4-11-2022 10:00 AM

An Exploration of the Facilitators and Barriers of Inclusion and Participation for Children with Intellectual and Developmental Disabilities at Informal Education Settings

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A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Education
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Abstract

This dissertation addresses the current practices, facilitators, and barriers toward inclusion and participation for children with neurodevelopmental disorders, including intellectual and developmental disabilities (IDD) at informal education settings (IES). The first research paper is a scoping review examining practices for supporting participation at IES for children with neurodevelopmental disorders. Characteristics of studies, practices used to promote inclusion, and outcomes measures were identified. The findings of this study emphasized the current practices being utilized at IES for children with neurodevelopmental disorders.

The second research paper is qualitative descriptive study of the facilitators and barriers to inclusion for children with IDD at museums, aquariums, zoos, and science centers (MAZSC) across Canada. Ten participants, each from 10 different MAZSC across Canada, participated in semi-structured interviews examining the practices within their organizations which lent themselves to facilitators and barriers to inclusion. The findings of this study illuminated three major themes: 1) profiles of children's learning and engagement; 2) facilitators toward participation and inclusion; and 3) barriers to inclusion and participation. These themes highlighted the progress which has been made in establishing facilitators toward inclusion, as well as highlighting barriers currently impacting children with IDD from fully participating.

The third research paper is a qualitative descriptive study of the nature of staff training in support of children with IDD and their families at MAZSC within Canada. Ten participants, each from 10 separate MAZSC participated in semi-structured interviews. Three overarching themes emerged from the data: 1) leveraging staff diversity in supporting families and children with IDD; 2) staff training opportunities; 3) staff training barriers. The emergent themes emphasized the rich and diverse backgrounds of staff members committed to engaging and supporting visiting children with IDD and their families and the opportunities and gaps in staff and volunteer training in support of children with IDD.

Overall, the findings of these studies suggest that, while progress has been made to improve opportunities for inclusion and participation for children with IDD, barriers continue to prevent participation and inclusion. Further research is needed to continue to reduce and

eliminate barriers toward inclusion for children with IDD at IES.

Keywords

Barriers, inclusion, informal educational settings, intellectual and developmental disabilities, facilitators, participation, practices

Summary for Lay Audience

This three-study dissertation highlights ways in which children with intellectual and developmental disabilities (IDD) can experience inclusion and participation at informal education settings (IES), such as camps, recreational programs, and museums. The first study was a scoping literature review which looked at the literature base to find what current practices help children with neurodevelopmental disorders, including children with IDD, experience participation. This study found that children with neurodevelopmental disorders experience improved self-esteem and sense of belonging when they experience inclusion and participation. Their ability to be social, think, read, learn, and remember also improves. The findings of this study emphasized the benefits and needs for practices which promote inclusion for children with neurodevelopmental disorders at IES.

The second study explored the facilitators and barriers that children with IDD encounter at museums, aquariums, zoos, and science centers (MAZSC) across Canada. Ten participants, each from 10 different MAZSC across Canada participated in interviews to explore this. The findings showed three major themes: 1) profiles of children's learning and engagement; 2) facilitators toward participation and inclusion; and 3) barriers to inclusion and participation. These themes show the progress that has been made in establishing facilitators toward inclusion, as well as highlighting barriers currently impacting children with IDD from fully participating.

The third research paper explored staff training at MAZSC in Canada specifically to support children with IDD when they visit these sites. Ten participants, each from 10 separate MAZSC participated in interviews. From these interviews, three themes emerged: 1) leveraging staff diversity in supporting families and children with IDD; 2) staff training opportunities; 3) staff training barriers. These themes showed the rich and diverse backgrounds of staff members committed to engaging and supporting visiting children with IDD and their families, as well as the opportunities and gaps in staff and volunteer training in support of children with IDD.

Overall, the findings suggest that, while progress has been made to improve opportunities for inclusion for children with IDD at IES, barriers to participation and inclusion continue to

exist. Further research is required to understand and eliminate barriers to participation and inclusion for this population within these settings.

Co-Authorship Statement

Study 1: Julia Ranieri: conceptualization, methodology, investigation, formal analysis, writing – original draft preparation, drafted the manuscript. Mohammad B. Azzam: validation, data curation, visualization, writing – reviewing and editing. Nicole Neil: conceptualization, methodology, writing – reviewing and editing, supervision, project administration.

Study 2: Julia Ranieri drafted the manuscript and completed data collection and analysis. Drs. Anton Puvirajah and Nicole Neil provided the conceptualization and framework and feedback for this study. All authors read, edited, provided feedback, and approved the final manuscript.

Study 3: Julia Ranieri drafted the manuscript and completed data collection and analysis. Julia Ranieri and Drs. Anton Puvirajah and Nicole Neil provided the conceptualization and framework and feedback for this study. All authors read, edited, and approved the final manuscript.

Acknowledgments

It is with great appreciation that I acknowledge, first and foremost, my dissertation co-supervisors Dr. Nicole Neil and Dr. Anton Puvirajah. Nicole, thank you for accepting me into your lab and being a phenomenal supervisor, role model, and mentor. Anton, thank you for your feedback, flexibility, and encouragement throughout the process. To you both, I sincerely thank you for supporting my projects, my timeline, and for helping me develop my research skills. Thank you. I also thank my examination committee for taking the time to be on my committee and for their willingness to make my research the best it can be. I am appreciative.

To the phenomenal supervisors within my clinical work: Dr. Karen Bax, Dr. Colin King, and Dr. Michelle Wesley. Karen, you were there with me from day one teaching, supporting, and encouraging me. I would not be the clinician I am without your guidance, expertise, and authenticity. I also thank you for helping me on my research journey. Colin, the depth and breadth of experience I received under your supervision and from our supervisory meetings helped build my skills, my confidence, and has prepared me for my entire career. Michelle, thank you for teaching me that this is where the magic happens…! Every minute that you spent with me teaching, guiding, and supervising was a gift.

A special word of thanks to Dr. Claire Crooks. For every bit of laughter, lessons taught, and genuine compassion.

A very special thank you to Dr. Linda Vasudev. I have never laughed as much as I have with you. Thank you for friendship, mentorship, supervision, connection, laughter. You are +538/10.

Thank you to my fellow PhD-getters, my writing group, my friends. I particularly would like to acknowledge Dr. Ashley Bildfell, Dr. Olivia Faulconbridge, Armush Salahadin, Val Semovski, Brad Daly, and Alex Smith. What an honour it has been. You know better than anyone the highs and lows of getting a PhD, the trials, the triumphs, the grind, and everything in between. Val and Armush, this dissertation and PhD would not have been survivable without both of you. From peasantry to beyond, the whole ride has been a journey.

Thank you to my friends who have made a tremendous impact on me, who have been there for me, who have been an inspiration to me, and who are just the best humans: Julie Walsh, Liz van Essen, Victoria Jackson, Erin Clutton, Yamina Abassi, Jason Solowoniuk, Erin Kardolus, Bruce Jensen, Katon Peniuk, and Tyler Phinney.

To my cohort. I am so thankful we always moved as a group! It has been a pleasure to be with all of you since the beginning, and I wish you all continued success on your paths. I could not have asked for a better group of humans to be colleagues and friends with.

Thank you to Dr. Lori Jones at the University of Guelph who, probably unknowingly, taught me to persist and work through academic challenges and who set me on the trajectory toward higher education. Thank you for the innumerable office hours spent working on chemistry, and the hours thereafter being friends.

Thank you to Jenna Driscoll for making me laugh so hard over the most ridiculous things, and for introducing me to Ivy, who I think started me on my entire path of working with children.

To James, who at his young age inspired me with his bravery, courage, and friendship.

Thank you to my parents. Mom, thank you for being there for me for my entire life. None of this would have been possible without you. Dad, I am thankful for our relationship.

To the parents and caregivers who trusted me to work with their children and youth during my training, thank you.

And lastly, I would like to dedicate this work to the staff at informal education settings who are working tirelessly to create inclusive spaces in which children with intellectual and developmental disabilities can fully participate, play, learn, and have fun. The work you do is invaluable, and you are making a difference every single day. This research is dedicated to you.

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Chapter 1

1   Introduction

Individuals with intellectual and developmental disabilities (IDD) are at a greater risk for experiencing exclusion in numerous settings, including academic and social settings, than their typically developing peers. Informal education settings (IES) provide rich environments where children can participate, learn, and experience inclusion. This dissertation addresses the current practices, facilitators, and barriers toward inclusion and participation for children with IDD at IES through three individual research studies. Overall, the findings of the studies suggest that barriers continue to prevent children with IDD from participating and experiencing inclusion, despite the presence of facilitators at IES. Further research is needed to continue to illuminate and reduce barriers such that IES can be an environment in which all children can participate, learn, grow, play, and be included.

1.1   Aims

This integrated dissertation is comprised of five chapters: an introductory chapter, three individual research papers, and a concluding chapter. Chapter one introduces background information pertaining to the topic and scope of the research problems, provides an overarching layout of current issues in informal education, introduces inclusion and participation, and discusses the historical and current understanding of intellectual and developmental disabilities and its implications within informal learning environments.

Chapter two is the first research paper and is titled *Practices for Supporting Participation in Informal Settings for Children with Neurodevelopmental Disorders: A Scoping Review.* The overall aim of the scoping review was to review the practices currently being used to support participation at IES for children with neurodevelopmental disorders, including children with IDD. Given the paucity of research examining IDD alone, this study examined neurodevelopmental disorder in addition to IDD. The

objectives of this study were to: (1) understand the characteristics of the studies in terms of research design, participants, type of informal education setting, and theory utilized; (2) determine what practices informal education settings used to promote inclusion; and (3) understand the outcomes measured for each study.

Chapter three is the second research paper and is titled *Facilitators and Barriers to Inclusion of Children with Intellectual and Developmental Disabilities at Informal Learning Centers in Canada.* Using a qualitative descriptive approach, interviews were utilized to achieve the following goal: determine the practices that are currently being used for participation and inclusion for children with IDD at museums, aquariums, zoos, and science centres (MAZSC) across Canada.

Chapter four is the third research paper and is titled *Staff Training at Informal Learning Settings to Support Children with Intellectual and Developmental Disabilities and Their Caregivers.* Using data collected from interviews, the following objectives were investigated: (1) describe how staff profiles and backgrounds can be used in support of children with IDD at MAZSC, (2) describe staff training opportunities and gaps at MAZSC in Canada to support children with IDD and their caregivers.

