service user with lived experience	1 young adult employee/advocate

Findings

Three interrelated themes emerged from the qualitative analysis of the focus groups (see figure 1): 1) the Y-PEM captures multiple factors in employment transition, 2) the Y-PEM responds to the need for tools to guide services of transitioning to employment, and 3) the Y-PEM provides a "piece of the pie" in this complex process.

Figure 1.

This figure demonstrates the interrelated themes and the corresponding subthemes



Theme 1: The Y-PEM captures multiple factors in employment transition

All stakeholders from both the clinical and community milieu described transitioning to employment as a multi-factorial and complex process that is affected by personal, familial, environmental, and contextual factors. To illustrate, stakeholders described that information about the person's medical history, current functional capacity, education, interests, culture, living situation, past work-related experiences, and career aspirations play a role in the youth/young adult's career planning. In addition, environmental factors such as support and attitudes of family, friends, peers, employers and colleagues, work demands, availability of transportation, accommodations and accessibility were among other considerations by stakeholders. In that regard, the workplace participation domain of the Y-PEM was perceived as a multi-dimensional tool that captures the youth/ young adult perspectives about their frequency of participation, involvement, and desire to see change in the workplace as well as environmental factors that impact their participation. This tool was found to be informative and promote conversation and reflection around some of these important considerations of transitioning to employment. As such, information pertaining to this theme was categorized into two main reflective subthemes; 1a) Y-PEM generates insights linked to one's context and 1b) it sparks conversations.

Subtheme 1a) The Y-PEM generates insights linked to one's context

The combination of the scales (i.e., frequency, involvement, and desire for change) seemed to further translate into relevant information about the youth/young adult's satisfaction, motivation, values, and sense of self-efficacy from the service providers' perspectives. Specifically, the subjective scales of involvement and desire for change received particular attention from stakeholders as it shed light on the youth/ young adult's intrinsic feelings.

Although service providers recognized that the involvement scale could be an abstract concept for some and may be difficult to answer as it requires self-reflection and critical thinking, they reported that it provides insight on ones' level of engagement and motivation. One clinician mentioned that the involvement scale provides information about whether the youth/ young adult is actively involved in the process of finding and maintaining employment or that they are only contemplating being employed. This clinician further stated that the youth/young adult's level of engagement can inform the type of approach that should be taken by service providers during the intervention.

Particularly, the Y-PEM was perceived as a tool that can imply the sense of self-efficacy of the youth and young adult through the way they see themselves, their goals and the steps taken to reach their goals. Moreover, the workplace participation domain was positively received because it demonstrates if the youth/young adult is active in the work market. It further helps to explore their career aspirations by looking at what has been done in the past, the barriers they faced, and areas that have not been explored yet. Service providers also believed that the Y-PEM was practical in flagging areas in which the service user needed assistance and support. For example, a community-based service provider interpreted the young woman case study by integrating data from one item as such:

> "*If I look at the engaging in the process of selecting work [item #1], […] she probably finds barriers even accessing employment because she's been doing it [engaging in the process of selecting work] a few times in the last four months, she has been very involved, and she would like to do it less often. […] that flags for me that from [her] perspective finding employment has been difficult."* (S1)

Another stakeholder deduced the following from data generated by the Y-PEM from the case study:

> *"… in fact, she should perhaps increase, for example her participation in networking in her field […] she would benefit greatly for example, by being accompanied in her job search." (CF1)*

According to stakeholders, the intake (done in their context) usually entails asking questions about the demographics of the young adult, past job experiences and future job aspirations without clear guidelines. Service providers perceived the value of this multi-dimensional tool especially for collecting data about participation in work-related activities and the environment holistically. Participants commented that this tool captures the interaction between the person and their environment. A community-based service provider saw the advantage of the Y-PEM as such:

> *"… [the Y-PEM] will force [service providers] a little bit more to be more structured and to think more about the interactions between the workplace environment and the person." (S1)*

Subtheme 1b) The Y-PEM Sparks conversations

The Y-PEM was perceived as a tool which sparks conversations and promotes reflection to further understand the context and factors impacting employment. Clinicians recognized that each activity set contains many elements to be explored further through discussion providing rich information. For example, participants commented that the first three items (selecting an area of work or a profession, seeking and acquiring employment, and training for a job) capture a client's underlying interests and strengths and how far they have gone in finding, acquiring, and preparing for a job. The desire for change scale further indicates service users' objectives, hopes

and aspirations in preparing for employment which can be further detailed out in a discussion to provide a deeper understanding. Furthermore, the last three items (volunteering, working in a paid job, and attending work-related events and social gatherings) pertain to engaging and performing work tasks such as attending meetings, following work schedule, and interacting with colleagues. As such, service providers explained that the responses provided could direct follow-up questions they would ask to clarify the specifics of each activity set to better understand the youth/ young adult. One community-based service provider mentioned:

> *"I'm already seeing how this could be a benefit for the sector where I am, you know, working right now to really understand and have more fulsome conversations about how people can be supported in the workplace." (S1)*

One service user with lived experience who holds a permanent job commented that the workplace environment domain could be used in annual reviews with their employer to have open discussions about environmental barriers that they face at work, and the accommodations that they believe could be helpful. They reported:

> *"From my perspective as an employee […] this tool would be particularly helpful […] if I wanted to make […] a career transition […] or say if I were doing an annual review with my employer that was coming up like to hand a sheet like this [the workplace environment section] in ahead of time so that […] they have a bigger picture of what I'm talking about when they ask for what sort of accommodations would you like to see from us going forward." (S2)*

It was also suggested that by going over this questionnaire on an annual basis, they could evaluate if barriers have been resolved and whether new ones have risen.

Theme 2: The Y-PEM responds to the need for tools to guide services of transitioning to employment

Stakeholders mentioned the value of having a structured and comprehensive tool to help them gather pertinent information during the initial assessment. Rather than one standardized method, stakeholders reported using different ways of gathering information such as interviews, medical charts and among some clinicians, questionnaires such as the Life-H. However, no single questionnaire or tool was identified as being used consistently to systematically gather information in a structured way. In this regard, the Y-PEM was identified to be a tool that evaluates workplace participation and the environment in a structured and holistic manner. Information in this theme was categorized into three subthemes demonstrating that Y-PEM can: 2a) provide a holistic approach to the evaluation of workplace participation, 2b) capture a snapshot of where the youth/young adult is in their transitioning to employment and 3c) serve a range of purposes.

Subtheme 2a) The Y-PEM provides a holistic approach to the evaluation of workplace participation

Stakeholders commended the comprehensiveness of the Y-PEM, and its ability to holistically and chronologically capture the entire process of entering the job market and participating in work. In that regard, the first three workplace participation items were interpreted as follow: item 1 (engaging in the process of selecting an area of work or a profession) was interpreted as looking into the youth/young adult's interests, and self-reflection, item 2 (seeking and acquiring employment) captures everything youth/young adults do to get a job and item 3 (training for a job) encompasses getting a job and maintaining it. These first three items spoke to the process that one would follow to acquire employment and were identified by

stakeholders as prerequisites of maintaining employment. To illustrate, one stakeholder mentioned:

> *"We talked about the person's interests and and kind of self-reflection which is [item] one [engaging in the process of selecting an area of work or a profession], [item] two [seeking and acquiring employment] is kind of a how to do it and how to get there what you need to be able to do to get a job and then the [item] three [training for a job] is kind of like getting the job and kind of maintaining it so it does speak to the process that one would follow in terms of getting a job." (C3)*

Subsequently, the last three items (i.e., volunteering or working in unpaid job, working in a paid job, and attending work-related events and social gatherings) were interpreted by stakeholders as evaluating engagement in the workplace. A community-based service provider reported that this structured questionnaire guides information gathering and allows them to discuss topics that may have otherwise been forgotten. They further stated:

> *"With this kind of questionnaire, it looks like it's complete. Then we're going to put together a lot of information and everything…. And yes, it will serve us… ..in accompanying clients in their job search or their return to school." (SF1)*

The item pertaining to participation in social events in the workplace received notable endorsement by all stakeholders and was highlighted as being a unique and important contribution of the tool. This item was reported to provide valuable information on youth/young adult's level of comfort in social events and willingness to participate in team meetings and interact with other colleagues, which is an integral component of work participation in some jobs, often overlooked. Additionally, some service providers mentioned that this item demonstrates the social aspect of work and evaluating it exhibits its importance to youth/ young

adults with disability. This was illustrated by a community-based service provider who believes that a sense of belonging and membership at work sets the foundation to developing social network and is imperative for productivity and satisfaction:

> *"If you don't find yourself being fully yourself at work Uhm, you don't feel like you belong and or people don't feel like you belong and […] that's critical for being productive […] for having satisfaction in the workplace, just knowing that you can be you […]" (S1)*

Moreover, the section of the Y-PEM that evaluates aspects of the environment in the workplace was reported to be extensive, and to cover the range and scope of environmental barriers/supports that people with disabilities face in the workplace. Service providers deemed the environmental items appropriate and suitable for the sectors that they worked in. One service provider reported:

> *"At the level of the items and examples of the work environment, I find that this is quite straight forward, and it might be able to tell me, and help me,… and these are major obstacles, as we know, for people with physical disabilities, it's if we look at the questionnaire, the, the physical layout, the noise, the environment, the sensory, the physical requirements and all that it is relevant, it is quite straight forward, and I can intervene. I would easily be able to track where I question myself." (CF2)*

To further validate their affirmation, one working young adult with lived experience reported:

> *"I definitely think […] it is a definite step in the right direction, especially in regard to […] figuring out what exactly the environment is like for a person working with a disability […]. I liked that it included not just the physical thing because oftentimes an*

employer will be like "okay" well we can accommodate you in these ways like physically […], but that often doesn't delve into like say, like the social aspects of the job, like attending meetings or scheduling for that […], the relationships like coworkers and supervisors, and that's what I really loved about this tool, because it gives us a section for that as well. That's definitely I feel the most important when it comes to keeping and retaining employment is maintaining those relationships and accommodating for that." (S2)

Subtheme 2b) Snapshot of where the youth/young adult is in their transition to employment

Stakeholders pointed out the ability of the Y-PEM to capture a snapshot of where the youth and young adult is in their transitioning to employment. The comprehensiveness of the workplace participation domain and the chronological order of the items created a picture of the client for service providers. In that regard, clinicians believed that the Y-PEM facilitated an appreciation of the youth/ young adult's "job readiness" or "closeness to the job market" by looking at how involved they are in this transition. Identifying the exact step(s) along this path where the youth/young adult is less active, can be used to target and develop interventions that specifically meets the needs of the youth/young adult. Service providers reported that the Y-PEM would be a useful tool at intake to provide a clear sense of where the youth is at, how involved they are and what they would like to change along this path. To demonstrate, one stakeholder explained:

"The tool would be like a very useful tool for that intake process as an employment service provider is trying to understand, uh, you know, a picture of the client that is coming to sit down with them and talk about their aspirations for career discovery and aspirations […] to be connected to employment." (S1)

Subtheme 2c) The Y-PEM serves a range of purposes

One of the advantages of the Y-PEM, expressed by stakeholders, was its ability to serve many purposes. Depending on service provider's role and sector in which they worked, they reflected on the many ways in which the Y-PEM could be used in their setting. All service providers acknowledged that the Y-PEM could be used as a goal-setting tool as it captured the youth/young adult's desire for change. They also saw its utility in identifying barriers to employment and developing targeted and client-centered intervention plans. Most agreed that the Y-PEM could be used as an educational tool for those without any work experience to create awareness about the required steps to acquire and maintain employment, as well as some of the environmental barriers that youth/ young adults with disabilities may face at work. Some service providers mentioned that they could use the Y-PEM to get a sense of the youth/ young adult's insight regarding the obstacles they may face at work based on their functional capacity. One clinician mentioned that data from the Y-PEM could indicate whether the youth/ young adult is a good fit for a specific transition program. A few stakeholders explained that the Y-PEM could be used to evaluate their client's progress and/or their own performance by re-administering the Y-PEM, or sections of the Y-PEM, after the intervention. This was particularly found to be helpful for clients whose progress were less evident. In this case, the Y-PEM could shed light on new information that could help service providers to better understand what the cause of this slow progress might be. This information could also indicate whether the targeted intervention has been helpful in removing environmental barriers, thus providing feedback to the service provider, as underlined by a community-based service provider:

> *"When, for example, we do [the Y-PEM] at the beginning, then the employment counselor detects certain problems and all that maybe towards the end as well there is a*

way to see, [..] for example has the employment counselor met the needs of [the client]." (SF1)