1.2 Literature Review

1.2.1 Intellectual and Developmental Disability

Neurodevelopmental disorders are a class of conditions, as defined by the Diagnostic and Statistical Manual, fifth edition, which have an onset within the developmental period (American Psychiatric Association, 2013). This category of disorders includes diagnoses such as intellectual disabilities, communication disorders, autism spectrum disorder, attention-deficit/hyperactivity disorder, specific learning disorder, motor disorder, and other neurodevelopmental disorders (American Psychiatric Association, 2013). Intellectual and developmental disabilities (IDD), specifically, is a broad, larger category which is characterized by limitations in intellectual and adaptive functioning and often describes situations in which intellectual disabilities *and* other disabilities co-exist

(National Institute of Child Health and Human Development, 2016). As such, the term "IDD" represents a larger category that encompasses intellectual disabilities, developmental disabilities, and the co-occurrence of both (American Psychiatric Association, 2013; National Institute of Child Health and Human Development, 2016). While varying intellectual and developmental disabilities may fall under the diagnostic category of neurodevelopmental disorders (American Psychiatric Association, 2013), intellectual and developmental disabilities, apart from physical neurodevelopmental disorders (i.e., hearing, vision, motor disorders, etc.) will be the focus of this dissertation.

Currently, there are varying prevalence rates of IDD in Canadian children; however, IDD is thought to affect between 0.5-3% of the Canadian population (Bradley et al., 2002; Lin et al., 2013; Ouellette-Kuntz et al., 2010). In Ontario, intellectual disability is thought to affect 0.78% of the adult population (Lunsky et al., 2013). Prevalence estimates continue to vary over time as surveillance and administrative data continues to improve for this population (Friedman et al., 2018). Because IDD is a broad category, there is a large amount of heterogeneity in terms of aetiology, developmental, and behavioural patterns. Examples of IDD include Rhett's syndrome, (Chahrour & Zoghbi, 2007), Kleefstra syndrome (Kleefstra et al., 2014), Down syndrome, Williams syndrome, Fragile X syndrome, and Prader-Willi syndrome (Di Nuovo & Buono, 2011). In addition to genetic aetiologies, there are also non-genetic aetiologies of IDD such as Fetal Alcohol Spectrum Disorder (FASD) (Chokroborty-Hogue et al., 2014).

1.2.2   What is Social Inclusion?

In 1990, the Americans with Disabilities Act became law (National Network, 2020). This law bans discrimination against individuals with disabilities in all domains of functioning: employment, education, transportation, telecommunications, and access to government services (National Network, 2020). The law provides protection for individuals with disabilities against exclusion based on disability and creates a guarantee of equal opportunities in the domains of functioning for these individuals (National Network, 2020). Similarly, the Ontarians with Disabilities Act is in place to improve

opportunities for individuals with disabilities and to reduce or prevent the barriers which serve to hinder full participation in their lives (Ontario, 2020). The Ontarians with Disabilities Act defines the term barrier as that which prevents an individual with a disability from fully participating as a result of their disability, and is then further defined as any physical, architectural, information, communications, attitudinal, or technological barrier, or any policy or practice which prevents full participation throughout the lifespan (Ontario, 2020). Despite provincial, state, and national legislature which prohibits discrimination, and which attempts to remove barriers to participation and inclusion, challenges regarding inclusion and participation remain.

While much work and research has been placed toward physical inclusion (Amado et al., 2013; Carter, 2007; DePauw & Doll-Tepper, 2000), the need for social inclusion and inclusion extending beyond physical inclusion is paramount, as the attitudes and perspectives of community members impact the sense of belongingness for this population (Amado et al., 2013). Social inclusion is access to socially valued activities such as employment and education, having a social network, and having meaningful relationships (Amado et al., 2013; Bates & Davis, 2004; Hewitt et al., 2013). Social inclusion centres around themes of relationships, social acceptance, peer acceptance, social competence, loneliness, and opportunities for group participation (Koster et al., 2009; Abbott & McConkey, 2006). Social inclusion has typically been defined through its opposite: social exclusion or the lack of accessibility or opportunity for participation (Brown et al., 2013). It encompasses social justice and solidarity for individuals with IDD, the lack of accessibility to opportunities for goods and services, recognition for self-efficacy and competency, and opportunities to experience a sense of belonging within a social network (Brown et al., 2013; Cobigo et al., 2012).

Given the complexities and dimensions of social inclusion, no single definition can be found within the literature. The United Nations (UN) (2016) examines both social inclusion and social exclusion to provide a comprehensive understanding of these concepts. The UN views social exclusion as "both an outcome and a process" (2016, p.

20). It describes the absence of participation in, or outright exclusion from, multiple areas of life involvement and functioning such as political, cultural, financial and economic, civic, and social life functioning (UN, 2016). In contrast, social inclusion is defined by the UN as "both a process and a goal" (2016, p. 20). As a process, social inclusion serves to improve participation within a societal context for individuals who have experienced marginalization or disadvantage due to physical attributes, disability, race, religion, or other such qualities or characteristics by being afforded opportunities and access to resources, and through opportunities to embody the rights provided to all others (UN, 2016).

Similar to the UN's definition of *social inclusion*, Jones (2011) defines *inclusion* as the principle or ideology that all individuals are entitled to engage in full participation in all domains of society, to participate meaningfully, and to have valued engagement and involvement in society and with others. Although social inclusion is a valuable concept, Jones (2011) argues that the terminology of social inclusion and social exclusion has been politically used to manage political oppositions. Jones (2011) describes that opposing parties argue that opportunities are available for individuals with disabilities, but that individuals with disabilities do not take advantage of them. Jones (2011) notes that this type of harmful thinking impedes opportunities for participation and creates barriers by removing facilitators which are needed to participate meaningfully.

Both Jones (2011) and the United Nations (2016) suggest that inclusion requires the removal of barriers themselves, and removal of that which prevents individuals from being able to fully participate and engage. Jones (2011) further outlines three dimensions of inclusion: non-discriminatory attitudes, guaranteed access to participation, and facilitation. Attitudes continue to be a barrier toward inclusion for individuals with disabilities (Walters, 2009). For example, attitudes may impede progress toward inclusive spaces by hindering decisions regarding which approaches would be beneficial to reduce barriers (Walters, 2009). Similarly, attitudes may continue to discriminate individuals with disabilities and may impact progress being made toward the development of

inclusive spaces (Walters, 2009). Historically, access to participation for individuals with disabilities has centred on physical inclusion, which saw barriers such as stairs being supplemented with ramps to improve physical accessibility (Jones, 2011). This model of inclusion suggests additional methods of accessibility, such as altering the way information is communicated through audio recordings, large text, or through simplified language (Jones, 2011). Lastly, Jones (2011) argues that participation and meaningful engagement only occurs when facilitators are in place to actively include individuals with disabilities. Examples of this can include having a support person or modifying the curriculum so that individuals with an intellectual disability can actively participate and be included (Jones, 2011).

Simplican and colleagues (2015) propose an ecological model of social inclusion specifically centered on individuals with IDD in which the individual, interpersonal, organizational, community, and socio-political domains are considered. Given that individuals with IDD are a historically marginalized population and research focusing on participatory approaches continues to be lacking (Simplican & Leader, 2015), an ecological model of social inclusion is warranted. While Jones (2011) and the United Nations (2016) suggest inclusion requires the removal of barriers, Simplican et al. (2015) suggest that social inclusion is the interaction between interpersonal relationships and community participation. In the absence of the interaction between both interpersonal relationships and community participation, social inclusion for individuals with IDD begins to centre on social interaction or social relationships rather than true inclusion (Simplican et al., 2015). As such, while other models focus on eliminating specific barriers such as attitudes as a barrier (Jones, 2011; Walters, 2009), Simplican and colleagues (2015) suggest that given the expansive definitions of participation and community participation, when the interaction between interpersonal relationships and community participation is absent, lack of community involvement may lead to increased segregation and reduced opportunities for true inclusion (Simplican et al., 2015). While Simplican and colleagues (2015) focus on the interaction between relationships and community and Jones (2011) focuses on the removal of barriers, both models argue that

meaningful engagement occurs through facilitators. For the purpose of this dissertation, our definition of inclusion is informed by both the UN model for inclusion, as both a process and a goal, and through Simplican and colleagues' (2015) definition of inclusion for individuals with IDD by centering on three key components: 1) meaningful relationships, 2) presence of facilitators and removal or absence of barriers which prevent inclusion, and 3) community participation.

1.2.3   What are Facilitators and Barriers to Inclusion?

Full inclusion is considered to extend to cognitive, social, and physical domains (Reich et al., 2010). Full inclusion for individuals with IDD continues to be a challenge, although strides have been made throughout the history of inclusive education. Many areas of research are currently focusing on the impacts and effects of inclusive education in informal settings, such as museums, which can benefit individuals who would otherwise not have opportunities to learn (Lussenhop et al., 2016). In addition, community participation of people with IDD is influenced by facilitators within the physical, social, and attitudinal environments. For example, physical, social, and attitudinal barriers are those which prevent an individual with a disability from engaging in full participation because of their disabilities (Ontario, 2020). Examples of such barriers can include any aspects of physical space, attitudes from self and others, technological barriers, policies, practices, sources of information, and communications which prevent full participation throughout the lifespan (Ontario, 2020). In contrast, facilitators are factors which increase inclusion and participation for individuals with disabilities and ranges from family support, peer involvement, improved opportunities, availability of skilled staff, improved access to information and its dissemination, attitudes toward acceptance and inclusion, physical sites or objects, and adaptable approaches and accessibility of sites (Shields et al., 2012; Shields & Synnot, 2016).

1.2.4   What is Participation?

While the above-mentioned models of inclusion refer to participation as a component of inclusion, participation needs further defining. In 2001, the World Health Organization

(WHO) published the *International Classification of Functioning, Disability and Health—ICF* which represented the shift between the medical model to a biopsychosocial model for the classification of disabilities emphasizing an inclusive agenda and focusing on participation. Moreover, the WHO (2007) published a version of the ICF specific for children and youth (ICF-CY) in which characteristics of children from infancy to adolescence are further documented. Both classification systems are informed by a medical model of disability and a social model of disability through exploring the interaction between the individual, and social and environmental factors.

The medical model of disability historically views disability through the lens of physical and chemical factors with the omission of the psychosocial factors which may contribute to disability (Hogan, 2019). The medical model of disability views deviations from typical development as something which requires treatment and adaptation of the individual into society (Barnes & Oliver, 1993; Fitzgerald, 2005; Nicolaisen et al., 2012). Further, the medical model of disability focuses on the bodily limitations of the individual, which defines that individual's disability and impairment (Nicolaisen et al., 2012).

In contrast to the medical model of disability, the social model of disability examines the differences between *impairment* and *disability*, in which impairment is the state of the body which deviates from what is considered typically developing, and disability is the outcome from which society and social constructs create the disablement (Goering, 2015; Oliver, 1996). Medical models have frequently viewed disability as an individual issue, in which an individual has a deficit; however, the social model of disability would argue that it is the context of society and culture which creates the deficits, and which create the disability that individuals experience (Davis, 2013; WHO, 2007). Notably, the social model of disability argues for the removal of such barriers which are created due to the contexts of society (Davis, 2013; WHO, 2007).

The ICF presents an integration of both the medical model and the social model of disability, and thus takes the perspective of being a biopsychosocial model, which

encompasses the perspectives of three domains: biological, social, and the individual's perspective (WHO, 2007). Shakespeare and Watson (2001) argue that the social model of disability historically excluded impairment and that to rebuff or deny differences is a problem within disability research. While Shakespeare and Watson (2001) argue that the medical model defines individuals solely on the basis of impairment, the social model of disability has the propensity to reduce disability to social barriers. The ICF, in integrating aspects of both the medical and social models of disability, is informed by typical human functioning. From the medical model of disability, it draws the aspects of the biological basis of human functioning through body structures and functions, while the ICF draws from the social model of disability through its examination of participation and environmental factors. It includes the domains of body functions, body structures, activities and participation, and environmental factors. Disability, then, is an impairment in body structure or function, that results in activity limitations and participation restrictions. Participation is a central component of the ICF framework. Within the context of the ICF (WHO, 2001), activities are defined as carrying out a task or activity by an individual while participation is defined as involvement in a life situation. In the ICF-CY (WHO, 2007), activities and participation are grouped together to encompass many life domains, from basic learning and acquisition to social tasks and activities. It is further noted that, activities and participation have two qualifiers: performance and capacity (WHO, 2007). The performance qualifier provides a description that the individual is doing within the environment, which, given the context of the lived experience within the environment, can then have overlap within the environmental factors component of the ICF-CY (WHO, 2007).

While the ICF defines participation as "involvement in life situations" (WHO, 2001, p. 8), participation can be further divided into an individual's capacity to participate, and an individual's performance in participation (Coster & Khetani, 2008). Given the holistic nature of the ICF-CY, definitive explanations and definitions are not provided when examining the exact construct of terms such as "life situations"; however, the ICF-CY does indicate that life situations symbolize the interaction between the individual and the

society in general (Coster & Khetani, 2008). In total, nine activity and participation chapters exist in the ICF, including learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions, major life areas, and community, social and civic life (Coster & Khetani, 2008; WHO, 2001). Given these nine areas of functioning, the interface between the capacity and performance of an individual with a functional disability will inevitably vary based on the interactions between each of the nine areas, as well as cultural and societal influences and expectations (Coster & Khetani, 2008). Coster and Khetani (2008), therefore, offer a working definition of participation and life situations in that they are organized activities that contribute toward a meaningful goal, both personally and/or socially, such as eating, getting dressed, hygiene, skill development, and tending to emotional well-being.

For Simplican and colleagues (2015) community participation is comprised of three notable characteristics: category, structure, and the degree of involvement for the individual. Within the categories, Simplican et al. (2015) describe multiple areas in which individuals can participate within their community, such as during leisure activities, being involved in political or civic engagements, having access to education, employment, religious practice, cultural practice, and access to goods and services. Structure is understood as participation through mainstream, segregated, or semi-segregated structures, whereas the degree of involvement refers to the degree in which individuals participate (Simplican et al., 2015).

While separate, inclusion and participation are largely intertwined concepts. Simplican et al (2015) notes that the overlap between community participation and interpersonal relationships is the model in which inclusion is created, while the United Nations (2016) views inclusion as the very process and goal which improves participation in society. Furthermore, the UN (2016) notes that participation is negatively impacted when individuals are lacking access to areas in which individuals can usually participate – employment, access to housing, healthcare, education, and further when individuals cannot have their voices heard or protected. Given the broad definitions of participation

and the interplay between participation, inclusion, belonging, and social interaction, there is often overlap and differing views on the definitions of these concepts and processes.

For this three-part dissertation, the ICF-CY (WHO, 2007) was used as the theoretical framework with which the research questions were centred and informed the assessment of barriers and facilitators to participation for children with IDD within various domains of functioning. The ICF-CY uses a common language to document the influence of the environment on the developing child and adolescent, specifically in terms body structures and function, activities and participation, and relevant environmental factors (WHO, 2007). It is these aspects of the ICF-CY which are particularly relevant throughout this dissertation.

1.2.5   The impacts of inclusion

The positive impacts of social inclusion and belonging are numerous: experiencing social support, access to resources, protection, and access to intimate partners (Bernstein et al., 2010; Duncan et al., 2007). Child development, social competency and acceptance within the community, and increased positive attitudes towards individuals with IDD are positive outcomes associated with social inclusion (Koster et al., 2007; Male, 2002; Nakken & Pijl, 2002; Tuersley-Dixon & Frederickson, 2016; Wiener & Tardif, 2004). When children, both typically developing (TD) children and children with IDD, are unable to access peer relationships and friendships there is a reduction of participation in community settings (McConkey et al., 2012). When participation within the community begins to build; however, acceptance of individuals with IDD also increases, building allies and relationships with supportive individuals increases, and alliances with community programs, organizations, and institutions also increase (McConkey et al., 2012). Social inclusion can lead to a sense of empowerment, which can then increase the subjective experience of quality of life (Brown et al., 2013). However, when personal choices and self-determination are controlled by others, as is frequently the case for individuals with IDD, stigma, discrimination, impacted interpersonal relationships, safety, missed educational opportunities and an overall decrease in quality of life are the

result (Brown et al., 2013). The necessity for social inclusion is of such paramount that Baumeister and Leary (1995) have reported that it is to be considered a basic need, such as the needs of food and shelter.

Individuals with IDD are among the most vulnerable populations for experiencing social exclusion. Barriers to social inclusion and community participation are faced by many individuals with IDD (Amado et al., 2013). Individuals with IDD have fewer friends than TD children and will frequently name their family members, staff they are supported by, or other individuals who require support for disabilities as their friends (Amado et al., 2013). The implications of a reduction in social and family support have been extensively studied (Iwase et al., 2017; Nowicki et al., 2018); however, the direct effects of social inclusion for individuals with IDD remains unsatisfactorily clear (Meininger, 2010). Some of the impacts of social exclusion include higher rates of school dropout, illiteracy, and difficulties both forming and establishing social relationships (Isaac et al., 2010; Nowicki et al., 2018). Given some of the impacts of social exclusion, (Isaac et al., 2010; Nowicki et al., 2018), inclusive education is significant for individuals with IDD.

1.2.6   Inclusive Education

Inclusive education is considered a human right, based on Article 24 of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006). Although inclusive education has differing definitions worldwide, in Canada inclusive education speaks to students who engage in a neighbourhood school with same-age peers where they feel physically, socially, and academically valued and included (Specht, 2013). The integration of diverse learners into inclusive classrooms ranges far beyond physical inclusion. For example, teachers' willingness to adopt inclusive teaching practices are enhanced when they believe all students should be included in diverse classrooms (Jordan et al., 2009; Specht, 2016).

Although efforts have been made to increase the depth and breadth of inclusion within formal educational settings, parents of children receiving inclusive education are

frequently asked to remove their children from these educational settings which then leads to sentiments of exclusion and missed opportunities (Brown et al., 2013). Furthermore, parents of children with IDD frequently feel excluded by parents of TD children, and children with IDD may experience bullying or be ignored by their peers which furthers the experience of both social and educational exclusion (Brown et al., 2013).

Informal education is learning which takes place outside of formal educational settings, such as within museums, zoos, aquariums, science centres, or camp settings (Spencer & Maynard, 2014). While formal inclusive education has many benefits, informal inclusive educational opportunities have also demonstrated positive effects for individuals with IDD. For example, when teaching science in a hands-on, inquiry-based manner, individuals with disabilities are more likely to engage in the materials as they depend on experiential learning to access the materials (Bennington, 2004; Melber, 2004; Melber & Brown, 2008). When individuals with disabilities are engaged in informal educational programming and opportunities, research has indicated that the experiences are not only well received, but also increase the individuals' experience of confidence in their abilities (Melber & Brown, 2008).

1.2.7   Informal Education

The absence of adequate opportunities for general learning for children with IDD is a violation of human rights and counters the United Nation's Convention on the Rights of the Child, particularly Article 2, Article 3, and Article 6 (Convention on the Rights of the Child, 1991). It is further contrary to the Ontario Human Rights Commission's reports *Education and Disability: Human Rights Issues in Ontario's Education System* (2006) and *The Opportunity to Succeed: Achieving Barrier-Free Education for Students with Disabilities* (2003). Furthermore, provincial policies and curriculum documents are also in place which emphasize that children should be afforded opportunities to thrive; noting that stakeholders must deliver learning opportunities which foster student success for all children (Ontario Ministry of Education, 2017).

Informal education is learning which takes place outside of formal educational settings, such as within museums or camps (Spencer & Maynard, 2014). Eshach (2007) described informal education as learning occurring spontaneously from life situations, without a formal teacher, and through the process of intrinsic motivation. Within the field of cognitive development, the impacts of both formal and learning and the contexts in which these occur play a major role in the cognitive development of children (Gong, 2022). Gong (2022) argues that formal learning in school is not the only place a child can learn, rather, informal learning settings invite children to build skills, expand their experiences and views, and become engaged in activities and tasks that they might not otherwise be able to experience. These settings, such as museums, gardens, zoos, and after-school programs are areas where children can experience free-choice learning, and engage in interactive and experiential learning, (Gong, 2022).

At times, formal education is viewed as mainstream, and as such, children with disabilities experience barriers by not being provided with facilitators to inclusion and participation in education in meaningful ways (Jones, 2011). When attitudes toward individuals, access, and facilitators are not ones of inclusion and participation, children with disabilities are physically present for formal learning, but are not a true community member as their voices are not valued or heard, particularly when segregated from TD children (Jones, 2011). Research has indicated that learning experiences within informal settings, such as museums, botanical gardens, zoos, and planetariums can play a crucial role in the development of children's desire for learning, curiosity, and interest in various academic fields (Bell et al., 2009; Eberbach & Crowley, 2017; Marcus et al., 2018; Palmquist & Crowley, 2007; Sobel & Jipson, 2016). For example, informal science activities can enhance a child's engagement with the natural sciences, and the success of these scientific activities is measured on whether the children generalize the information learned to novel settings (Marcus et al., 2018; Klahr & Chen, 2011). Family engagement and participation in learning in informal settings may be fundamental for both learning the material and for supporting the ability to transfer newfound knowledge to novel situations (Marcus et al., 2018). Furthermore, much literature has supported that family

engagement and conversations occurring at the time of learning can increase children's understanding of the material, particularly as learning in museums often combines visual with verbal learning strategies which benefits many different learning styles for children (Bell et al., 2009; Gentner et al., 2016; Gunderson & Levine, 2011; Marcus et al., 2018; Pruden et al., 2011). As such, given that informal settings provide opportunities to engage in conversation and experiential learning, informal settings provide a platform for which individuals with IDD can access informal education.