Information generated by the Y-PEM and a discussion with youth/young adults could be used to group youth/young adults with similar goals in one program. The evaluation of the social aspect of work participation and the ability of the Y-PEM to capture participation using different scales was seen as a strength of this tool in transition programs with the potential to be used as an outcome measure. A rehabilitation-based program manager reported:

"In terms of program development, we're always looking for outcome measures related to transition to adulthood for a client of youth living with disabilities and one thing that comes frequently as a potential outcome measure is social participation uhh so I really like that aspect of this questionnaire. I really like that it focuses on participation in the different variable of participation uhh and I …if the results given by that were um uh useful, I can really see this tool […] being used in a program like transition." (C4))

Stakeholders also mentioned that the Y-PEM could be used to match youth/young adults with disabilities to a more appropriate job depending on their career aspirations and environmental factors that they believe might be a barrier to their participation. For example, one stakeholder commented on the item pertaining to training and its impact on deciding the appropriate type of job for their client. This community-based service provider described:

"[…] if it is a growing business and the person does not want to get training but rather wants repetitive tasks, we will perhaps not refer him to a company like that, so it's interesting to know if [the client] wants to grow… ..And is ready to put energy precisely on getting trained." (SF2)

Lastly, it was noted that information generated from the Y-PEM from specific populations could be used to advocate for better services and policies at a broader societal level. A community-based service provider reported that the Y-PEM not only allows comprehensive re-evaluation of their client's contexts and challenges that might have been overlooked during the initial assessment, it also allows them to gather information about similar challenges that their clientele experiences. They further stated:

> *" […] it is certain that we can make reports and then take it to the regional, provincial level, […] we push to uh to integrate people with disability who do not have adequate […] services. [The Y-PEM] can lead to […] different information that could be used." (SF2)*

Theme 3: Y-PEM's workplace participation domain provides a "piece of the pie"

Service providers emphasized that transitioning to employment is a complex process that is impacted by various contextual factors. Although the tool was perceived as comprehensive, some stakeholders conceded that the Y-PEM provides "a piece of the pie" in their evaluation of the youth/young adult and could be used in conjunction with other tools. Stakeholders also provided suggestions for its use in practice. Information pertaining to this theme is categorized into the following subthemes: 3a) complementary tool and 3b) considerations for use.

Subtheme 3a) Complementary tool

All stakeholders noted that although the Y-PEM provides a snapshot of the youth/young adult's work-related involvement in the last four months, it should be used in conjunction with a discussion or other tools depending on the context/services. One community-based stakeholder identified that the Y-PEM would be another tool for employment-service providers who support

people with disabilities to add to their toolkit. Discussion to further detail out important aspects of each item with follow-up questions was noted to be beneficial in certain cases. For example, item 5 of the workplace participation domain (working in a paid job) entails examples of activities (i.e., performing job related tasks, attending work-related meetings, monitoring one's own performance, etc.) that might each be worth exploring with the youth/ young adult in detail especially, if they would like to see a change in this type of activity. Similarly, a discussion about each item can provide in-depth information that could help service providers to better understand the first-hand experience of youth and young adults in this transitioning process. Information from the Y-PEM can be complemented through the use of other tools depending on the setting. Service providers suggested that other tools or additional questions such as the type of work (full-time vs part-time) that the service user is looking for and previous accommodations that have facilitated work participation could also be valuable in informing their practice and service provision. The use of other outcome measures and tools might be beneficial in accurately assessing client's physical and cognitive abilities. One clinician portrays this as follows:

> *"I find that [item] 5 [working in a paid job] in bold is much too large while there are other elements detailed in the examples which I find as important skills for me as a rehabilitation specialist to identify, measure, then to further explore with a measurement tool." (CF2)*

Subtheme 3b) Consideration for use

Service providers described having clients with multiple types of diagnosis and a wide range of functional and cognitive abilities. The Y-PEM could be complex and difficult to complete as a self-reported measure by youth and young adults with cognitive impairment. Service providers reported that adapting the tools they use to the youth/ young adult's level of

comprehension is part of their typical practice. The Y-PEM was perceived as a tool that could be adapted by the service provider to be appropriate for their client. Stakeholders suggested that the Y-PEM be administered by the service provider using lay language in certain cases to ensure that youth/young adults understand the items and adequately respond to them. This was explained by a stakeholder as such:

> *"The highly cognitive functioning people I can just give the test or the questions and they'll do it. We do a lot of adapting whatever we do because […] everybody is so individually different, and their needs are so different that we uh we do have to adapt whatever we do." (C2)*

Service providers also noted the flexibility with which the Y-PEM could be used depending on their needs. For example, some service providers reported that it is more appropriate to only administer the workplace environment domain to gain information on specific environmental barriers and supports that their client is experiencing at work. Other service providers mentioned that they would only administer the workplace participation domain if their client is still in the first steps of acquiring a job and is not deemed "close to the job market" or ready for employment. Some saw the benefit of administering the entire workplace participation setting, including the environment domain to service users who are "close to the job market" but have no previous work experience as a way to raise awareness about the impact of the environment on work participation. Others reported that they would re-administer the Y-PEM as an outcome measure to assess the youth/ young adult's progress or the effectiveness of their intervention. Some reported that they may only re-administer parts of the Y-PEM that they deem relevant, while others mentioned that they do not see the advantage of re-administering the Y-PEM at all.

Discussion:

This qualitative study provides initial insights on the potential utility of the newly developed workplace participation domain of the Y-PEM among various groups of stakeholders including clinicians, transition counselors, employment-related service providers, and a service user with disability. Having a diverse sample of participants in the focus groups allowed us to gather stakeholder's opinions about the Y-PEM and its potential role in informing decision-making in a range of contexts and purposes. Results of the focus groups illustrated that the Y-PEM is unique in being a comprehensive tool that evaluate both workplace participation and features of the work environment. This tool could be used by various professionals across different settings and sectors, health and social. In that sense the Y-PEM begins to address one of the gaps (i.e., lack of measures that can be used across different settings/sectors) of existing employment outcome measures currently used in practice, identified in a recent scoping review (Di Rezze, 2018). Further investigation across a broader sample including stakeholders of the educational sector can complement these findings.

The Y-PEM was perceived as a tool that responds to the need to guide employment transition services that can be used in many contexts such as a clinical rehabilitation setting, community organizations, and within the workplace. Thereby, it may serve as a form to facilitate communication (and potential collaborations) between professionals from different sectors working towards a shared goal – improving transitioning to employment among people with disability (Magee & Plotner, 2021). As such, youth- from an early age- can be evaluated and supported continuously in their journey to acquiring employment by their rehabilitation specialist, followed by the employment counselor in the community and then the employer at the workplace. This may further facilitate the provision of service delivery on a continuum basis,

promoting a life course approach to transition to adulthood (Landmark et al., 2022; McCormick et al., 2021; Palisano et al., 2017). Furthermore, stakeholders in our study indicated that the Y-PEM can be used with employers of people with disability during annual meetings to facilitate communication about workplace barriers that employees with disability face. They stressed that it can promote open discussion about the accommodations that people with disability require to perform their jobs. As such, this tool can help increase employers' awareness concerning their employees' needs. It may also serve as a tool for those with disabilities to advocate for adequate accommodations at work and may enhance effective communication with employers. These were previously found to be important facilitators for successful participation in the workplace (Lindsay et al., 2018; Lindsay et al., 2021; Lu et al., 2021).

The Y-PEM was also found to serve many purposes. Stakeholders working with youth/young adults with disabilities in transition and employment programs revealed the use of this tool to set goals, guide individualized intervention planning, and determine youth/ young adults' job readiness. Such information can guide customized care, allocating appropriate resources and services based on identified needs. This aligns with evidence supporting the use of a client-centered approach with individualized interventions to remove barriers and build on supports to ease employment acquisition and transition to adulthood (Leahy et al., 2014). Furthermore, another purpose served by the Y-PEM emerged by stakeholders is worth reflection on. The Y-PEM was perceived as appropriate for use with people with and without work experience as an educational tool to increase awareness about the steps involved in acquiring employment as well as environmental obstacles/ facilitators that could impact their future work participation. These findings coincide with a systematic review recommending that stakeholders support youth and young adults with disabilities to become more aware of their condition and

build self-advocacy skills to facilitate maintaining employment (Lindsay et al., 2018). Thus, the versatility of the Y-PEM allows for its use in different ways depending on the discretion and reasoning of the service providers to be implemented in a way that aligns with their context/service and addresses the needs of their clients.

As illustrated by the theme "Y-PEM responds to the need for tools to guide services of transitioning," stakeholders saw the benefits of the Y-PEM in additional aspects of their practice. Specifically, they acknowledge it could direct and impact service provision and decision making in various levels. At the client level, in addition to goal setting and intervention planning, Y-PEM can guide matching clients to appropriate jobs that fit within their functional ability, interests, and career aspirations. At an organizational level, depending on the needs and values of institutes, our findings suggest the Y-PEM may be used to identify the needs and evaluate the youth/ young adults in their transitioning to employment and possibly assess the effectiveness of the intervention and/ or program. As such, this implied function of the Y-PEM can potentially address the need for tools to evaluate the effectiveness of employment services (Agans et al., 2020; Hamilton, 2015; Stewart et al., 2006), yet future studies are needed to confirm this assumption. In a broader societal context, the Y-PEM was seen as a valuable data collection tool to advocate for better services and policies in facilitating transition to employment – a critical barrier to participation identified in a recent scoping review (Shahin et al., 2020). Addressing barriers at the individual, sociostructural and environmental levels is in line with current approaches for promoting better employment outcomes among youth and young adults with disabilities (Lindsay, McDougall, Menna-Dack, et al., 2015).

Service providers not only valued the ability of the Y-PEM to collect extensive data in a relatively short amount of time, they also saw its use beyond just gathering information about the

frequency, involvement, desire for change, and the environment. Service providers interpreted the data holistically by looking at all three scales (i.e., frequency, involvement, desire for change) which generated new thoughts and links about their client's participation. These were youth/ young adult's motivation, satisfaction, sense of self-efficacy, job readiness, ability to do abstract and critical thinking, and awareness of how the environment could play a role in either facilitating of hindering their workplace participation given their functional capacity. These employment outcomes are in line with outcomes that are commonly evaluated in vocational rehabilitation among people with neurodevelopmental disability (Di Rezze et al., 2018).

All stakeholders commented on the comprehensiveness and pertinence of the workplace activity sets and environmental items, further adding to the content validity of this domain (Shahin, DiRezze, et al., 2022). Specifically, the social aspect of work (i.e., engagement in work-related social gathering and meetings, relationships and interaction with colleagues, supervisors, employers as well as customers) received particular attention by stakeholders as an important aspect of employment, often overlooked. In fact, a recent scoping review revealed that support and relationships from colleagues and employers were among one of the main environmental facilitators to maintaining employment among young adults with disabilities (Shahin et al., 2020). Hence, identifying and addressing social barriers (not merely physical barriers) at the workplace to better integrate and socially include this population can increase sense of belonging and satisfaction which could further facilitate work engagement as identified in previous research (Barf et al., 2009; de Beer et al., 2014).

In our study, the Y-PEM was perceived by stakeholders as a tool that provides an important "piece of the pie" within this complex process, especially when used in conjunction with other methods. Specifically, stakeholders commented on the ability of the Y-PEM to guide

the interview process by sparking conversations, generating follow-up questions, and promoting reflection around the multi-factorial components of work participation to better understand youth/ young adult's context. This finding coincides with the idea that a range of methods (including qualitative interviews) may be required to fully account for this complex concept of participation at work, as discussed elsewhere (Di Rezze et al., 2018).

Limitations and future directions

Although stakeholders had varying roles and experiences, most of them were located in Quebec. Since employment-related service provision and policies may vary in different provinces, caution should be exercised in generalizing the data to other Canadian provinces and beyond. The study also included a relatively small sample size (and a small group size for some groups) considering methods used which may affect the transferability of the results. However, we tried to address this by including stakeholders from different organizations, contexts, and professional backgrounds through purposive recruitment. This study explored the utility of one (newly developed) domain of the Y-PEM that focuses on employment/participation in work. Further studies can examine the utility of the Y-PEM in its entirety (across the other 3 settings; home, school/educational and community settings) to get a deeper understanding of its utility within the transition to adulthood. Seeking feedback from service providers who are actively using the Y-PEM in their day-to-day practice is also warranted. The findings provide initial support for the potential uptake of the Y-PEM in different settings of service delivery. Future implementation studies are needed to ensure the use of the Y-PEM in a sustainable way across different settings; both clinical (rehabilitation centers) and non-clinical (community-based employment-related organizations, the workplace) contexts.