1.2.8   Informal Education for Children with IDD

Inclusion of children with IDD in informal educational experiences continues to be lacking. Individuals with disabilities continue to report a feeling of exclusion from locations such as museums (Linton, 2006). Furthermore, museums have been purported to centre their efforts on physical and cognitive inclusion so that participants attending the museum can physically interact with the environment and cognitively interact with the presented material (Lussenhop et al., 2016). In a study investigating the barriers that families of children with ASD experience when attending a fine arts museum, it was found that although parents of children with ASD were thankful for the sense of community experienced, frustration was also reported regarding reactions from others during typical museum times (Kulik & Fletcher, 2016). Additionally, Antonetti and Fletcher (2016) reported that despite parental willingness to have child participation in museum activities, parents of children with ASD reported three times as many negative emotions than parents of children without ASD when frequenting a museum. Some of the negative emotions experienced included fear, nervousness, anger, irritability, guilt, shame, sadness and feeling alone, whereas parents of children without ASD did not report fear, anger, guilt, shame, or sadness (Antonetti & Fletcher, 2016).

Individuals with IDD are likely to benefit from a fully inclusive experience in these informal settings (Lussenhop et al., 2016) and some informal learning settings have begun to offer programming and adaptations to meet the needs of individuals with IDD. One such example includes hosting sensory-friendly events which may reduce the

amount of stimulation through the five senses to meet the needs of individuals with sensory difficulties (Lussenhop et al., 2016). For participants who rarely engage in public outings such as museum ventures due to overstimulation of the senses, these sensory-friendly events may assist in increasing social activities and expand informal education opportunities through programming, performances, workshops, and exhibits (Little et al., 2015; Orsmond et al., 2004).

Children with IDD continue to experience barriers to inclusion within IES, despite the positive benefits associated with inclusion and participation. Some informal settings have begun offering programming for individuals with IDD to meet their diverse needs; however, though changes toward inclusion are being made, research in the area of facilitators and barriers toward participation and inclusion at IES for children with IDD remains sparse.

1.2.9   Staff Support

Staff play in an important role in IES, through their roles as activists, community members, through their individual values within IES, and in their role of teaching and supporting visitors (Hollows et al., 2019). Individuals with IDD frequently require staff support depending on their ability and level of need. Social care staff have supported adults with IDD in developing and maintain relationships (Bates et al., 2020) which falls within the environmental factors of the ICF-CY (WHO, 2007). Social care stuff supporting adults with IDD within these relationships were found to express that they themselves do not always have the support needed to support individuals with IDD – such as through policies or through staff training (Bates et al., 2020). Within the study, Bates and colleagues (2020) reported that staff found it challenging to address their own concerns and the concerns of individuals with IDD within their care due to lack of knowledge and training. Staff found that the lack of organizational support through lack of training and policies impacted their ability to support individuals with IDD who were in their care (Bates et al., 2020). Similarly, it has been found that community support staff for individuals with IDD have felt the difficulties in providing adequate resources,

safety, and the rights of the individuals given the lack of legislation and support models that are offered to the staff (Clifford et al., 2018).

At informal settings, staff members need professional development and learning to best support visitors, and visitor learning (Pattison & Dierking, 2013). Museum educators, for example, provide learning and interactions through facilitation for visitors through both structured interactions, as in the case of tours or programs, or unstructured interactions, as in the case of organic and spontaneous conversations (Pattison & Dierking, 2013).At times, however, despite staff attitudes in supporting individuals with IDD is one of care, organizational barriers prevent the quality of care provided to individuals with IDD (Hermsen et al., 2014). Examples of such barriers include commercialization of care (Hermsen et al., 2014), requiring more training, resources, and leadership (McConkey & Collins, 2010), and staff not having the specific skills, knowledge, or professional support needed to support the individuals with IDD with whom they work (McConkey & Bhlirgri, 2003). Clifford and colleagues (2018) encourage that, given the amount of time support staff spend with individuals with IDD, that their perspectives and voices be heard so that they can offer both emotional and practice support to individuals with IDD.

1.3   Methodology

This dissertation uses two methodologies to examine the research questions. The methodology utilized in the first study is a scoping literature review based on Tricco and colleagues' PRISMA extension for scoping reviews (Tricco et al., 2009). Scoping literature reviews can be used to determine the amount of evidence on a topic, the nature of the evidence, and the range of evidence to answer a research question (Tricco et al., 2009). Scoping literature reviews are also effective in summarizing findings and identifying gaps within the body of literature (Tricco et al., 2009). For the purpose of the first study, a scoping literature review is warranted in order to summarize the findings of diverse studies in both outcomes, disciplines, and methodologies, while also providing evidence to the current gaps in the literature; thus, providing insight into future research.

The second and third studies of this dissertation utilize a qualitative descriptive methodology (Sandelowski, 2000) in an effort to provide "a comprehensive summary of events in the everyday terms of those events" (p. 1). Qualitative descriptive is a qualitative research methodology which draws from constructivist and naturalistic perspectives with the aim to produce information for applied health disciplines (Hunt, 2009). The merit of utilizing a qualitative descriptive methodology is such that the data is generally not *interpreted,* but rather, *described* in everyday language (Sandelowski, 2000). This is a general deviation from other qualitative methodologies, such as phenomenology or narrative approaches which present the data through interpretation or through the re-telling of stories in other terms (Sandelowski, 2000). The second and third studies are thus completed through a qualitative descriptive approach to provide a comprehensive summary of the nature of practices at MAZSC within Canada in support of children with IDD and their families.

1.4 Summary

Informal education studies for children with IDD continues to be lacking, despite increased research in the areas of other neurodevelopmental-classified disorders such as ASD specifically (Damiano et al., 2015). Given the importance of inclusion and participation at IES for children with IDD, research in this area is needed to gain a greater understanding of the current practices, facilitators, and barriers toward inclusion and participation for this population. Therefore, this dissertation contributes to the existing body of literature by examining the following: (1) the complete and current body of literature pertaining to practices toward participation offered by IES for children with neurodevelopmental disorders by completing a scoping literature review; (2) exploring the current facilitators and barriers to inclusion for children with IDD at MAZSC across Canada; and (3) exploring the facilitators and barriers to staff training in support of children with IDD at MAZSC across Canada.

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Chapter 2

2 Practices for Supporting Participation in Informal Education Settings for Children with Neurodevelopmental Disorders: A Scoping Review

2.1 Abstract

Informal education settings (IES), such as museums, camps, or aquariums, can provide powerful learning opportunities for children. When designed to be inclusive, IES support independent thinking, evaluation, and enhance autonomy. Legislation reduces barriers for people with disability; however, IES have primarily focused on physical accessibility—disadvantaging individuals with disabilities extending beyond the physical domain—as is the case for children with neurodevelopmental disorders, including children with intellectual and developmental disabilities (IDD). A review of research studies and grey literature is necessary to gain a full understanding of the practices for inclusion in IES. We conducted a comprehensive scoping review of literature investigating practices participation in IES examining 1) the characteristics of studies currently within the body of literature; 2) the practices IES currently use to promote participation; and 3) the outcome measures identified pertaining to participation. Thirty-two studies were included for data extraction and analysis. Study designs included mixed methods, quantitative, and qualitative designs with practices ranging from coping strategies and modifying language of questionnaires and surveys to vocational training and receiving 1:1 support. Study outcomes included increased interactions between campers, increased support at IES, increases in target goals, and development cognitively, socially, emotionally, and in language and identity. The implications of this research can inform future policies and practices at IES for children with neurodevelopmental disorders.

2.2 Introduction

Informal education settings (IES) are environments where learning takes place outside of formal education classrooms, including museums, aquariums, and camps (Spencer &

Maynard, 2014). IES have a duty to be inclusive. In Canada, for instance, the Ontarians with Disabilities Act (2001) mandates standards for accessibility to reduce and/or prevent barriers that incumber full participation for individuals with disabilities. While IES have made improvements in accessibility and inclusion for people with disabilities, efforts have primarily focused on physical accessibility (Cho & Jolley, 2016; Kaushik, 1999), and individuals with neurodevelopmental disabilities continue to experience exclusion from informal education opportunities.

When designed to be inclusive, positive effects of participating in IES include opportunities to learn new skills, share experiences within families, and develop a sense of community belonging (Langa et al., 2013; Ryuh et al., 2019). For example, children with neurodevelopmental disorders who attended an art museum were more likely to bond with peers, feel comfortable in large groups, and display increased social communication skills (Deng, 2016). Children with neurodevelopmental disorders continue to experience barriers, however, resulting in missed educational opportunities and reduced feelings belonging (Lussenhop et al., 2016). For example, parents of children with neurodevelopmental disorders are frequently requested to remove their children from IES as they are deemed disruptive or behave in ways that differ from typically developing (TD) children (Langa et al., 2013). Similarly, Kulik and Fletcher (2016) found that children with autism spectrum disorder (ASD), an example of a neurodevelopmental disorder, and their families experienced both a sense of community but also frustration due to reactions from other visitors at a fine art museum. Given the challenges children with neurodevelopmental disorders face in IES, continued research is needed to understand the facilitators and barriers to participation in these settings. Understanding these factors can support the design of inclusive IES and enhance children's experiences.

The World Health Organization (WHO)'s International Classification of Functioning, Disability and Health and the subsequent Child and Youth version (ICF-CY) provide a framework that guide this work (2007). In the ICF-CY, disability and functioning are

considered through the interaction between individuals and their environment, where participation is an essential dimension of functioning (WHO, 2007). The ICF model is organized into two parts: (1) Functioning and Disability, and (2) Contextual Factors (WHO, 2007). Functioning and Disability includes body functions, structures, activities, and participation (WHO, 2007). Further, participation is defined as "involvement in a life situation" through interaction with others and includes informal education among other major life areas (WHO, 2007, p. 9). Contextual Factors include environmental (physical, social, and attitudinal) and personal factors (e.g., gender, age, upbringing, or coping styles; WHO, 2007). The ICF-CY is a useful theoretical framework for studying participation in children with IDD because it considers the person-environment interaction and constitutes a common language for describing facilitators and barriers to inclusion and participation.

Previous reviews incorporating the ICF framework focus on community participation of people with IDD (Andrews et al., 2015; Verdonschot et al., 2009), but none target IES. Verdonschot and colleagues (2009) completed a systematic review of 23 studies investigating community participation of individuals with IDD by categorizing studies using the ICF domains. Verdonschot et al. (2009) found lack of research on community participation. Only a few studies referred to a conceptual framework guiding their work and studies were of generally low methodological quality. Similarly, Andrews and colleagues (2015) completed a systematic review of 13 studies of community participation interventions for children and youth with IDD using the ICF (WHO, 2007) as a theoretical framework for data analysis. The authors concluded that community participation interventions are effective in increasing inclusion of children and youth with IDD and highlighted the importance of developing inclusive programs (Andrews et al., 2015).

Within the current body of literature, no studies have reviewed practices related to participation for children with neurodevelopmental disorders and IDD in IES using the ICF-CY (WHO, 2007) as a guiding framework. A better understanding of the evidence

for current practices can support research, service providers, and people with disabilities in IES. This scoping review, therefore, investigated practices for participation in IES examining 1) the characteristics of studies currently within the body of literature; 2) the practices IES currently use to promote participation; and 3) the outcome measures identified pertaining to participation.

2.3   Methods

The methods within this scoping review were guided by Arksey and O'Malley's (2005) framework including identification of research question; identification of relevant studies; study selection; data charting; and collating, summarizing, and reporting results. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMAScR; Tricco et al., 2018) table can be found in Appendix A.

2.3.1 Search Strategy and Study Selection

Searches were conducted for published research between January 2005 and November 2020 in the following databases: ERIC, Web of Science, Academic Search Ultimate, PsycINFO, and ProQuest Dissertations and Theses Full Text database. Keywords for disability were paired with keywords for IES with the Boolean operator *AND* (see Table 1). Reference lists of included studies were hand-searched and identified studies were directly added to full-text screening.

Table 1: Search Terms

Concept	Terms
Diagnosis of Disability	disab* OR "mild* handicap*" OR "moderate* handicap*" OR "severe* handicap*" OR "mental* handicap*" OR "multi* handicap*" OR "profound handicap*" OR "developmental* handicap*" OR "developmental* delay*" OR "delay* development" OR "mental* delay*" OR "intellectual* delay*" OR "mental* impair*" OR "intellectual* impair*" OR "cognitive impair*" OR "intellectual disab*" OR "learning disab*" OR autis* OR "pervasive developmental disorder*" OR "pervasive developmental delay*" OR "pervasive developmental disab*" OR asperger* OR Rhett* OR "Fragile

	X" OR "childhood schizophrenia" OR "Down* Syndrome" OR "Tourette" OR "Kleefstra" OR "cerebral palsy" OR "spine bifid" OR "fetal alcohol*" OR "visual impair*" OR "hearing impair*" OR "genetic disorder*"
Informal Settings	Education "Museum*" OR "Informal Science cent*" OR "Aquarium" OR "Camp" OR "Zoo" OR "Galler*" OR "Informal science institution"

All search results were exported to Covidence (Veritas Health Innovation Ltd, 2021) where duplicates were removed. Initially, two authors (JR and MA) independently screened all titles and abstracts, resulting in 90.7% agreement. The full texts were independently reviewed for inclusion by the same two authors, resulting in 68.1% agreement. Disagreements were discussed; inclusion and exclusion criteria were refined, and consensus on included articles was reached (Figure 1).

Figure 1: PRISMA-ScR Flow Diagram (Adapted from Moher et al., 2009)
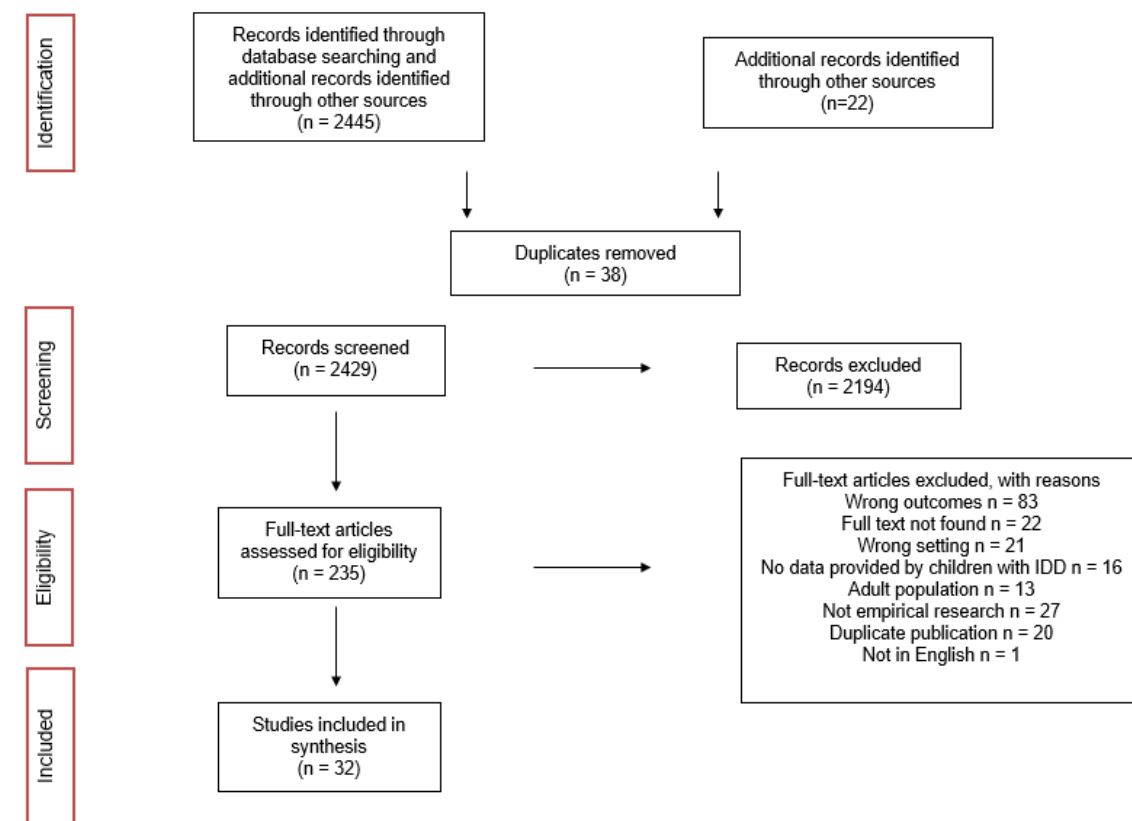
2.3.2 Inclusion and Exclusion Criteria

Articles included in this review met the following criteria: (1) empirical data; (2) participants ≤ 21 years old with a neurodevelopmental disorder; (3) took place in an IES; (4) measured outcomes pertaining to activities and participation; and (5) data collected from children with IDD (as informants or via direct observation). Quantitative, qualitative, and mixed methods studies were included. Studies were excluded if they (1) were not written in English; (2) focused exclusively on physical practices or outcomes; and/or (3) took place in formal educational settings.

2.3.3 Data Extraction

The first two authors (JR and MA) independently extracted all data. Extracted data included participant characteristics (sample size, age range, diagnosis), IES (museums, camps, or recreational programming), country, study design, practices, theoretical framework used to inform practices, outcome measures, informants, and findings.

2.3.3.1 Theoretical Frameworks

Authors coded the theoretical framework, conceptual frameworks, and skills theories used to inform the studies included in this review as present or not present. Authors then recorded the model as described by the authors if it was indicated that the model was used as a framework in which to position or inform the original research. Authors located the theoretical models used within the abstract and introduction sections.

2.3.3.2 Practices Used to Support Participation

Authors recorded practices as present or not present, and what practice was described within the original study within methods sections. ICF-CY codes were then applied to the practices using second-level codes (Cieza et al., 2002; Cieza et al., 2005).

2.3.3.3 Outcomes

Authors categorized the outcomes as qualitative or quantitative. Analysis of qualitative results was completed using Thomas and Harden's (2008) three-step process of thematic synthesis. Stage one includes coding the text 'line-by-line'; stage two consists of developing descriptive themes, and stage three consists of generating analytical themes (Thomas & Harden, 2008). First, familiarization with the study findings was achieved through repetition of article reading and extraction of the data pertaining to the characteristics of the studies. We then summarized the key themes and concepts that study authors reported. Next, we read each results section, completed descriptive coding, and summarized the primary topic of the qualitative data. These codes were then reviewed for repetition across studies and descriptive themes emerged (Thomas & Harden, 2008). Descriptive themes were analyzed through the intersection of the themes and the research question posed within this study. MA initially developed the analytical themes, which were then reviewed with JR through ongoing discussion. Thomas and Harden describe the difference between descriptive and analytical themes such that descriptive themes remain similar to themes within the primary studies, whereas analytical themes extend beyond the primary studies to generate novel constructs or explanations. For example, descriptive themes across the primary articles may have included terms such as "acceptance," "rapport," and "inclusion," after which an analytical theme of "belonging" was then established within this review. This process of coding, emergence of descriptive themes, then establishment of analytical themes was completed across all qualitative data included within this review. Author JR then repeated the coding, descriptive analysis, and development of analytical themes.

2.4   Results

2.4.1   Characteristics of Included Studies

A total of 32 studies were included in this scoping review including a total of 1,108 children. Four hundred and ninety-nine participants were TD and 609 children had one or more neurodevelopmental disorders. Participants were 3-22 years old. The most common

diagnoses were autism spectrum disorder (ASD, $n = 17$) and attention deficit hyperactivity disorder (ADHD, $n = 5$). Most studies were conducted in camps ($n = 24$, 75.0%). Geographically, the studies took place in the United States ($n = 27$, 84.3%), followed by Canada ($n = 3$, 9.4%), then Europe ($n = 1$, 3.1%). One study did not provide a location. Tables 2 through 4 below illustrate the characteristics of the included studies.

More than half of the studies employed quantitative approaches (56.3%; Table 2) including quasi-experimental studies ($n = 2$), cross-sectional studies ($n = 1$), single group pretest-posttest designs ($n = 6$), case studies ($n = 1$), descriptive studies ($n = 1$), longitudinal studies ($n = 1$), single case experimental designs ($n = 5$), and social network analyses ($n = 1$). Qualitative studies (18.8%) collected data using interviews, observations, and photovoice (Table 3). Mixed methods studies (25.0%) used a combination of qualitative and quantitative traditions, including combinations of interviews, observations, questionnaires, surveys, and rating/sorting tasks (Table 4).

2.4.2   Theoretical frameworks

Twelve articles within this review explicitly rooted their studies within theoretical models. Models included psychological and sociological models including social identity theory (Tajfel, 1981), while some articles used specific frameworks including the SENSE theatre approach (Corbett et al., 2014) and the LET US Play principles (Brazendale et al., 2020).

2.4.3   Practices used to Promote Inclusion

To promote inclusion, both components of functioning and disability and components of contextual factors were utilized. Specifically, practices falling within body functions and structures, activities and participation, and environmental factors as outlined within the ICF-CY (WHO, 2007) were found (Table 5).

2.4.4 Outcomes

2.4.4.1 Quantitative Outcomes

Quantitative studies used behavioural (e.g., Behavioral Assessment System for Children—Second Edition; Reynolds & Kamphaus, 2004), affective (e.g., Childhood Depression Inventory; Kovacs, 2010), self-perception (e.g., Self-Perception Profile for Children; Harter, 1985), and physical measures such as calculating the body mass index (BMI). Quantitative outcomes provided evidence to suggest that different activities offered varying experiences and opportunities for development. For example, participants rated that the opportunities for skill development were greater in more structured activities. Participants rated higher self-perceptions of social acceptance and quality of life at post-camp and at follow up. Furthermore, it was found that self-efficacy is linked with the concept of self-perception.