Conclusion

Findings suggest the workplace participation domain of the Y-PEM is a structured and comprehensive tool that appears to be appropriate and relevant for use in various contexts and for different purposes by employment-related service providers and service users to capture workplace participation and the environment. As such, it may serve as an additional tool within stakeholders' toolkit that could guide service provision to support youth and young adults with disabilities in the complex transitioning to employment.

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Conflict of interest

The authors have no conflict of interest to report.

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Supplementary Material

Supplemental material contains the workplace participation domain of the Y-PEM including 6 items pertaining to workplace participation and 16 environmental items. Guiding questions used in the focus group are also supplied.

References:

Agans, J. P., Maley, M., Rainone, N., Cope, M., Turner, A., Eckenrode, J., & Pillemer, K. (2020). Evaluating the evidence for youth outcomes in 4-H: A scoping review. *Children and Youth Services Review, 108*. https://doi.org/10.1016/j.childyouth.2019.104617

Ayrton, R. (2019). The micro-dynamics of power and performance in focus groups: an example from discussions on national identity with the South Sudanese diaspora in the UK. *Qualitative Research, 19*(3), 323-339. https://doi.org/10.1177/1468794118757102

Barf, H. A., Post, M. W., Verhoef, M., Jennekens-Schinkel, A., Gooskens, R. H., & Prevo, A. J. (2009). Restrictions in social participation of young adults with spina bifida [Research Support, Non-U.S. Gov't]. *Disability & Rehabilitation, 31*(11), 921-927. https://doi-org.proxy3.library.mcgill.ca/10.1080/09638280802358282

Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a Qualitative Description Approach in Health Care Research. *Global Qualitative Nursing Research, 4*, 233339361774228. https://doi.org/10.1177/2333393617742282

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Coster, W., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Liljenquist, K., Gleason, K., & KAO, Y. C. (2011). Psychometric evaluation of the Participation and Environment Measure for Children and Youth. *Developmental Medicine & Child Neurology, 53*(11), 1030-1037. https://doi.org/10.1111/j.1469-8749.2011.04094.x

Coster, W., Law, M., Bedell, G., Khetani, M., Cousins, M., & Teplicky, R. (2012). Development of the participation and environment measure for children and youth: conceptual basis. *Disability and rehabilitation, 34*(3), 238-246.

Creswell, J. W., & Poth, C. N. (2017). *Qualitative inquiry and research design: Choosing among five approaches*. Sage publications.

de Beer, J., Engels, J., Heerkens, Y., & van der Klink, J. (2014). Factors influencing work participation of adults with developmental dyslexia: a systematic review [Review]. *BMC Public Health, 14*, 77. https://doi.org/10.1186/1471-2458-14-77

Di Rezze, B., Viveiros, H., Pop, R., & Rampton, G. (2018). A review of employment outcome measures in vocational research involving adults with neurodevelopmental disabilities. *Journal of Vocational Rehabilitation, 49*(1), 79-96. https://doi.org/10.3233/JVR-180956

Gorter, J., Stewart, D., & Woodbury-Smith, M. (2011). Youth in transition: care, health and development. *Child: care, health and development, 37*(6), 757-763.

Hamilton, S. F. (2015). Linking Research to the Practice of Youth Development. *Applied Developmental Science, 19*(2), 57-59. https://doi.org/10.1080/10888691.2015.1030016

Janus, A. L. (2009). Disability and the Transition to Adulthood. *Social Forces, 88*(1), 99-120.

Landmark, L. J., Stockall, N., Cole, C. V., Mitchell, V. J., Durán, J. B., & Gushanas, C. M. (2022). Using Vertical Transitions From Early Childhood to Postsecondary Environments

to Improve Transition Outcomes. *TEACHING Exceptional Children*, 00400599211073141.

Leahy, M. J., Del Valle, R., Sherman, S., Chan, F., Rosenthal, D., Tansey, T., Lui, J., Anderson, C. A., Menz, F. E., Wehman, P., Kundu, M., & Dutta, A. (2014). An analysis of evidence-based best practices in the public vocational rehabilitation program: Gaps, future directions, and recommended steps to move forward. *Journal of Vocational Rehabilitation, 41*(2), 147-163. https://doi.org/10.3233/JVR-140707

Lindsay, S., Cagliostro, E., & Carafa, G. (2018). A systematic review of workplace disclosure and accommodation requests among youth and young adults with disabilities. *Disability and rehabilitation, 40*(25), 2971-2986. https://doi.org/10.1080/09638288.2017.1363824

Lindsay, S., Cagliostro, E., Leck, J., & Stinson, J. (2021). Career aspirations and workplace expectations among youth with physical disabilities. *Disability and rehabilitation, 43*(12), 1657-1668.

Lindsay, S., McDougall, C., Menna-Dack, D., Sanford, R., & Adams, T. (2015). An ecological approach to understanding barriers to employment for youth with disabilities compared to their typically developing peers: views of youth, employers, and job counselors. *Disabil Rehabil, 37*(8), 701-711. https://doi.org/10.3109/09638288.2014.939775

Lindsay, S., McDougall, C., Sanford, R., Menna-Dack, D., Kingsnorth, S., & Adams, T. (2015). Exploring employment readiness through mock job interview and workplace role-play exercises: comparing youth with physical disabilities to their typically developing peers. *Disabil Rehabil, 37*(18), 1651-1663. https://doi.org/10.3109/09638288.2014.973968

Lu, W., Oursler, J., Gao, N., Herrick, S., Mariani, J., Socha, C., & Beninato, J. (2021). Service needs assessment of employment-related soft skills for transition age youth with disabilities. *Journal of Vocational Rehabilitation*, 1-11. https://doi.org/10.3233/JVR-211173

Magee, E., & Plotner, A. (2021). Examining barriers and strategies for effective professional or interagency collaboration in secondary transition. *Journal of Vocational Rehabilitation*, 1-14. https://doi.org/10.3233/JVR-211170

McCormick, S. T., Kurth, N. K., Chambless, C. E., Ipsen, C., & Hall, J. P. (2021). Case Management Strategies to Promote Employment for Transition-Age Youth with Disabilities. *Career Development and Transition for Exceptional Individuals, 44*(2), 120-131.

Newman, L., Wei, X., Shaver, D., Nagle, K., Marder, C., Knokey, A.-M., Wagner, M., & National Center for Special Education, R. (2011). *The Post-High School Outcomes of Young Adults with Disabilities Up to 8Years After High School: A Report from the National LongitudinalTransition Study-2 (Nlts2). Ncser 2011-3005*.

Palisano, R. J., Di Rezze, B., Stewart, D., Rosenbaum, P. L., Hlyva, O., Freeman, M., Nguyen, T., & Gorter, J. W. (2017). Life course health development of individuals with neurodevelopmental conditions. *Developmental medicine and child neurology, 59*(5), 470-476. https://doi.org/10.1111/dmcn.13402

Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed. ed.). Sage. http://digitool.hbz-nrw.de:1801/webclient/DeliveryManager?pid=1560583&custom_att_2=simple_viewer

Shahin, S., Ahmed, S., Di Rezze, B., & Anaby, D. (2022). Reliability and validity of the Youth and young adult Participation and Environment Measure (Y-PEM) among youth and young adults: An initial evaluation [Manuscript submitted for publication]. *School of Physical and Occupational Therapy. McGill University.* .

Shahin, S., DiRezze, B., Ahmed, S., & Anaby, D. (2022). Development and content validity of the youth and young-adult participation and environment measure (Y-PEM). *Disability and rehabilitation*, 1-13. https://doi.org/10.1080/09638288.2022.2030809

Shahin, S., Reitzel, M., Di Rezze, B., Ahmed, S., & Anaby, D. (2020). Environmental factors that impact the workplace participation of transition-aged young adults with brain-based disabilities: a scoping review. *International journal of environmental research and public health, 17*(7), 2378. https://doi.org/10.3390/ijerph17072378

Smart, A. (2006). A multi-dimensional model of clinical utility. *International journal for quality in health care : journal of the International Society for Quality in Health Care, 18*(5), 377-382.

Stewart, D., Stavness, C., King, G., Antle, B., & Law, M. (2006). A Critical Appraisal of Literature Reviews About the Transition to Adulthood for Youth with Disabilities. *Physical & Occupational Therapy in Pediatrics, 26*(4), 5-24. https://doi.org/10.1080/J006v26n04_02

WHO. (2011). World report on disability, chapter 8: Work and employment.

Chapter 11: Comprehensive Discussion

Summary of All the Findings from All the Manuscripts

The *first manuscript* synthesized existing knowledge on the impact of the environment on the workplace participation of transition-aged youth and young adults with a range of brain-based disabilities. A scoping review of peer-reviewed studies, published between January 1995 and June 2018, was conducted by searching OVID MEDLINE, EMBASE, PsychINFO, PubMed and CINHAL. Studies that explored the environmental impact on mainstream and competitive work participation in transition-aged youths aged 18-35 years old, written in English, were included. Information based on 31articles, both qualitative and quantitative, was synthesized and categorized into the environmental domains of the ICF; products and technology & natural environment, supports and relationships, attitudes, and services, systems and policies. Findings revealed that all aspects of the ICF environmental domains had an impact on the workplace participation of transition-aged youth with a variety of brain-based disabilities (e.g., ASD, spina bifida, cerebral palsy, sensory impairment, intellectual disability, traumatic brain injury). Specifically, availability of jobs and professional support, clear guidelines and policies to implement accommodations, efficient service delivery, flexible work schedules and demands at the services, systems and policy level either facilitated or hindered employment participation. Support and attitudes of family, peers, coworkers, and employers mostly facilitated workplace participation. Environmental factors such as the physical layout, lighting and temperature of the building, accessibility to transportation, and availability of specialized assistive devices (i.e., voice recognition software, special mouse, etc.) were also among environmental barriers/supports to consider. The scoping review provided support for the importance of

evaluating the environment in conjunction with work participation and afforded specific examples of environmental factors that impact participation.

In the *second manuscript* the content of the PEM-CY was adapted and then validated to comprehensively capture participation at home, school, and the community for a youth and young adult population aged 12-30 years old as a self-reported outcome measure. In this study we developed and examined the initial content validity of items for a new section on work participation as well as adapted the environmental items to capture environmental barriers/facilitators that impact work participation in this age group. This was done through a multi-phase sequential mixed-method study based on elements of the Flowchart for Instrument Development, cultural equivalence framework, and COSMIN. Specifically, 24 participants aged 12-33 (mean=21; n=19 with physical disability) took part in five consecutive rounds of cognitive interviews. Experts (n=15) in the field of employment were also consulted for the development and validation of the new work-related items. Findings from the cognitive interviews resulted in significant changes and adaptations to the PEM-CY, and its transformation to the Y-PEM. Specifically, new roles and responsibilities pertinent to this age group including caregiving, preparing meals, dating, and driving were added to the Y-PEM. Furthermore, a new section to evaluate work participation was added as suggested by youth and young adult participants. This new section included 6 work-related items in addition to 16 environmental items that were adapted to the work context. The results of this study suggested that the content of the Y-PEM is clear, relevant, and comprehensive for, and can be completed by individuals aged 12-30 years old.

In the *third manuscript* the measurement properties of the Y-PEM were evaluated with regards to its construct validity, internal consistency, short-term test-retest reliability as well as

utility in terms of value and burden. Using a cross-sectional study design, 113 participants with (n = 56) and without (n = 57) physical disabilities aged 12 to 31 ($\bar{x}$ = 23) completed an online survey containing the Y-PEM and the QQ-10 questionnaire to evaluate perceived value and burden. Subsequently, a test-retest design was used on a sub-sample of 70 participants who completed the Y-PEM a second time 2-4 weeks apart to examine test-retest reliability. Construct validity was tested against a priori hypothesis which was partially accepted. As expected, descriptive results demonstrated that participants with disabilities had lower levels of frequency and involvement across all four settings. Significance differences in the home were observed with fewer seen in the community and work settings. Findings revealed moderately high internal reliability ($\alpha \geq 0.60$) and test-retest reliability (ICC ≥ 0.60) across most scales. Reliability coefficients were moderate for the internal consistency of the home frequency (0.52) and test-retest reliability of the workplace frequency (0.43). Finally, the Y-PEM was perceived as valuable with relatively low burden. Preliminary findings on psychometric properties were promising. Although further testing is needed, results indicated that the Y-PEM can be used as a feasible and acceptable participation and environment measure among youth and young adults, aged 12-30 years old with physical disabilities.

With the *fourth manuscript,* the utility of the newly developed workplace participation domain of the Y-PEM was explored from the perspectives of stakeholders providing/receiving employment-related services to youth and young adults with various disabilities (e.g., physical, intellectual, developmental disabilities). This descriptive qualitative study was done through four focus groups that were conducted with 11 stakeholders through videoconferencing. Stakeholders came from three different contexts; rehabilitation settings (n= 7 clinicians), community-based employment-related services (n= 3 employment consultants/advocators), and the workplace (n=1

employed service user with lived experience). Open-ended questions were used to explore the interpretation, meaning and relevance of the Y-PEM in practice. A thematic analysis of the transcripts resulted in three themes describing the practicality of the tool. The first theme reflected Y-PEM's ability to address the *need for tools to guide services of transitioning to employment* as it is comprehensive in assessing participation and the environment. Service providers further reported that the Y-PEM can be used to capture a "snapshot" of where the young person is at in their transition. Additionally, they saw its benefits in serving other purposes such as planning interventions and setting goals. The second theme depicted that *Transitioning to employment is multi-factorial.* In that regard, the Y-PEM can be used to generate insights and spark conversations to better appreciate and support transitioning to employment. The third theme illustrated Y-PEM's ability to *provide a "piece of the pie"* within this complex process. Stakeholders mentioned that to fully capture the process of transitioning to employment, other tools/ assessment methods (e.g., interviews) may be needed in conjunction with the Y-PEM. Overall, the Y-PEM was perceived as a comprehensive and a multi-dimensional tool that can gather pertinent information to inform practice and guide decision-making to facilitate transitioning to employment.

Overview

This PhD project provides a unique self-reported participation and environment measure, the Y-PEM, that covers the important developmental stage of individuals transitioning to adulthood, from as early as 12 years of age to 30 years old. This participation-based outcome measure comprehensively evaluates participation and the environment in four settings: home, school/educational setting, community, and the workplace. Inspired by the PEM-CY, the Y-PEM was developed and evaluated from the perspectives of youth and young adults with lived

experience as well as stakeholders and experts in the field of rehabilitation and transitioning. This process was done through systematic and multiple rounds of cognitive interviews based on a rigorous methodology in line with COSMIN. Having multiple perspectives and the input of the target population as well as key stakeholders in this research project ensured that the full range and breadth of activities that are relevant for those transitioning to adulthood are captured. This project also contributed initial support related to the measurement properties of the Y-PEM in terms of its content validity, construct validity, internal consistency, short-term test-retest reliability, and utility.

Contributions of the Y-PEM

Little is known about the participation experiences, particularly involvement of youth and young adults with disabilities during the complex phase of transitioning to adulthood [1]. The lack of PROMs [2], covering the transition period, that capture the essence of participation as suggested by the fRPC framework, in conjunction with the environment, illustrate a pressing gap in knowledge [3]. This further hinders the provision of transition-related and client-centered evidence-based practice for young people with disabilities, adversely impacting their transition outcomes and quality of life. The Y-PEM significantly contributes to the field of rehabilitation and transitioning by addressing many of these gaps.

The self-reported Y-PEM advances the use of PROM questionnaires that are gaining increasing popularity in rehabilitation [2]. By doing so, it also addresses one of the limitations of the PEM-CY, namely being a parent/proxy report [4]. Although parent/proxy reports can increase our understanding of the participation-environment interplay among youth and young adults with cognitive impairment, as a self-reported measure, the Y-PEM can capture the firsthand experiences of youth and young adults with physical disabilities. This can further

contribute to generating knowledge about their participation profile, particularly their involvement (a highly subjective element) in different activities, across settings [1]. The detailed information generated by the Y-PEM can further help bridge the gap between clinicians' awareness and understanding of transition needs, particularly during this challenging period [5]. For instance, the desire for change scale can inform goal setting that is client-centered transition-specific as well as guide intervention planning directed at transitioning processes [5]. The Y-PEM can also be used to identify areas of participation restriction and environmental barriers among this population, to inform intervention planning, and likely evaluate the success of such interventions [5].

Another substantial contribution of the Y-PEM is its ability to capture the range of activities that are pertinent for transition-aged youth and young adults. Therefore, this tool supports the provision of services on a life course continuum as it allows for the early evaluation of participation and can be used as youth mature and enter post-secondary education and employment [6,7]. While younger youth can skip the employment setting altogether, others may find it relevant to start thinking about work at early stages and indicate their desires via this domain. In fact, for youth in pre and post high school, finding and applying for a job, and getting the necessary training are important steps in acquiring employment, as perceived by parents of youth with disabilities [8]. Youth can also begin to think about potential barriers/supports within the environment – preparing them to transition to adulthood [9,10]. Moreover, the Y-PEM, with its new items/examples of activities can start a discussion with the young adult on participation domains such as dating/developing romantic relationships that are often not well attended in practice [11].

The Y-PEM responds to the need for assessment measures that are embedded within the person's "ecological inventory," at the home, school/educational, community and the workplace [12-15]. As shown in our study on initial psychometric properties (manuscript 3; chapter 7), environmental supportiveness was significantly (and positively) correlated with participation frequency, involvement, and desire for change. This suggests that the Y-PEM captures the impact of the environment on participation patterns and, therefore, it can be used to better understand the dynamic interaction between personal and environmental factors among this population. More specifically, the Y-PEM can identify environmental barriers and supports that impact participation. Such information can be used by clinicians and service providers to enhance the "person-environment fit" and in turn improve participation and transition outcomes [16]. In fact, recent intervention studies that focus on changing aspects of the environment have shown promising results on improving participation outcomes among youth with disabilities [17-20].

The Innovative Features of the Y-PEM

The Y-PEM can be distinguished from other participation-based measures in many ways. One of the original features of this outcome measure is that it encompasses the broadened age band that currently defines youth and young adults [21], namely youth as young as 12 years old and young adults as old as 30 years old. While other participation-based measures (e.g., Life-H, QYPP, CAPE/PAC) provide valuable information, they do not fully capture this important developmental stage [22-24]. The content of the PEM-CY was enhanced and adapted to this population through multiple rounds of interviews in three phases (phase 1 with youth aged 12 to 17, phase 2 with youth aged 18-21 and phase 3 with young adults aged 22-31; see manuscript 2 [25]). This ensured that the range of activities presented in each setting is comprehensive and

appropriate for our target population. In particular, activities that were added in the Y-PEM as suggested by young participants, such as engaging in routine appointments, planning meals, caring for others, taking lessons (e.g., driving), dating, and working, are in line with transition outcomes (e.g., independent living, post-secondary education, community engagement, building relationships) and rehabilitation goals set in collaboration with service providers, young persons, and their families [8,26,27].

The addition of a workplace participation domain is another innovative element of the Y-PEM. This new domain contains 6 workplace participation items capturing the process of obtaining, acquiring, and maintaining employment. In line with the INCOME framework [28], service providers who participated in the utility study [29] depicted that the Y-PEM laid out the process of transitioning to employment in a logical manner. Specifically, the first three items pertain to work preparation activities such as engaging in the process of selecting an area of work or a profession, seeking and acquiring employment, and training for a job. Such activities, as perceived by parents of youth with disabilities in a study conducted by Henninger et al. [8], can result in successful transitioning to employment that include engaging in any type of volunteering, part-time or full time paid or unpaid job. In fact, the last three work items of the Y-PEM capture actual work participation such as volunteering or working in unpaid job, working in a paid job, and attending work-related events and social gatherings. Although competitive employment is the employment goal of many young people, for youth with disabilities and their parents engaging in any kind of productive occupation, paid or unpaid, is meaningful [8]. Unlike most measures of work [15], the Y-PEM fully captures these important activities and can elicit a discussion around a young person's engagement in activities that are prerequisites to acquiring and maintaining employment [28].

The Y-PEM is a participation-based outcome measure that is unique in its ability to evaluate both the concept of participation and environmental factors that impact participation. Distinct to most participation-based measures [3,12], the Y-PEM is structured based on settings: home, school/educational setting, community, and the workplace. Therefore, it captures participation in activities that are embedded within the environmental context while considering environmental barriers and supports that impact participation [3]. Such an approach bridges the gap between evidence on the key role of the environment on participation [9,30] and current participation-based measures that do not comprehensively evaluate the environment [3]. Similar findings, based on Di Rezze and colleagues' literature review [80], reveal that most measures of work do not evaluate the environment [15], despite evidence of its influence on work participation among young people with disabilities (manuscript 1) [9]. Particularly, the inclusion of items capturing the social aspect of work (unfortunately not often addressed in practice), was perceived by service providers in our utility study (Manuscript 4) [29] as an important addition to the work domain of this tool. Capturing the social aspect of work is particularly important since early assessment and development of youth's soft skills (including their ability to communicate with their employers and colleagues) increases their chances of acquiring employment [31]. Furthermore, having social supports (and relationships) in the workplace is an environmental feature known to enhance participation, as seen in our scoping review [9].

Implications of the Workplace Participation Domain for Services of Transitioning to Employment

The development of a new workplace participation domain of the Y-PEM has several implications for the field of rehabilitation, specifically for the provision of services geared to transitioning to employment. This newly developed workplace participation domain responds to

the need for psychometrically sound and comprehensive measures to evaluate participation and the environment in the workplace [15,32]. In fact, this domain was perceived as applicable in clinical and non-clinical contexts by various service providers and a young adult service user with lived experience, as shown by the utility study we conducted (manuscript 4) [29]. Specifically, our findings revealed that the Y-PEM can be used by employment-related service providers from the community and rehabilitation sectors to gather information about work participation and features of the environment that impact work participation. Furthermore, the results suggested the potential benefits of this tool for employers of people with disabilities. The Y-PEM can identify environmental barriers and supports and be re-administered by the employer after accommodations are given to evaluate the effectiveness of such accommodations. The applicability of this tool in different contexts of care (or even sectors) could facilitate continuity of service provision as youth with disabilities transition to acquiring and maintaining employment in their own community. Moreover, the Y-PEM could potentially be used to facilitate collaboration and communication between rehabilitation specialists, community-based employment counsellors and employers, to promote employment inclusion among people with disabilities [33-35]. Once responsiveness has been established, the Y-PEM could also be used to evaluate the effectiveness of intervention studies aiming at promoting employment in youth with disabilities.

As found in the utility study (manuscript 4), service providers noted that the workplace participation domain of the Y-PEM captures the process of work preparation [29] which, congruent with a recent scoping review [33], is one of the limiting factors in employment of youth and young adults with disabilities. Capturing this process from a young age can help identify potential areas for intervention to promote the successful inclusion of people with

disabilities in the workforce [36]. In fact, the Y-PEM can provide a snapshot of where the young person is at in this process and indicate their job readiness [29] (manuscript 4). This information can further inform the development of job readiness programs and interventions that help youth seek and acquire employment [31]. Furthermore, the Y-PEM not only evaluates work participation but also features of the environment related to work, making this tool unique among other measurements used to assess workplace participation [15]. Our findings further suggest that service providers saw the potential benefits of this outcome measure, particularly the environment section as an educational tool to increase youth and young person's awareness of potential environmental barriers that they may face in the workplace. Helping young people recognize their strengths and needs is a step toward preparing them for the job market [37].

Evaluating the Environment in Conjunction with Participation at the Workplace

Findings from the scoping review on environmental factors that impact participation [9], (chapter 3) provided additional support to the importance of evaluating the environment when assessing participation at work. To that end, several elements of this thesis, based on different sources of information, contributed to the content validity of the workplace environmental section. For instance, the scoping review (manuscript 1, chapter 3) informed the specific examples of environmental barriers and supports presented in the Y-PEM. This was further supported through the results of the utility study (Shahin et al., in press; manuscript 4) [29] as service providers confirmed that the environmental items allowed for a comprehensive evaluation of environmental barriers and facilitators to work participation. This was even further strengthened by an employed service user with disability who affirmed that the extent of the environmental items and examples indeed cover and represent the reality experienced by people with disabilities in the workplace. The combination of results generated by these studies involving

input from varying perspectives provides a strong support that the content of Y-PEM is a relevant reflection of environmental factors that impact participation in the workplace. These findings are in line with previous research acknowledging the importance of considering environmental factors when evaluating participation [10,35].