Table 2: Characteristics of Quantitative Studies

Author, Year	*nIDD (N)*	Age	Diagnosis	IES	Design	Informant	Theoretical Framework	Key Findings
(Boyd et al., 2008)	6(12)	5-10	Emotional disorder, ASD, visual impairment, language delay/limited language use	Camp	Single-case experimental design - Observation	Self, staff	None	The average percentage of interactions between campers with disabilities and campers without disabilities increased after the STAR (stay, play, talk, reward) program.
(Brazendale et al., 2020)	47(52)	4-21	DD	Camp	Quasi-experimental pretest-posttest - Accelerometers, anthropometric measurements	Self	LET US PLAY-A principles	Children showed increased time spent in moderate-to-vigorous physical activity and decreased sedentary time during LET US Play- Adapted physical activity sessions compared to traditional physical activities.
(Corbett et al., 2014)	12(12)	8-17	ASD, PDD-NOS, AS	Camp	Single group, pretest-posttest - Questionnaires, observation, salivary cortisol	Caregivers, self, staff	SENSE Theatre Approach	Children demonstrated an increase in active involvement with familiar peers Engagement with novel peers outside the treatment setting did not change.

(Dawson et al., 2018)	76(76)	8-18	Muscular dystrophy, spinal muscular atrophy, CP, SB	Camp	Social network analysis - Surveys	Self	Egocentric social network analysis	True reciprocal relationships were reported 42.86% of the sample, reciprocal relationships came from camp contacts 50% of the time.
(D'Eloia & Sibthorp, 2014)	109(209)	12-17	DD, CP, neurofibromatosis, organ transplant, PD	Camp	Quasi-experimental - Questionnaires	Self	Positive youth development framework, mechanisms of relatedness	Campers with and without disabilities perceived camp as more supportive of the mechanisms of relatedness (challenging experiences, informal social interactions, meaningful roles, learning experiences, and peer role modeling) than other environments. When compared to their TD peers, youth with disabilities experienced greater engagement with peer roles models and greater social opportunities at camp than non-camp experiences.
(Jia et al., 2016)	24(85)	7-10	ADHD	Camp	Longitudinal - Questionnaires, interviews	Self, staff	None	For children with ADHD, problem behaviour predicted low peer preference and oppositionality. For typically developing children, problem behaviour did not predict any outcomes. For all children, lower teacher ratings of social competence predicted lower peer preference.
(Kaboski et al., 2015)	8(16)	12-17	ASD	Camp	Single group, pretest-posttest - Questionnaires	Self, staff	None	Participants with ASD demonstrated a significant decrease in social anxiety but no change in social skills. TD participants and participants with ASD showed significant improvements on their knowledge of robots.
(Koegel et al., 2019)	4(4)	6-14	ASD	Camp	Single-case experimental design	Self, staff	None	All participants showed increases in targeted social goals (engagement, eye contact, turn taking

					- Observation		and conversation) because of positive behavioural support strategies (priming, peer mediation and self-management).
(Ledford et al., 2020)	4(4)	3-6	ASD	Camp	Single-case experimental design - Observation	Self	None	Participants showed decreased engagement when a fidget bin was present compared to baseline and a token reinforcement condition.
(Liljenquist et al., 2017)	10(10)	14-22	IDD	Recreational programming	Descriptive - Survey, assessment	Self	None	The Participatory Experience Survey and the Setting Affordances Survey was found to be feasible for assessing experiences of people with IDD when participating in recreational activities.
(Maich et al., 2015)	9(9)	5-10	ASD	Camp	Case study - Observations, surveys	Self, staff	None	Ratings of social skills for children with ASD increased pre- to post-intervention. Four of the nine participants demonstrated increases in the overall number of social interactions. Changes were noted in the quality of interactions.
(Mitchell et al., 2015)	20(20)	6-11	HFASD	Camp	Single group, repeated measures - Observation	Caregivers, staff, self	None	Significant improvements in attention, following activity rules, contributing to group discussions, and complaining were reported across the 6 weeks of the program.
(Na & Mikami, 2018)	24(137)	7-10	ADHD	Camp	Descriptive - Questionnaires	Self	None	Children who were inclined to interact with and help hypothetical classmates with ADHD gave fewer "dislike" nominations and higher "like" ratings to real-life classmates with ADHD. Children who initially believed ADHD symptoms were not controllable gave more "dislike"

								nominations and lower liking ratings. Children who had ADHD and who attributed their uncontrollability for ADHD symptoms predicted fewer "like" nominations and more "dislike" nominations toward classmates with ADHD.
(Quinn et al., 2014)	3(3)	8	ASD	Camp	Single-case experimental design - Observation	Self	None	The baseline demonstrated low and variable levels of compliance to directive, with variable levels of disruptions. From baseline to intervention, increases in compliance to adult directives and a decrease in disruptive behaviours was observed.
(Schenkelberg et al., 2015)	6(12)	5-6	ASD	Camp	Cross-sectional - Observations, surveys, BMI	Caregivers, self	None	With free play, children with ASD spent significantly less time using moderate to vigorous physical activity while with a peer compared to with a peer group or when alone and demonstrates significantly light to moderate to vigorous physical activity while alone within a social context when compared to alone with an adult, alone with a peer, or with a peer group. Overall, no significant differences were reported during organized activities.
(Siperstein et al., 2009)	29(67)	8-13	MID	Recreational programming	Single group, pretest-posttest - Observation, questionnaires skills assessments	Self	None	Most children without an intellectual disability made at least one new friend with a child with an intellectual disability.
(Wenninger, 2012)	5(5)	7-9	ASD	Camp	Single-case experimental design	Self, staff	None	All participated demonstrated at least two behaviour changes, such as target behaviours

					- Observation			decreasing or replacement behaviour increasing. For all participants, 68% of behaviors changed as intended, with 65% of participated demonstrating a moderate rate of change during camp.
(Willemin et al., 2018)	14(14)	5-14	ASD	Camp	Single group, pretest-posttest - Surveys	Self	None	Children with ASD scored significantly higher on the post-test when compared to their pretest scores. While the Social Personal Relationship Scale demonstrated improvements, results were not statistically significant.

Notes: ADHD, Attention-Deficit/Hyperactivity Disorder, *AS,* Asperger Syndrome, *ASD,* Autism Spectrum Disorder, *BMI,* Body Mass Index, *CP,* Cerebral Palsy, *DD,* Developmental Disabilities, *HFASD,* High-Functioning Autism Spectrum Disorder, *IDD,* Intellectual and Developmental Disabilities, *MID,* Mild Intellectual Disability, *SB,* Spina Bifida, *PD,* Physical Disabilities, *PDD-NOS,* Pervasive Developmental Disorder-Not Otherwise Specified, *TD,* Typically Developing

2.4.4.2   Qualitative Outcomes

Qualitative data were categorized into three major themes: (1) Sense of Belonging; (2) Self-Esteem/Self-Perception; and (3) Improved Social and Cognitive Skills.

Table 3: Characteristics of Qualitative Studies

Author, Year	*nIDD (N)*	Age	Diagnoses	IES	Design	Informant	Theoretical Framework	Key Findings
(Aggerholm & Moltke Martiny, 2017)	11(11)	14-18	CP	Camp	Phenomenology - Semi-structured group interviews	Self	Phenomenology	Participants gained bodily control in difficult situations, learned new ways to approach challenges, learned the importance of sharing and learning from one another, and self-understanding and acceptance.
(Devine & Parr, 2008)	4(8)	12-16	AS, CP, spinal muscular atrophy	Camp	Constant Comparison - Semi-structured interviews, field notes	Self	Inclusive leisure, contact theory, social capital	The conceptual categories revealed that the social relationships between campers were mixed in the reinforcement of a shared set of values to continue relationships, network together, and work effectively as a group

(James, 2019)	13(13)	10-18	CP	Camp	Phenomenology - Semi-structured interviews	Self	Social Identity Theory	Participants with CP reported that participating in a residential soccer camp supported two of three processes within social identity theory and provided favourable circumstances for participants to experience connection and like their peers without disabilities.
(Griswold et al., 2014)	18(18)	10-16	Tourette Syndrome	Camp	Phenomenology - Focus groups, semi-structured interviews, observations	Self, staff	None	Four major themes were identified: relatedness, social development, and programmatic outcomes. Subthemes were further identified: not alone and self-assurance, friendships, optimist, educational experience, and bullying, and unique program opportunities and cabin bonding.
(O'Heaney, 2018)	4(4)	10-15	LD, ADHD	Camp	Case Study - Interviews, document analysis, focus groups, observations	Stakeholders, self, staff, caregivers	Positive youth development framework, 5 C's approach, and Developmental Systems Theory	Pairing a child with an LD with a mentor of a similar diagnosis helps the child envision their futures and learn self-advocacy skills, perseverance, and grit – thus leading to feelings of empowerment.
(Rapp, 2005)	6(18)	Elementary school students	LD, emotional impairment; speech and language impairment; physical and health impairments, mild and moderate intellectual disability.	Museum	Case Study - Observations, interviews, survey, documents, journal	Self, teachers, staff	Theories of social constructivism and holism	Benefits such as scaffolded instruction, meaningful and contextualized activities, self-regulated learning, the establishment of learning communities, play, and parental involvement were reported.

Notes: ADHD, Attention-Deficit/Hyperactivity Disorder, *AS,* Asperger Syndrome, *CP,* Cerebral Palsy, *LD,* Learning Disabilities

1. Sense of Belonging

Most studies reported children's increased sense of belonging as a result of their participation in the programmes. Participants exhibited increased active participation and decreased stress. One study at a camp involving children with cerebral palsy (Aggerholm & Martiny, 2017) stated that,

> Typically, the participants experienced themselves as not being as normal as other peers in their daily life. They all had mild degree spastic [cerebral palsy] and felt like they are in a gray zone because they do not feel as disabled or abnormal as the ones who are not able to walk and, for example, have to use wheelchairs. But

on the camp, they were among other peers with similar degrees of [cerebral palsy], and they expressed a sense of belonging. (p. 14).

Some studies reported that participants felt safe and supported, largely due to the counsellors' efforts. One study revealed that, "the roles people played in the camp setting were critical to relationship development and forging a sense of belonging needed in the formation of social capital" (Devine & Parr, 2008, p. 404).

2. Self-Esteem/Self-Perception

Some studies (Aggerholm & Moltke Martiny, 2017; O'Heaney, 2018) revealed that the participants' parents felt their children had positive experiences following participation. One of the most noted findings was that through participation, participants acquired the confidence to attempt new activities. One study at a camp involving children with LD and ADHD indicated that, "what this camper was describing was the safety of finding a peer group, a community, that understood her, and in this way, she explained that she felt better about herself" (O'Heaney, 2018, p. 107).