The environmental items included in the Y-PEM cover the range of environmental domains of the ICF. For example, the item *physical layout or the amount of space inside and outside buildings* pertain to the environmental domain of *products & technology*. The items *outside weather conditions,* and *sensory qualities of the work setting (e.g., temperature)* relate to *the natural environment* domain. The domain of *support and relationships* is represented by the item *your relationship with co-workers, supervisors, customers and/or external partners*. The item *the attitudes and actions of others towards you* pertain to the domain of *attitudes*. Finally, the *services, systems & policies* domain is represented by the items pertaining to the availability of *programs, services and regulations, e.g., terms of employment, salary, flexible schedule, availability of jobs, etc*. This is in line with the results of the scoping review that we conducted in which environmental factors that impact work participation covered the range of the environmental domains of the ICF [9]. The comprehensiveness of the workplace environmental section may allow service providers to adequately identify aspects of the environment that hinder youth from entering the workforce, and pinpoint and build on supports to promote their transitioning to employment. Such knowledge can also guide interventions that empower youth/young people to advocate for workplace accommodations (i.e., knowledge about workplace policies and employee's rights) [38]. Moreover, this section can be directly used by employers and employees with disabilities to facilitate discussion around accommodations and

obstacles within the workplace environment that are more easily amenable to change, further promoting participation in work [39].

Measurement Properties of the Y-PEM

Establishing the validity of a newly developed PROM is an important component of measurement development [40]. In this regard, data from more than 100 participants in the psychometric properties testing were promising. The construct validity of this tool was examined to see whether the Y-PEM does in fact capture the construct of participation and can distinguish between groups. Although our hypotheses were partially confirmed, the Y-PEM demonstrated — descriptively and as expected — lower participation frequency and involvement among those with disabilities compared to those without disabilities matched by sex and age. Participants with disabilities also reported lower numbers of environmental supports. This is in line with previous PEM studies that found significant differences in participation patterns between children and youth with and without disabilities [4,41,42]. A post-hoc analysis also revealed, as anticipated, that among participants with disability (N=57), those with higher number of self-reported functional issues (>4.6; based on the median) had lower participation frequency, involvement, environmental support, and higher desire for change across all scales (except for school frequency) in all 4 settings (see chapter 8.1). This finding also coincides with previous research demonstrating that among people with disabilities, those with higher number of self-reported functional issues experience greater participation restriction [43]. Furthermore, results suggest (see chapter 8.2) that the Y-PEM has the potential to capture change in participation patterns in adverse times such as the COVID-19 pandemic. Although not conclusive, data generated by the Y-PEM may suggest that the participation of youth and young adults, regardless of their abilities, was affected by the pandemic. This was evident as those that reported that COVID-19 had a

greater impact on their participation also reported a greater number of activities to which they wished to see change, and lower frequency of participation in the community. Indeed, as shown in other studies, participation in community activities were significantly reduced due to COVID-19 related closures [44,45].

The reliability of a PROM is another important factor in its application in practice and research [40,46]. Data gathered from more than 100 participants in the psychometric properties testing study (manuscript 3), yielded adequate internal consistency for all the scales of the Y-PEM except for one scale pertaining to home frequency. Similar results were observed for the home frequency scale of the PEM-CY [47]. This could be because youth and young adults participate in a wide variety of activities in the home setting; from playing computer and video games, using social media to communicate with others, planning meals, to more complex tasks such as taking care of others. Evidence shows that youth with disabilities engage in significantly more sedentary behavior, such as playing computer and video games, compared to their typically developing peers, adversely affecting their health outcomes [48]. Capturing participation in such activities can help clinicians and other service providers identify areas for intervention. The Y-PEM was found to have adequate test-retest reliability across all scales except for the workplace frequency, which can be explained by workplace closures due to illness and the COVID-19 pandemic.

Evaluating other components of measurement properties such as aspects of utility in terms of the value and burden of a PROM from the perspective of the target population provides valuable information for its uptake in practice [49]. The relatively high mean value score and low burden score, reported by the participants, as demonstrated by the QQ-10 questionnaire, indicated that the Y-PEM has good face validity and is acceptable to the target population [50].

Particularly, on average, participants mostly agreed that the Y-PEM helped them communicate about their participation, was relevant to their participation, and included all aspects of their participation that they are concerned about. Most participants also agreed that the Y-PEM was easy to complete and would be happy to complete it again as part of their routine care. Furthermore, participants with and without physical disabilities were able to complete the Y-PEM, on average, in 40 minutes with one break. These findings illustrate the ease of use of the Y-PEM by youth and young adults with physical disabilities, which can facilitate its uptake in practice.

Strengths and Limitations

Strengths

The main strength of this PhD project is that the content validity of the Y-PEM was established based on several sources of evidence through a sequence of studies. Specifically, the findings of manuscript 1 contributed to the addition of environmental examples pertinent to the work context in the workplace environmental section/items. This ensured that the examples describing environmental characteristics were relevant and covered the breadth of environmental barriers and support, based on the ICF framework and grounded in the literature. Manuscript 2 used the thorough and rigorous process of involving youth and young adults themselves to adapt the content of the PEM-CY for a youth and young adult population and to develop a new work domain (and underpinning items). The content of the new workplace participation domain was developed and examined with reference to current and well-recognized models and frameworks in the field of rehabilitation. The pool of work-related items was modified and enhanced based on input from young participants and key stakeholders (researchers, parents of young people with disabilities, clinicians, community-based employment service providers) supporting youth

in their employment in different contexts. This was further supported through focus groups with employment-related service providers from varying backgrounds, as evident in manuscript 4. In manuscript 2, in line with COSMIN, the cognitive interviews with young participants allowed for the fine tuning of items and examples and ensured the relevance, comprehensibility as well as the comprehensiveness of the Y-PEM, with special attention to the newly developed workplace participation domain and the corresponding environmental items. Results of manuscript 3 lend further support to the content validity of the Y-PEM as none of the items were marked "never" or "not an issue / not needed" by all participants, suggesting their relevance to the target population.

Limitations

One of the main limitations of this project is that data for the measurement properties testing and utility studies (manuscripts 3 and 4) was gathered during the COVID-19 pandemic. During his period, participation and service provision were affected in most settings and for many people, regardless of their abilities. This affected our ability to fully demonstrate that the differences in participation between the groups were statistically significant. Furthermore, in manuscript 4, we had a relatively small sample size of stakeholders for exploring the utility of the workplace participation domain in practice. The recruitment of stakeholders was affected by the reduced activity and closures of rehabilitation and community services due to the COVID-19 pandemic. Another limitation was that most youth and young adult participants, experts, and service providers were recruited from Quebec, with a small number from Ontario. Their experiences may therefore only relate to the Quebec and Ontario contexts. Policies around transition services of youth and young adults with disabilities may differ in other Canadian provinces [51]; hence, caution should be exercised when generalizing our findings. Additionally, cultural adaptation of

the Y-PEM is warranted especially when being translated for use in different parts of the world and among diverse cultural contexts. This can be done by using the guiding process for culturally adapting measures of participation developed by Tomas et al. [52].

Future studies

A detailed user guide including administration guidelines and scoring algorithms is under development to facilitate the uptake of the Y-PEM by service providers and researchers. Future studies should further test Y-PEM's measurement properties, particularly in terms of the construct validity of the English and French versions of the Y-PEM in 'non-COVID' times or other 'non-adverse' situations, using a broader sample. Our sample included young people with physical disabilities (or mobility restrictions) with adequate cognitive abilities due to the demands required for completing this self-reported questionnaire. Making the Y-PEM accessible for other populations including those with cognitive and/or communication problems [53] and testing its performance is another important future line of inquiry. Furthermore, stakeholders from the educational setting were not represented in examining the utility of the workplace participation domain of the Y-PEM. Considering their important role in the employment and education of youth and young adults with disabilities, future studies should include the perspectives of educators. Additionally, a larger sample of service providers, particularly those using the Y-PEM (including all four settings; home, school/educational, community and the workplace) in their practice, will advance our understanding of the application of this tool in supporting transition services. Finally, future studies should evaluate other components of COSMIN for measurement properties (i.e., structural validity and responsiveness) that were not examined in this project.

Knowledge translation (KT)

The Y-PEM can be disseminated for use locally, nationwide, and worldwide, drawing on the principles of the Participation-focused KT roadmap [54]. Stakeholders in this project are researchers, clinicians, and managers of programs across the entire transition-age range, allowing access to various community partners and expertise for consultation and dissemination. Specifically, an integrated information sheet describing the measure, its purpose, and utility can be developed and disseminated using the team's extensive network throughout participation-focused community programs, agencies, and parent's associations. A wide range of partnerships, covering transitioning programs, employment services for youth and young adults with disabilities, rehabilitation centers, and participation-based programs across different provinces can be developed to ensure the applicability, and adoption of this tool, within Quebec and outside the province at the national level. Additionally, the tool can be presented to relevant knowledge users through local, national, and international conferences. Information on the Y-PEM can also be accessible on the ASPIRE Lab and CanChild Center for Childhood Disability Research websites to ensure its accessibility on an international level.

References

1. Schlebusch, L., Huus, K., Samuels, A., Granlund, M., & Dada, S. (2020). Participation of young people with disabilities and/or chronic conditions in low-and middle-income countries: a scoping review. *Developmental Medicine & Child Neurology, 62*(11), 1259-1265.

2. Briggs, M. S., Rethman, K. K., Crookes, J., Cheek, F., Pottkotter, K., McGrath, S., DeWitt, J., Harmon-Matthews, L. E., & Quatman-Yates, C. C. (2020). Implementing patient-reported outcome measures in outpatient rehabilitation settings: a systematic review of facilitators and barriers using the consolidated framework for implementation research. *Archives of physical medicine and rehabilitation, 101*(10), 1796-1812.

3. Adair, B., Ullenhag, A., Rosenbaum, P., Granlund, M., Keen, D., & Imms, C. (2018). Measures used to quantify participation in childhood disability and their alignment with

the family of participation-related constructs: a systematic review. *Developmental Medicine & Child Neurology, 60*(11), 1101-1116. https://doi.org/10.1111/dmcn.13959

4. Coster, M., Law, M., Bedell, G., Khetani, M., Anaby, D. . (2013). The Participation and Environment Measure for Children and Youth (PEM-CY): An innovative measure for home, school and community. *CanChild*. https://canchild.ca/en/resources/228-the-participation-and-environment-measure-for-children-and-youth-pem-cy-an-innovative-measure-for-home-school-and-community

5. Panyo, K., Lersilp, S., Putthinoi, S., & Hsu, H. Y. (2021). Transition service in the occupational therapy process for students with disabilities: A systematic review. *Journal of Occupational Therapy, Schools, & Early Intervention, 14*(3), 343-355. https://doi.org/10.1080/19411243.2020.1862727

6. Palisano, R. J., Di Rezze, B., Stewart, D., Rosenbaum, P. L., Hlyva, O., Freeman, M., Nguyen, T., & Gorter, J. W. (2017). Life course health development of individuals with neurodevelopmental conditions. *Developmental medicine and child neurology, 59*(5), 470-476. https://doi.org/10.1111/dmcn.13402

7. Shogren, K. A., & Wittenburg, D. (2020). Improving outcomes of transition-age youth with disabilities: A life course perspective. *Career Development and Transition for Exceptional Individuals, 43*(1), 18-28.

8. Henninger, N. A., & Taylor, J. L. (2014). Family perspectives on a successful transition to adulthood for individuals with disabilities. *Mental Retardation, 52*(2), 98-111.

9. Shahin, S., Reitzel, M., Di Rezze, B., Ahmed, S., & Anaby, D. (2020). Environmental factors that impact the workplace participation of transition-aged young adults with brain-based disabilities: a scoping review. *International journal of environmental research and public health, 17*(7), 2378. https://doi.org/10.3390/ijerph17072378

10. Lindsay, S. (2011). Discrimination and other barriers to employment for teens and young adults with disabilities. *Disability and rehabilitation, 33*(15-16), 1340-1350.

11. Heifetz, M., Lake, J., Weiss, J., Isaacs, B., & Connolly, J. (2020). Dating and romantic relationships of adolescents with intellectual and developmental disabilities. *Journal of Adolescence, 79*, 39-48.

12. Dijkers, M. P. (2010). Issues in the conceptualization and measurement of participation: an overview. *Archives of physical medicine and rehabilitation, 91*(9), S5-S16.

13. McConachie, H., Colver, A., Forsyth, R., Jarvis, S., & Parkinson, K. (2006). Participation of disabled children: how should it be characterised and measured? *Disability and rehabilitation, 28*(18), 1157-1164.

14. Coster, W., & Khetani, M. A. (2008). Measuring participation of children with disabilities: issues and challenges. *Disability and rehabilitation, 30*(8), 639-648.

15. Di Rezze, B., Viveiros, H., Pop, R., & Rampton, G. (2018). A review of employment outcome measures in vocational research involving adults with neurodevelopmental disabilities. *Journal of Vocational Rehabilitation, 49*(1), 79-96. https://doi.org/10.3233/JVR-180956

16. Stewart, D. A., Law, M. C., Rosenbaum, P., & Willms, D. G. (2002). A qualitative study of the transition to adulthood for youth with physical disabilities. *Physical & Occupational Therapy in Pediatrics, 21*(4), 3-21.

17. Anaby, D., Mercerat, C., Tremblay, S., Wingo, B. C., & Rimmer, J. H. (2017). Enhancing Youth Participation Using the PREP Intervention: Parents' Perspectives. *International journal of environmental research and public health, 14*(9). https://doi.org/10.3390/ijerph14091005

18. Anaby, D. R., Law, M., Feldman, D., Majnemer, A., & Avery, L. (2018). The effectiveness of the Pathways and Resources for Engagement and Participation (PREP) intervention: improving participation of adolescents with physical disabilities. *Developmental medicine and child neurology, 60*(5), 513-519. https://doi.org/10.1111/dmcn.13682

19. Anaby, D., Law, M., Teplicky, R., & Turner, L. (2015). Focusing on the environment to improve youth participation: experiences and perspectives of occupational therapists. *International journal of environmental research and public health, 12*(10), 13388-13398.

20. Kramer, J. M., Helfrich, C., Levin, M., Hwang, I. T., Samuel, P. S., Carrellas, A., Schwartz, A. E., Goeva, A., & Kolaczyk, E. D. (2018). Initial evaluation of the effects of an environmental-focused problem-solving intervention for transition-age young people with developmental disabilities: Project TEAM. *Developmental Medicine & Child Neurology, 60*(8), 801-809.

21. Orgabization), U. U. N. E. S. C. (2014). Youth. https://unevoc.unesco.org/go.php?q=TVETipedia+Glossary+A-Z&id=9

22. Noreau, L., Fougeyrollas, P., & Vincent, C. (2002). The LIFE-H: Assessment of the quality of social participation. *TECHNOLOGY AND DISABILITY, 14*(Part 3), 113-118.

23. King, G. A., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., Rosenbaum, P., & Young, N. (2004). *Children's assessment of participation and enjoyment (CAPE) and preferences for activities of children (PAC)*. PsychCorp.

24. Tuffrey, C., Bateman, B., & Colver, A. (2013). The Q uestionnaire of Y oung P eople's P articipation (QYPP): a new measure of participation frequency for disabled young people. *Child: care, health and development, 39*(4), 500-511. https://doi.org/10.1111/cch.12060

25. Shahin, S., DiRezze, B., Ahmed, S., & Anaby, D. (2022). Development and content validity of the youth and young-adult participation and environment measure (Y-PEM). *Disability and rehabilitation*, 1-13. https://doi.org/10.1080/09638288.2022.2030809

26. Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on autism and other developmental disabilities, 24*(2), 77-88. https://doi.org/10.1177/1088357608329827

27. Cobb, R. B., & Alwell, M. (2009). Transition Planning/Coordinating Interventions for Youth with Disabilities: A Systematic Review. *Career Development for Exceptional Individuals*. https://doi.org/10.1177/0885728809336655

28. Beveridge, S., Craddock, S. H., Liesener, J., Stapleton, M., & Hershenson, D. (2002). INCOME: A framework for conceptualizing the career development of persons with disabilities. *Rehabilitation Counseling Bulletin, 45*(4), 195-206.

29. Shahin, S., Ryan, M., Di Rezze, B., Ahmed, S., & Anaby, D. (in press). Utility of the Workplace Participation Domain of the Youth and Young-adult Participation and Environmnet Measure (Y-PEM): Stakeholder's perspectives. *Journal of Vocational Rehabilitation*.

30. Anaby, D. P., Law, M. P., Coster, W. P., Bedell, G. P., Khetani, M. S., Avery, L. M., & Teplicky, R. M. (2014). The Mediating Role of the Environment in Explaining Participation of Children and Youth With and Without Disabilities Across Home, School, and Community. *Archives of physical medicine and rehabilitation, 95*(5), 908-917. https://doi.org/10.1016/j.apmr.2014.01.005

31. Lindsay, S., McDougall, C., Sanford, R., Menna-Dack, D., Kingsnorth, S., & Adams, T. (2015). Exploring employment readiness through mock job interview and workplace role-play exercises: comparing youth with physical disabilities to their typically developing peers. *Disabil Rehabil, 37*(18), 1651-1663. https://doi.org/10.3109/09638288.2014.973968

32. Rezai, M., Kolne, K., Bui, S., & Lindsay, S. (2020). Measures of workplace inclusion: a systematic review using the COSMIN methodology. *Journal of Occupational Rehabilitation, 30*(3), 420-454.

33. Engelbrecht, M., Shaw, L., & van Niekerk, L. (2017). A literature review on work transitioning of youth with disabilities into competitive employment. *African journal of disability, 6*, 298. https://doi.org/10.4102/ajod.v6i0.298

34. Smits, S. (2004). Disability and employment in the USA: The quest for best practices. *Disability & Society, 19*(6), 647-662.

35. Lindsay, S., McDougall, C., Menna-Dack, D., Sanford, R., & Adams, T. (2015). An ecological approach to understanding barriers to employment for youth with disabilities compared to their typically developing peers: views of youth, employers, and job counselors. *Disabil Rehabil, 37*(8), 701-711. https://doi.org/10.3109/09638288.2014.939775

36. Wehman, P., Sima, A. P., Ketchum, J., West, M. D., Chan, F., & Luecking, R. (2015). Predictors of successful transition from school to employment for youth with disabilities. *Journal of Occupational Rehabilitation, 25*(2), 323-334.

37. Lindsay, S., Adams, T., McDougall, C., & Sanford, R. (2012). Skill development in an employment-training program for adolescents with disabilities [Research Support, Non-U.S. Gov't]. *Disability & Rehabilitation, 34*(3), 228-237. https://doi.org/https://doi.org/10.3109/09638288.2011.603015

38. Lindsay, S., Cagliostro, E., Leck, J., Shen, W., & Stinson, J. (2019). Disability disclosure and workplace accommodations among youth with disabilities. *Disability and rehabilitation, 41*(16), 1914-1924.

39. Lindsay, S., Cagliostro, E., & Carafa, G. (2018). A systematic review of workplace disclosure and accommodation requests among youth and young adults with disabilities. *Disability and rehabilitation, 40*(25), 2971-2986. https://doi.org/10.1080/09638288.2017.1363824

40. Gadotti, I., Vieira, E., & Magee, D. (2006). Importance and clarification of measurement properties in rehabilitation. *Brazilian Journal of Physical Therapy, 10*, 137-146.

41. Khetani, M., Coster W., Law M., Bedell GM. . (2013). Young Children's Participation and Environmnet Measure (YC-PEM). (Fort Collins: Colorado State University (Copyright to authors))

42. Khetani, M., Marley, J., Baker, M., Albrecht, E., Bedell, G., Coster, W., Anaby, D., & Law, M. (2014). Validity of the Participation and Environment Measure for Children and Youth (PEM-CY) for Health Impact Assessment (HIA) in sustainable development projects. *Disability and health journal, 7*(2), 226-235. https://doi.org/10.1016/j.dhjo.2013.11.003

43. Cheatham, L. P., & Randolph, K. (2022). Education and employment transitions among young adults with disabilities: Comparisons by disability status, type and severity. *International Journal of Disability, Development and Education, 69*(2), 467-490.

44. Bricout, J., Baker, P. M., Moon, N. W., & Sharma, B. (2021). Exploring the smart future of participation: Community, inclusivity, and people with disabilities. *International Journal of E-Planning Research (IJEPR), 10*(2), 94-108.

45. Kaufmann, K., Straganz, C., & Bork-Hüffer, T. (2020). City-life no more? Young adults' disrupted urban experiences and their digital mediation under Covid-19. *Urban Planning, 5*(4), 324-334.

46. Ahmed, I., & Ishtiaq, S. (2021). Reliability and Validity: Importance in medical research. *Journal of the Pakistan Medical Association, 71*(10), 2401-2406.

47. Coster, W., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Liljenquist, K., Gleason, K., & KAO, Y. C. (2011). Psychometric evaluation of the Participation and Environment Measure for Children and Youth. *Developmental Medicine & Child Neurology, 53*(11), 1030-1037. https://doi.org/10.1111/j.1469-8749.2011.04094.x

48. Ng, K. W., Augustine, L., & Inchley, J. (2018). Comparisons in screen-Time Behaviours among adolescents with and without long-term illnesses or disabilities: results from 2013/14 HBSC study. *International journal of environmental research and public health, 15*(10), 2276.

49. Kroenke, K., Monahan, P. O., & Kean, J. (2015). Pragmatic characteristics of patient-reported outcome measures are important for use in clinical practice. *Journal of clinical epidemiology, 68*(9), 1085-1092.

50. Moores, K. L., Jones, G. L., & Radley, S. C. (2012). Development of an instrument to measure face validity, feasibility and utility of patient questionnaire use during health care: the QQ-10. *International journal for quality in health care : journal of the International Society for Quality in Health Care, 24*(5), 517-524. https://doi.org/10.1093/intqhc/mzs051

51. Zeidan, J., Shikako-Thomas, K., Ehsan, A., Maioni, A., & Elsabbagh, M. (2019). Progress and gaps in Quebec's autism policy: a comprehensive review and thematic analysis. *Canadian Journal of Public Health, 110*(4), 485-496.

52. Tomas, V., Srinivasan, R., Kulkarni, V., Teplicky, R., Anaby, D., & Khetani, M. (2022). A guiding process to culturally adapt assessments for participation-focused pediatric practice: the case of the Participation and Environment Measures (PEM). *Disability and rehabilitation, 44*(21), 6497-6509.

53. Kramer, J. (2022). Measuring Participation for All.

54. Anaby, D., Khetani, M., Piskur, B., van der Holst, M., Bedell, G., Schakel, F., de Kloet, A., Simeonsson, R., & Imms, C. (2022). Towards a paradigm shift in pediatric rehabilitation: Accelerating the uptake of evidence on participation into routine clinical practice. *Disability and rehabilitation, 44*(9), 1746-1757.

Chapter 12: Conclusion

This PhD project resulted in an innovative assessment called the Y-PEM, designed specifically for youth and young adults aged 12 to 30 years old, that generates a detailed profile of the participation (and the impact of the environment) in four settings: home, school, community and workplace. Results of this project support the content validity of this participation and environment measure. This project also provides initial evidence to support the measurement properties of the Y-PEM in terms of its construct validity, internal consistency, test-retest reliability, and aspects of utility. Further larger studies are needed to test the performance of the Y-PEM in non-adverse times and among other populations.

Appendices

Appendix 1

The Youth and young-adult Participation and Environment Measure

Youth, Young-adult Participation and Environment Measure (Y-PEM)

Form & User's Guide

FOR OFFICE USE ONLY: _____ (ID)

Youth, Young-adult Participation and the Environment Measure (Y-PEM)©

Developed by Dana Anaby and Saeideh Shahin

based on:

Participation and Environment Measure – Children and Youth©

Wendy Coster, Mary Law, Gary Bedell

SURVEY INSTRUCTIONS

Participation refers to your involvement in important everyday activities at home, in school, community, and at work. The meaning of participation includes both how often you do activities AND how involved you are when doing these activities.

The survey asks a set of questions about your participation in 31 types of activities that take place in four environments: home, school, community, and work. In the work section, you will find activities that relate to work preparation as well as those related to actual participation in work. We give a few examples to illustrate each type of activity. However, you should think about all of the activities that belong to the category when answering these questions.

For each type of activity we ask:

1. **how often** you have participated over the last 4 months
2. **how involved** you are when participating in 1 or 2 activities of this type that you do most often
3. whether or not you would like your participation **to change**, and if so, how you would like it to change

IMPORTANT

This survey is not asking about your level of independence when participating in activities. "Involvement" refers to how engaged you are in an activity, using whatever supports, assistance, adaptations or methods you routinely use or have available.

When selecting your response, please think about your level of attention, concentration, emotional engagement, or satisfaction (using whatever supports or assistance are usually available).

Very involved = In general, you are engaged throughout the activity. You show a lot of initiative and/or interest in and attention to what you and others are doing during the activity.