3. Improved Social and Cognitive Skills

Several studies indicated that participants displayed increased social (Corbett et al., 2014; Griswold et al., 2014; Maich et al., 2015; Wenninger, 2012) or cognitive skills (Langa, 2013; Lee, 2016; Zwicker, 2015), or both (Collier, 2018; Deng, 2015; Hartman, 2018; Rapp, 2005). Analyses of the participants' behaviours and responses indicated increased sociability and learning, higher-level thinking, and central coherence, particularly given the programmes' practices utilized to promote inclusion. One study found that, "these intentional programmatic aspects of the live-in cabin experience were seen to produce increased levels of rapport between campers and staff, as well as the learning of various social skills" (Griswold et al., 2014, p. 30).

Table 4: Characteristics of Mixed Method Studies

Author, Year	nIDD (N)	Age	Diagnosis	IES	Design	Informant	Theoretical Framework	Key Findings
(Boeder, 2012)	31(31)	12-21	ASD or a related disorder	Camp	Mixed methods - Interviews, goal setting and self-monitoring	Caregivers, self, staff	None	At the end of camp, each camper made at least some progress in a minimum of one home living, self-care, self-direction, leisure, social, or communication goal.
(Collier, 2018)	8(8)	13-18	ASD	Camp	Mixed methods - Photovoice, photos, interviews, observations, survey	Self, staff	Photovoice	Five themes reported: Positive Emotions, Socialization, Unique Experiences, Collective Identity, and Self-Improvement. Overall, it was found that increased independent experiences and increased self-confidence emerged when campers spent time with like-minded peers.
(Deng, 2017)	10(10)	8-15	HFASD	Museum	Mixed methods - Pre-gallery and post-gallery tour task, observations, semi-structured interviews, surveys	Self, caregivers, staff	Free-choice learning	Participation in a tailored educational museum program positively influences cognitive and social behaviors of children with ASD and contributes to overall well-being.
(Dipeolu et al., 2016)	27(173)	8-17	ADHD, multiple disabilities, LD, PD	Camp	Concept Mapping - Interviews, sorting and rating	Self	None	Seven thematic concepts emerged: healthy camp fun, extraordinary experiences, structured opportunities, personal and social transformations, safe and supportive place to learn, acceptance of self and others, respite and reward.
(Hartman, 2018)	4(4)	13-17	HFASD	Museum	Case studies and case vignettes - Checklist, transcripts, artwork and	Self	Art therapy and museum education theoretical frameworks (pragmatism)	Four main themes of development were identified: cognitive and language development, adolescent identity development,

Citation	n (n)	Age	Disability	Setting	Methodology	Informants	Control	Findings
(Langa et al., 2013)	10(10)	7-11	ASD	Museum	visual images, written responses, survey Mixed methods - Surveys, interviews	Self, Caregivers	None	socioemotional development, and sensory and affect regulation development. Interest-driven enjoyment was reported as a primary motivation, while to relax and to socialize outside of the family boundaries were ranked as less important motivators.
(Lee et al., 2016)	42(42)	8-16	ADHD, LD, PD, speech impairment, IDD, bipolar disorder	Camp	Concept Mapping - Interviews, sorting and rating	Self	None	Seven thematic concepts emerged: personal growth, nurturing relationships, non-judgemental environment and attitude, traditional/classic camp fun, beneficial and unique opportunities, learning/thinking with structures and rules, and independence and recognition, which suggests that children with disabilities experienced positive personal growth and learned new skills through the camp.
(Zwicker et al., 2015)	11(11)	7-12	DCD	Camp	Mixed methods - Semi-structured interviews, surveys	Self, caregivers	None	Statistically significant improvements were reported in both performance and satisfaction for child-chosen goals. Parents and children further reported positive benefits of camp, including increased confidence, sharing experiences with other peers with DCD, and learning more about DCD.

Notes: ADHD, Attention-Deficit/Hyperactivity Disorder, *DCD,* Developmental Coordination Disorder, *HFASD,* High-Functioning Autism Spectrum Disorder, *IDD,* Intellectual and Developmental Disabilities, *LD,* Learning Disabilities, *PD,* Physical Disabilities

Table 5: Practices Used to Promote Inclusion

Components of Functioning and Disability	Practices [ICF-CY Level 2 Code]
Body Functions and Structures	• Coping strategies training (*n* = 1) [Mental Functions: Specific Mental Functions: Emotional Functions (b152)]
Activities and Participation	• Offering both traditional and modified versions of physical activities (*n* = 3) [Mobility: Walking and Moving: Moving Around (d455)] • Offering a wide variety of recreational activities (*n* = 2) [Community, Social, and Civic Life: Recreation and Leisure (d920)] • Modifying language of questionnaires and surveys (*n* = 1) [Communication: Conversation and Use of Communication Devices and Techniques: Using Communication Devices and Techniques (d360)] • Embedding behavioural strategies in activities and tasks (*n* = 1) [Learning and Applying Knowledge: Applying Knowledge: Solving Problems: d175] • Vocational training (*n* = 1) [Major Life Areas: Vocational Training: (d825)] • Instructional support (*n* = 1) [Major Life Areas: Education: Informal Education (d810)]
Environmental Factors	• Receiving 1:1 support from peers, paraprofessionals, inclusion counsellors, and coaches (*n* = 3) [Support and Relationships: Acquaintances, peers, colleagues, neighbours, and community members (e325) for "support from peers", and Support and Relationships: Other Professionals (e360) for paraprofessionals, inclusion counsellors, and coaches] • Pairing TD children with children with IDD to learn behavioural strategies (*n* = 1) [Support and Relationships: Acquaintances, peers, colleagues, neighbours, and community members (e325)] • Small groups accompanied by facilitators trained in inclusion and disabilities (*n* = 1) [Support and Relationships: Acquaintances, peers, colleagues, neighbours, and community members (e325) for "small groups" and Support and Relationships: People in Positions of Authority (e330) for "facilitators trained in inclusion and disabilities"] • Access to physical and occupational therapists (*n* = 1) [Support and Relationships: Health Professionals (e355)] • Providing supervision during tasks (*n* = 1) [Support and Relationships: Other Professionals (e360)] • Modifying method of administration (*n* = 1) [Products and Technology: Products and Technology for Communication (e125)] • Self-contained classes and inclusive classes (*n* = 1) [Services, Systems and Policies: Education and Training Services, Systems and Policies (e585)]

2.5 Discussion

This scoping review examined the inclusive education practices in IES for children with neurodevelopmental disorders, the theories that inform them, and their outcomes. Thirty-two studies were included in which more than half the studies employed quantitative approaches. Of the 32 studies, 12 were rooted within theoretical models. Quantitative and qualitative outcomes demonstrated that in the presence of practices for participation, children with neurodevelopmental disorders have greater opportunities for skill development, rated higher self-perceptions of social acceptance, and experienced a sense of belonging, and improved social and cognitive skills. The practices used to promote inclusion were coded using level 2 codes within the ICF-CY (WHO, 2007).

Most of the research on IES settings for children with neurodevelopmental disorders within this scoping review took place in camp settings in the United States. Various camp settings were described within the studies, such as recreational camps, sports camps, summer camps, and winter camps. The versatility in programming and the ability to modify camp schedules, recreational activities, and supports may make them ideal for investigating inclusive practices for children with neurodevelopmental disorders. For example, providing social skills support for individuals with ASD within a camp context was documented as a highly effective approach in a study by Collier (2018). Similarly, Griswold and colleagues (2014) also found that participants experienced positive social experiences through specialized programs (i.e., themed twilight activities, cabin periods, and challenges course activities) during a weeklong inclusive camp for children with Tourette's syndrome. These positive experiences increased engagement between campers and camp staff (Griswold et al., 2014). Similar sentiments were also reported by Aggerholm and Martiny (2017), who found that participants focused on the social relations established at the camp and through experiencing an inclusive camp for other individuals living with cerebral palsy, they felt a sense of belonging that they generally did not feel outside of the camp setting. Given that most studies within this review were placed within camps, these results also demonstrate a need to understand how practices

will promote participation of children with neurodevelopmental disorders at IES that extend beyond camp settings.

Several studies within this review used single-case research designs, a frequent practice within neurodevelopmental disorder and IDD research (Lobo et al., 2017). Single-case research designs are useful in this area as they can demonstrate control even when the participant population is rare, when researcher resources are restricted, and when examining the effects of innovative interventions (Lobo et al., 2017) as is frequently the case for neurodevelopmental disorder and IDD research. The United Nations discussed that participation is negatively impacted when individuals cannot have their voices heard (2016). Over three-quarters of the studies included within this review employed either quantitative or mixed method approaches, while over half the studies employed quantitative methods alone. The voices of individuals with neurodevelopmental disorders are rare in research, and while the studies within this review shed some light on the impact and meaningfulness of practices toward inclusion, it can be difficult to capture subject thoughts and feelings through surveys and questionnaires alone. As such, there is merit in completing further research employing qualitative methods to capture the lived experiences and voices for individuals with neurodevelopmental disorders. Further investigation into qualitative methods is suggested to continue adding the voices of participants with neurodevelopmental disorders to the current body of literature.

While this review centred upon diagnoses of children with neurodevelopmental disorders and IDD, included studies reported other co-morbidities and diagnoses such as emotional impairment, mental health disorders, diabetes, brain injury, muscular dystrophy, and organ transplant; this demonstrates the broad benefits of adopting inclusive practices not only for individuals with neurodevelopmental disorders, but across populations. The first objective of this scoping literature review was to determine what practices promote participation in IES. Seven practices within the environmental factors were noted, while six practices within activities and participation were found. Only one practice within body functions was identified, with no practices identified within body structures. Within

activities and participation, varied categorizations were noted, including mobility, community, social, and civic life, communication, learning and applying knowledge, and major life areas. Conversely, of the seven environmental factors, five practices fell within the support and relationships category, with the remaining two being coded within the products and technology category and services, systems and policies category, respectively. These findings highlight the need for and importance of support and relationships for individuals with neurodevelopmental disorders in informal and community settings.

Andrews and colleagues (2015) described specific targeted interventions, rather than recreational or leisure participation. The interventions found within Andrews et al.'s review noted that the development of friendships further improved with teaching appropriate social skills and promoting peer inclusion. Similarly, the review completed by Verdonschot and colleagues (2009) also centred upon community participation within the context of peer relationships and friendships and noted that individuals with IDD are more likely to live in community settings when compared to living in segregated settings and continue to have lower participation than TD individuals. Our findings also highlight that support and relationships within the environment are emphasized practices within IES, with additional practices highlighted through activities and participation including vocational training, mobility, recreation and leisure, communication, and applying knowledge. However, despite our findings, it should be noted that participation and inclusion are being experienced within segregated settings, rather than true community inclusion. For example, the camp settings within this study were camps designed specifically for individuals with neurodevelopmental disorders and IDD, rather than camps for children in general in which individuals with neurodevelopmental disorders and IDD were participating. As such, the opportunities for inclusion were limited as the camps were targeting this specific population, rather than targeting integration and inclusion of children with neurodevelopmental disorders and IDD into the community. Therefore, although there are strengths of supports in providing inclusion and participation in these areas, further evidence is required to demonstrate how participation

can be enhanced through effective programming and IES for children with neurodevelopmental disorders and IDD within community settings, apart from segregated opportunities.