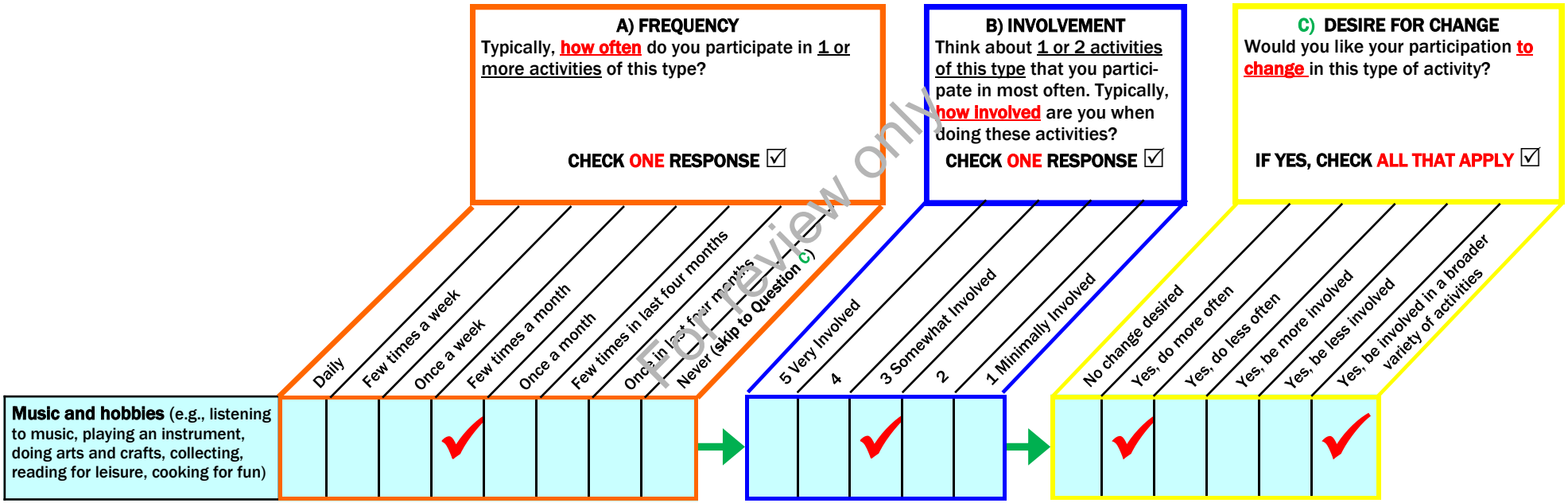
Somewhat involved = You are engaged in the activity some of the time. You show some initiative and/or interest in and attention to what you and others are doing during the activity.

Minimally involved = You are engaged in a small part of the activity. You only show a little initiative and/or interest in and attention to what you and others are doing during the activity.

If there are things that help or make your participation more difficult, such as equipment or support from others, you can tell us about their impact in the home environment, school environment, community environment, and the work environment sections of this survey.

An example of how to fill in this survey is given below.
At home, you play a musical instrument a few times a month; You are somewhat involved while playing; You would like to do this type of activity more often, and be involved in a greater variety of hobbies in the home as well, such as reading and cooking for leisure.

You have filled out the questionnaire as below:



HOME Participation

	A) FREQUENCY Typically, how often do you participate in 1 or more activities of this type? CHECK ONE RESPONSE ☑								B) INVOLVEMENT Think about 1 or 2 activities of this type that you participate in most often. Typically, how involved are you when doing these activities? CHECK ONE RESPONSE ☑					C) DESIRE FOR CHANGE Would you like your participation to change in this type of activity? IF YES, CHECK ALL THAT APPLY ☑					
	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never (skip to Question C)	5 Very Involved	4	3 Somewhat Involved	2	1 Minimally Involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
1) Computer games and video games (e.g., playing Wii, PlayStation)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
2) Socializing using technology (e.g., cell phone/smartphone, email, video calling, online dating sites, social media)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
3) Watching episodes, video clips and movies (e.g., on computer, TV, tablet, or smartphone)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
4) Music and hobbies (e.g., listening to music, playing an instrument, doing arts and crafts, collecting, reading for leisure, cooking for fun)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	
5) Getting together with other people (e.g., interacting with peers, family, other houseguests)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

HOME Participation

A) FREQUENCY
Typically, how often do you participate in 1 or more activities of this type?

CHECK ONE RESPONSE ☑

B) INVOLVEMENT
Think about 1 or 2 activities of this type that you participate in most often. Typically, how involved are you when doing these activities?

CHECK ONE RESPONSE ☑

C) DESIRE FOR CHANGE
Would you like your participation to change in this type of activity?

IF YES, CHECK ALL THAT APPLY ☑

	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never (skip to Question C)	5 Very Involved	4	3 Somewhat Involved	2	1 Minimally Involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
6) Indoor play and games (e.g., board games, chess, cards, games with younger family members)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
7) Household chores (e.g., unloading/ loading the dishwasher, cleaning room or other areas of the house, cooking and planning meals, taking out the garbage, setting the table, managing personal finances)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
8) Personal care management (e.g., getting dressed, choosing clothing, brushing hair or teeth, applying makeup, taking medications, managing appointments)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
9) Care for others (e.g., pets, children, siblings, and other family members)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
10) Preparation for school and/or work (e.g., gathering materials, packing school/ work bag, packing lunch, reviewing schedule, daily reading, homework/ assignments, school projects)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

HOME Environment

Do the following things help or make it harder for you to participate in activities at home? CHECK ONE RESPONSE ☑	Not an issue	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder
1. The physical layout or amount of space in your home (e.g., width of passageways, organization of furniture, presence of ramps and/or elevators)	☐	☐	☐	☐
2. The sensory qualities of the home environment (e.g., amount and/or type of sound, light, temperature, textures of objects)	☐	☐	☐	☐
3. The physical demands of typical activities in the home (e.g., strength, endurance, coordination)	☐	☐	☐	☐
4. The cognitive demands of typical activities in the home (e.g., concentration, attention, problem-solving)	☐	☐	☐	☐
5. The social demands of typical activities in the home (e.g., communication, interacting with others)	☐	☐	☐	☐
6. Your relationships with family members in the home (e.g., siblings, parent, grandparent)	☐	☐	☐	☐
7. The attitudes and actions of personal aides, caregivers, healthcare professionals, service providers who assist you at home	☐	☐	☐	☐

CHECK ONE RESPONSE ☑	Not needed	Usually, yes	Sometimes yes; sometimes no	Usually, no
8. Are services in your home available and/or adequate to support your participation?	☐	☐	☐	☐

HOME Environment

Are the following available and/or adequate to support your participation at home? CHECK ONE RESPONSE ☑	Not applicable	Usually, yes	Sometimes yes; sometimes no	Usually, no
9. Supplies in the home (e.g., sports equipment, cleaning equipment, food, internet, crafts supplies, reading materials, assistive devices or technology, picture or word schedules)	☐	☐	☐	☐
10. Information (e.g., about activities, services, programs)	☐	☐	☐	☐
11. Do you (and/or your family) have enough time to support your participation at home?	☐	☐	☐	☐
12. Do you (and/or your family) have enough money to support your participation at home?	☐	☐	☐	☐

What are some things that you or your family members do that help you participate successfully in activities at home? (e.g., I use an agenda to manage and schedule my time, my parents remind me of my responsibilities and chores) **PLEASE LIST UP TO 3 STRATEGIES**
1.
2.
3.

Participation in the SCHOOL/ EDUCATIONAL SETTING

School and education setting refers to any type of learning activity that occurs in high school, CEGEP, college/university, continuing education, certificate and diploma programs and online courses.

	A) FREQUENCY Typically, how often do you participate in 1 or more activities of this type? CHECK ONE RESPONSE ☑								**B) INVOLVEMENT** Think about 1 or 2 activities of this type that you participates in most often. Typically, how involved are you when doing these activities? CHECK ONE RESPONSE ☑					**C) DESIRE FOR CHANGE** Would you like your participation to change in this type of activity? IF YES, CHECK ALL THAT APPLY ☑					
	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never (skip to Question C)	5 Very Involved	4	3 Somewhat Involved	2	1 Minimally Involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
1) In-class activities (e.g., group work, classroom discussions, tests, assignments/projects, following class/course schedule)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
2) Outings and social events (e.g., going to a museum, spring concert or play, dances, fundraisers, career fair)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
3) Sponsored teams, clubs and organizations (e.g., groups, clubs, teams)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
4) Getting together with peers outside of class (e.g., hanging out during lunch, at recess, or other breaks between classes and within the student residential area/dormitory)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
5) Special roles (e.g., student society representative, student mentor, student tutor, lunchroom/cafeteria supervisor, committee member)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

SCHOOL Environment

Do the following things help or make it harder for you to participate in activities at school? CHECK ONE RESPONSE ☑	Not an issue	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder
1. The physical layout or amount of space and furniture in the classroom, on the playground, or on other parts of school premises (e.g., presence of sidewalks, availability of ramps or elevators in school building, parking)	☐	☐	☐	☐
2. The sensory qualities of the school environment (e.g., noise, crowds, lighting, etc.)	☐	☐	☐	☐
3. Outside weather conditions (e.g., temperature, climate)	☐	☐	☐	☐
4. The physical demands of typical school activities (e.g., strength, endurance, coordination)	☐	☐	☐	☐
5. The cognitive demands of typical school activities (e.g., concentration, attention, problem-solving)	☐	☐	☐	☐
6. The social demands of typical school activities (e.g., communication, interacting with others)	☐	☐	☐	☐
7. Attitudes and actions of teachers, coaches, or staff towards you	☐	☐	☐	☐
8. Your relationships with peers	☐	☐	☐	☐
9. The safety of the school (e.g., supervision, crime, violence)	☐	☐	☐	☐

Are the following available and/or adequate to support your participation at school? CHECK ONE RESPONSE ☑	Not needed	Usually, yes	Sometimes yes; sometimes no	Usually, no
10. Access to personal transportation to get to school (e.g., family car, bicycle)	☐	☐	☐	☐
11. Access to public transportation to get to school (e.g., school bus, campus shuttle, train, subway)	☐	☐	☐	☐
12. Programs and services (e.g., after school programs, recreational, special resources, educational assistant/aide, counseling, career guidance, accessibility services)	☐	☐	☐	☐
13. School–related policies and procedures (e.g., eligibility criteria for services, rules for behavior)	☐	☐	☐	☐

SCHOOL Environment

Are the following available and/or adequate to support your participation at school? CHECK ONE RESPONSE ☑	Not applicable	Usually, yes	Sometimes yes; sometimes no	Usually, no
14. Supplies (e.g., assistive devices or technology, reading materials, sports equipment)	☐	☐	☐	☐
15. Information (e.g., about activities, services, programs)	☐	☐	☐	☐
16. Do you (and/or your family) have enough time to support your participation at school?	☐	☐	☐	☐
17. Do you (and/or your family) have enough money to support your participation at school?	☐	☐	☐	☐

What are some things that help you participate successfully in activities at school? (e.g., I use a note-taker and lecture recordings, I contact the office of students with disabilities, I seek and request accessible services, I write exams with accommodations, a student volunteer assists me in extracurricular activities, I join a club together with my siblings to encourage us to participate) **PLEASE LIST UP TO 3 STRATEGIES**
1.
2.
3.

COMMUNITY Participation

	A) FREQUENCY Typically, how often do you participate in 1 or more activities of this type? CHECK ONE RESPONSE ☑								B) INVOLVEMENT Think about 1 or 2 activities of this type that you participates in most often. Typically, how involved are you when doing these activities? CHECK ONE RESPONSE ☑					C) DESIRE FOR CHANGE Would you like your participation to change in this type of activity? IF YES, CHECK ALL THAT APPLY ☑					
	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never (skip to Question C)	5 Very Involved	4	3 Somewhat Involved	2	1 Minimally Involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
1) Neighborhood outings and community events (e.g., shopping at the store/mall, going to a movie, eating out at a restaurant, visiting the local library/bookstore, music or comedy festivals, attending a play, concert, sports game, parade)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
2) Routine appointments and errands (e.g., hair/nail salons, doctor visits, dentist appointment, grocery shopping, bank/post office, pharmacy)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
3) Organized physical activities (e.g., sports teams or classes such as baseball, hockey, martial arts, dance, yoga, horseback riding, swimming, gymnastics)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
4) Unstructured physical activities (e.g., nature trail walks, bicycle riding, rollerblading, skateboarding, playing pick-up games like basketball, going to the gym)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
5) Classes and lessons (not school-sponsored) (e.g., music, art, languages, computers, cooking, driving)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

COMMUNITY Participation

	A) FREQUENCY Typically, how often do you participate in 1 or more activities of this type? CHECK ONE RESPONSE ☑								B) INVOLVEMENT Think about 1 or 2 activities of this type that your participates in most often. Typically, how involved are you when doing these activities? CHECK ONE RESPONSE ☑				C) DESIRE FOR CHANGE Would you like your participation to change in this type of activity? IF YES, CHECK ALL THAT APPLY ☑					
	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never (skip to Question C)	5 Very Involved	4	3 Somewhat Involved	2	1 Minimally Involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
6) Organizations, groups, clubs, and volunteer or leadership activities (e.g., youth groups, animal rescue, charity, food shelters, social causes, union assemblies)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
7) Religious or spiritual gatherings and activities (e.g., attending places of worship, religion classes, groups)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
8) Getting together with friends in the community (e.g., hanging out, informal gatherings outside of the home or school, BBQ, going out on a date)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
9) Occasional work* (e.g., babysitting, paper route, working in a store, camp counsellor, doing chores or running errands for pay)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
10) Overnight visits or trips (e.g., sleepovers, camp, vacations)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

* **Please note that work preparation activities and work participation will be further assessed in the next section.**

COMMUNITY Environment

Do the following things help or make it harder for you to participate in activities in the community? CHECK ONE RESPONSE ☑	Not an issue	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder
1. The physical layout or amount of space outside and inside buildings (e.g., distances to stores, presence of sidewalks, availability of ramps or elevators)	☐	☐	☐	☐
2. The sensory qualities of community settings (e.g., noise, crowds, lighting, etc.)	☐	☐	☐	☐
3. The physical demands of typical activities (e.g., strength, endurance, coordination)	☐	☐	☐	☐
4. The cognitive demands of typical activities (e.g., concentration, attention, problem-solving)	☐	☐	☐	☐
5. The social demands of typical activities (e.g., communication, interacting with others)	☐	☐	☐	☐
6. Your relationships with peers	☐	☐	☐	☐
7. The attitudes and actions of other members of the community towards you (e.g., instructors, coaches, shopkeepers, other families)	☐	☐	☐	☐
8. Outside weather conditions (e.g., temperature, climate)	☐	☐	☐	☐
9. The safety of the community (e.g., traffic, crime, violence)	☐	☐	☐	☐

Are the following available and/or adequate to support your participation in the community? CHECK ONE RESPONSE ☑	Not needed	Usually, yes	Sometimes yes; sometimes no	Usually, no
10. Access to personal transportation to access community activities (e.g., family car, bicycle)	☐	☐	☐	☐
11. Access to public transportation to access community activities (e.g., bus, train, subway, taxi, adapted transport, bike and car sharing services)	☐	☐	☐	☐
12. Programs and services (e.g., inclusive sports programs, personal support worker)	☐	☐	☐	☐

COMMUNITY Environment

Are the following available and/or adequate to support your participation in the community? CHECK ONE RESPONSE ☑	Not applicable	Usually, yes	Sometimes yes; sometimes no	Usually, no
13. Information (e.g., about activities, services, programs)	☐	☐	☐	☐
14. Equipment or supplies (e.g., sports equipment, reading materials, assistive devices or technology)	☐	☐	☐	☐
15. Do you (and/or your family) have enough time to support your participation in the community?	☐	☐	☐	☐
16. Do you (and/or your family) have enough money to support your participation in the community?	☐	☐	☐	☐

What are some things that help you participate successfully in activities in the community? (e.g. I plan ahead of time to arrange transportation and find accessible and adapted activities in the community, I sign up for local newsletters to stay updated on events and activities, my parents find ways to make activities accessible for me) **PLEASE LIST UP TO 3 STRATEGIES**
1.
2.
3.

Work Participation

Work refers to any paid or unpaid jobs, volunteering and activities that prepare you for work/career.

	A) FREQUENCY Typically, how often do you participate in 1 or more activities of this type? CHECK ONE RESPONSE ☑									B) INVOLVEMENT Think about 1 or 2 activities of this type that your participates in most often. Typically, how involved are you when doing these activities? CHECK ONE RESPONSE ☑					C) DESIRE FOR CHANGE Would you like your participation to change in this type of activity? IF YES, CHECK ALL THAT APPLY ☑					
	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never (skip to Question C)	Not applicable (skip to Question C)	5 Very Involved 4	3 Somewhat Involved	2	1 Minimally Involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
1) Engaging in the process of selecting an area of work or a profession (e.g., identifying work interest, strengths and challenges, consulting with career guidance counsellor/employment service, attending career fair)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
2) Seeking and acquiring employment (e.g., preparing a CV/resume, networking for potential jobs, contacting employers, applying for a job and preparing for interviews, advocating for oneself, discussing terms and conditions of employment, accessing job search websites, placement services or youth-employment services)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
3) Training for a job (e.g., training programs for a specific job, apprenticeship/"stage," vocational training, education, shadowing, improving specific skills)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
4) Volunteering or working in unpaid job (e.g., for public agencies, charity, religious group, non-profit organization)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Work Participation

	A) FREQUENCY Typically, how often do you participate in 1 or more activities of this type? CHECK ONE RESPONSE ☑									B) INVOLVEMENT Think about 1 or 2 activities of this type that your participates in most often. Typically, how involved are you when doing these activities? CHECK ONE RESPONSE ☑					C) DESIRE FOR CHANGE Would you like your participation to change in this type of activity? IF YES, CHECK ALL THAT APPLY ☑					
	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never (skip to Question C)	Not applicable (skip to Question C)	5 Very Involved	4	3 Somewhat Involved	2	1 Minimally Involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
5) Working in a paid job (full or part time or self-employment) (e.g., perform job related tasks, attending work-related meetings, monitoring one's own performance, following work schedule/ shifts, proceedings, taking initiative, getting promoted, being supervised or supervising workers)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
6) Attending work-related events and social gatherings (e.g., employee lounge, work sponsored activities-lunches, yoga, birthday or company celebrations, staff night out, informal interaction with colleagues)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

WORK Environment

Do the following things help or make it harder for you to participate in activities at work? CHECK ONE RESPONSE ☑	Not an issue	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder
1. The physical layout or amount of space outside and inside buildings (e.g., accessible parking space, availability of ramps or elevators, accessible bathrooms and cafeterias, space to manoeuver indoors and out, office layout, workstation)	☐	☐	☐	☐
2. The sensory qualities of the work setting (e.g., noise, number of people, lighting, temperature)	☐	☐	☐	☐
3. The physical demands of typical work activities (e.g., strength, endurance, sitting or standing tolerance, moving around, coordination)	☐	☐	☐	☐
4. The cognitive demands of typical work activities (e.g., concentration, attention, organization, problem-solving, multi-tasking)	☐	☐	☐	☐
5. The social demands of typical work activities (e.g., communication, interacting with colleagues, supervisors, and/or customers in person or by email, telephone and/or social media)	☐	☐	☐	☐
6. Your relationship with co-workers, supervisors, customers and/or external partners	☐	☐	☐	☐
7. The attitudes and actions of others towards you (e.g., co-workers, supervisors, customers, family members, personal aides, other service providers who assist you at work)	☐	☐	☐	☐
8. Outside weather conditions (e.g., temperature, climate)	☐	☐	☐	☐
9. The safety of the workplace (e.g., air quality, accessibility to protective equipment, emergency procedures, bullying, harassment and confrontation)	☐	☐	☐	☐

Are the following available and/or adequate to support your participation at work? CHECK ONE RESPONSE ☑	Not needed	Usually, yes	Sometimes yes; sometimes no	Usually, no
10. Access to personal transportation to get to and from work, including training programs or unpaid work, or to perform job related travel (e.g., personal car, car pool, family car, car sharing program, parking)	☐	☐	☐	☐
11. Access to public transportation to get to and from work, to training programs or to unpaid work, or to perform job related travel (e.g., adapted transport, bus, train, subway, company car/shuttle)	☐	☐	☐	☐
12. Programs, services and regulations (e.g., terms of employment, salary, flexible schedule, on job training, job benefits, union support, personal support worker, special accommodations, mentoring, counselling and employment seeking services, job coaches, availability of jobs)	☐	☐	☐	☐
13. Information (e.g., about services available to employees, job placement/searching services, programs, activities offered at work, employment rights)	☐	☐	☐	☐

WORK Environment

Are the following available and/or adequate to support your participation at work? CHECK ONE RESPONSE ☑	Not applicable	Usually, yes	Sometimes yes; sometimes no	Usually, no
14. Equipment or supplies (e.g., specialized software, voice recognition, microphone, adjustable work surface, adapted computer/keyboard, assistive device, visual aides)	☐	☐	☐	☐
15. Do you (and /or your support person) have enough time to support your unpaid work/volunteering or to engage in activities to prepare you for work?	☐	☐	☐	☐
16. Do you (and /or your caregiver) have enough money to support your unpaid work/volunteering, or to engage in activities to prepare you for work?	☐	☐	☐	☐

What are some things that you or your family members do that help you participate successfully in activities at work? (e.g., I use an agenda to schedule my appointments around my work hours, I advocate to obtain accommodations to my job) PLEASE LIST UP TO 3 STRATEGIES
1.
2.
3.

Appendix 2

Workplace participation domain of the Y-PEM

Workplace participation items
1. Engaging in the process of selecting an area of work or a profession (e.g., identifying work interest, strengths and challenges, consulting with career guidance counsellor/employment service, attending career fair)
2. Seeking and acquiring employment (e.g., preparing a CV/resume, networking for potential jobs, contacting employers, applying for a job and preparing for interviews, advocating for oneself, discussing terms and conditions of employment, accessing job search websites, placement services or youth-employment services)
3. Training for a job (e.g., training programs for a specific job, apprenticeship/ "stage," vocational training, education, shadowing, improving specific skills)
4. Volunteering or working in unpaid job (e.g., for public agencies, charity, religious group, non-profit organization)
5. Working in a paid job (full or part time or self-employment) (e.g., perform job related tasks, attending work-related meetings, monitoring one's own performance, following work schedule/ shifts, proceedings, taking initiative, getting promoted, being supervised or supervising workers)
6. Attending work-related events and social gatherings (e.g., employee lounge, work sponsored activities-lunches, yoga, birthday or company celebrations, staff night out, informal interaction with colleagues)

This table illustrates the workplace participation items of the Y-PEM.

Workplace environmental items
1.The physical layout or amount of space outside and inside buildings (e.g., accessible parking space, availability of ramps or elevators, accessible bathrooms and cafeterias, space to manoeuvre indoors and out, office layout, workstation)
2.The sensory qualities of the work setting (e.g., noise, number of people, lighting, temperature)
3. The physical demands of typical work activities (e.g., strength, endurance, sitting or standing tolerance, moving around, coordination)
4. The cognitive demands of typical work activities (e.g., concentration, attention, organization, problem-solving, multitasking)
5.The social demands of typical work activities (e.g., communication, interacting with colleagues, supervisors, and/or customers in person or by email, telephone and/or social media)
6. Your relationship with co-workers, supervisors, customers and/or external partners
7. The attitudes and actions of others towards you (e.g., co-workers, supervisors, customers, family members, personal aides, other service providers who assist you at work)
8. Outside weather conditions (e.g., temperature, climate)
9. The safety of the workplace (e.g., air quality, accessibility to protective equipment, emergency procedures, bullying, harassment and confrontation)
10. Access to personal transportation to get to and from work, including training programs or unpaid work, or to perform job related travel (e.g., personal car, carpool, family car, car sharing program, parking)

11. Access to public transportation to get to and from work, to training programs or to unpaid work, or to perform job related travel (e.g., adapted transport, bus, train, subway, company car/shuttle)
12.Programs, services and regulations (e.g., terms of employment, salary, flexible schedule, on job training, job benefits, union support, personal support worker, special accommodations, mentoring, counselling and employment seeking services, job coaches, availability of jobs)
13.Information (e.g., about services available to employees, job placement/searching services, programs, activities offered at work, employment rights)
14.Equipment or supplies (e.g., specialized software, voice recognition, microphone, adjustable work surface, adapted computer/keyboard, assistive device, visual aids)
15. Do you (and /or your support person) have enough time to support your unpaid work/volunteering or to engage in activities to prepare you for work?
16. Do you (and /or your caregiver) have enough money to support your unpaid work/volunteering, or to engage in activities to prepare you for work?

This table illustrates the workplace environmental items of the Y-PEM.

Guiding Questions Used in the Focus Groups

In relation to the case study of Alice:

1. Describe what Alice's responses on the workplace section of the Y-PEM tell you?

Probs:

a. What do the results that are demonstrated in the "workplace participation" section of the Y-PEM mean to you?

2. Would you use this information when working with Alice, and if so, how?

Probs:

a. Do you think that the results of the Y-PEM are important in your practice? If so, why?
b. How else can you use the Y-PEM in your setting?

In relation to your practice:

3. What information do you need from your clients?
4. Can the Y-PEM complement your evaluation? If so, how?

Probs:

a. How would you use the results of the Y-PEM?
b. Could this information guide your practice? If yes, how?