The second objective of this scoping literature review was to determine theoretical frameworks informed included studies. The theoretical frameworks found within this review were broad and more than half of the included studies did not describe using a framework to position the research study at all. Qualitative studies were more likely to describe positionality through a theoretical framework than mixed methods or quantitative studies; however, the theoretical frameworks were not necessarily related or specific to participation or disabilities research. No study reported utilizing the ICF-CY (WHO, 2007) as a theoretical framework. This is consistent with previous reviews of community participation of people with IDD finding few named guiding frameworks (Verdonschot et al., 2009). As a result, studies in this review did not always have clear definitions of inclusion or participation. For example, while Lee and colleagues (2015) noted that a benefit to their study was that participants were able to express the benefits of camp participation in their own way, the actual definition of participation was not defined throughout the study. We recommend the use of frameworks such as the ICF-CY (WHO, 2007) to ensure research outcomes are comparable. Further, because people with neurodevelopmental disorders, including IDDs in both children and adults, are often supported by multidisciplinary support teams, there is a benefit to using shared language. However, it was found within this review that there is some overlap within the body functions and activities and participation definitions of the ICF-CY (WHO, 2007) which can, at times, limit the shared language that is being used as some practices can be viewed through the lens of both definitions. For examples, "attention" can be seen both as a body function and as a component of activities and participation. While this does not negate the effectiveness of shared language, it may be a limitation in how we view practices when using the ICF-CY (WHO, 2007) as a framework.

The third and final objective of this scoping literature was to understand the outcomes measured for each study pertaining to inclusion and participation. Qualitative findings from included studies suggest participation in IES impacts sense of belonging, cognitive and social skills, and self-esteem/self-perceptions for children with neurodevelopmental disorders. Given that the literature suggests that structured and targeted practices can lead to improved self-efficacy for children with disabilities (Wickman et al., 2018), it is notable to reveal through this scoping review that enhanced self-efficacy contributes to improving self-perceptions which impacts children's social-emotional development. Thematic analyses revealed that children with neurodevelopmental disorders experienced improved social emotional and cognitive experiences. Quantitative findings, as evidenced using various behavioural, affective, social-emotional, self-perception/self-efficacy, and physical measures, provided evidence to suggest that different activities offered varying experiences and opportunities for development. Additionally, questionnaires ratings indicated higher self-perceptions of social acceptance, indicating that although quantitative studies demonstrated improved skills development, both socially and cognitively, only some areas of participation were examined. Given that social inclusion centres on relationships, social acceptance and social competence, and opportunities for participating within groups (Koster et al., 2009; Abbott & McConkey, 2006), offering varied experiences and opportunities for development is in line with social inclusion and opportunities for participation. Furthermore, participants rated higher self-perceptions for social acceptance and quality of life after experiencing participation at IES. Within this domain, self-efficacy was found to be a factor in the improvement of self-perception for children with neurodevelopmental disorders at the IES.

2.6 Limitations

There are some limitations to this review. First, a quality assessment of the included articles was not performed; all articles were included if they met the eligibility criteria. Second, our search terms related to IES may not have captured all informal education spaces. Given that IES has a broad definition as places in which learning and education occur outside of a formal classroom, there may be additional settings which were not

included. For example, we did not search for barns, as studies involving equestrian practices tended to focus on targeted interventions for people with neurodevelopmental disorders rather than inclusive spaces. Third, given that decisions for children with neurodevelopmental disorders are frequently directed by parents and caregivers (Brown et al., 2013), we excluded studies that did not have children with neurodevelopmental disorders as primary respondents either through surveys, interview, or via direct observation. Excluded studies may contain staff and/or family perspectives that were not captured within this review. Fourth, the majority of identified studies were conducted in the USA at camps and therefore the findings may have more limited applicability in countries where disability support policies and service provisions differ. It is unclear how these practices may translate to IES other than camps such as in aquariums, or science centres. Finally, multiple studies included participants with a diagnosis of neurodevelopmental disorders and other co-morbidities or participants with disabilities other than neurodevelopmental disorders. The diverse samples combined with the lack of controlled studies make it difficult to compare outcomes across studies. Few studies evaluated the success of practices in a way that allows effectiveness to be evaluated. More rigorous empirical studies with comparable samples are needed to build a knowledge base on best practices for promoting inclusion at IES.

2.7 Conclusion

This scoping literature review provides an overview of the current practices supporting full inclusion and participation for children with neurodevelopmental disorders within IES. At this time, there is some evidence to suggest that there are benefits of inclusion and participation within IES. However, further research into inclusion and participation is needed within community programming, rather than in isolated or segregated programming specifically for children with disabilities, to illuminate the true benefits of inclusion and participation. This research has facilitated the illumination of what practices currently are being executed for participation for children with neurodevelopmental disorders at IES, such as scoping skills training and pairing TD children with children with neurodevelopmental disorders. Given the positive benefits of

the current existing practices, continued and future practices should continually be developed in accordance with provincial, national, and international legislature pertaining to full inclusion and participation for children with neurodevelopmental disorders within their communities. The domains outlined by the ICF-CY (WHO, 2007) provide a common language for practices as they pertain to participation in disability. Recommendations for future research include expanding disability research to focus on inclusive practices and interventions for abilities beyond the physical realm, to complete studies examining practices within the activities and participation components of functioning and disability as outlined by the ICF-CY (WHO, 2007) for children with neurodevelopmental disorders at diverse IES. Finally, recommendations for future research also include studies centering on the individual with disability, their family members, and support staff who also seek to provide inclusive practices in which they can achieve experience participation and inclusion.

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Chapter 3

3   Facilitators and Barriers to Inclusion of Children with Intellectual and Developmental Disabilities at Informal Learning Centers in Canada

Informal learning experiences are those occurring outside a traditional classroom such as within museums, aquariums, zoos, and science centres (MAZSC). These sites are learning centres which seek to provide inclusion for individuals of all ages and abilities. However, MAZSC are challenged with decreasing the barriers for participation for individuals with intellectual and developmental disabilities (IDD). As such they are encouraged to use strategies to facilitate participation and a more inclusive learning experience for individuals with IDD. Through semi-structured interviews with staff members, this study examines the facilitators and barriers at informal learning centers in Canada for children with IDD. The interviews revealed three overarching themes: profiles of children's learning and engagement; facilitators toward participation and inclusion; and barriers to participation and inclusion. Barriers toward inclusion and participation are diverse, and range from narrowly focused advertisements, to needing additional staff, to high sensory environments, while the diversity of facilitators is also varied and ranges from communication facilitators, calming or separate environments, and staff attitudes. When specific barriers and facilitators are identified, in conjunction with understanding the broad needs of children with IDD, while also understanding the need for flexibility in support the individual with individual needs, the opportunities for inclusion and participation increase.

3.1   Introduction

Individuals with IDD are among the most vulnerable populations for experiencing barriers to social inclusion (Amado et al., 2013; Patterson, 2007; Thorn et al., 2009). Social inclusion is multi-dimensional and refers to having access to socially valued community activities such as employment, education, recreation, and entertainment (Amado et al., 2013; Bates & Davis, 2004; Hewitt et al., 2013). Furthermore, social

inclusion extends past being a passive member and includes meaningful social connections and participation in everyday activities both in formal settings (e.g., schools, employment) and in informal settings (camps, clubs, museum/gallery visits) (Abbott & McConkey, 2006; Clement & Bigby, 2009; Hall, 2005; Milner & Kelly, 2009; Thorn et al., 2009, United Nations, 2020). Informal learning experiences are those occurring outside a traditional classroom such as museums, where children can experience hands-on play and conversations with adults about content material (Tougu et al., 2017). Museums, zoos, science centers, art museums, and the like are informal learning places for which inclusion is both relevant and necessary (Lussenhop et al., 2016; Reich et al., 2010). Informal learning opportunities are frequently offered through places such as museums, aquariums, and camps, where learning takes place outside of formal schooling environment (Spencer & Maynard, 2014).

The impacts of educational opportunities for children with IDD at informal learning settings are significant. Research has indicated that informal educational opportunities for children with disabilities are not only well received, but also increases the individuals' experience of confidence in their abilities (Melber & Brown, 2008). For example, science learned outside of a formal classroom setting takes on a different meaning and role within the informal setting and is often directed by the specific interests of the individual engaging with the material (Dierking et al., 2003). Falk and Storksdieck (2005) refer to these experiences in museums and similar spaces as "free-choice learning" (p.117). This is best defined as allowing the learner to decide what, how, and when they would like to learn within the setting (Falk & Storksdieck, 2005). It is this nature of engagement that creates agency in the learner to have meaningful and rich learning experiences (Falk & Storksdieck, 2005). Puvirajah and colleagues (2012) argue that by engaging with informal experiences, individuals can take more initiative and direct interest in the types of experiences available, and at the level at which the individual would like to participate with the materials. When the learner is able to engage with the materials on their own volition, they can learn in a more meaningful way and at their own pace (Puvirajah et al., 2012). Science taught in this manner (hands-on, inquiry-based), may benefit individuals

with IDD and other disabilities as they are more likely to engage or depend on experiential learning to access the material (Bennington, 2004; Melber, 2004; Melber & Brown, 2008).

While inclusion in formal settings is relatively well studied, studies examining inclusion in informal settings are only beginning to be considered. Given that participation and engagement for individuals with disabilities has been needed and has not always been met, museums and other similar informal learning spaces have been encouraged to use strategies to facilitate participation and engagement with the materials (Bullock et al., 2010; McMillen & Alter, 2017). Sandell (2003) suggests that museums should attempt to increase social inclusion in a tri-faceted approach: at the individual, community, and societal levels. Of particular importance within the context of this study are the individual and community levels. Within the individual level, visitors of museums experience impacts such as improved self-esteem and creativity, whereas at the community level, confidence and skills are developed for community empowerment and development of neighbourhoods (Sandell, 2003). Similarly, science centres and other informal education settings are venues which can provide significant and engaging experiences "that support the intellectual, emotional, and motivational desires of all visitors" including those with IDD (Puvirajah et al., 2020, p. 438). However, they are also challenged with decreasing the barriers to participation for individuals with disabilities (McMillen & Alter, 2017). Emerging research has revealed the positive effects participating in informal educational opportunities for individuals with IDD. For example, children with IDD who visited an art museum were found to feel more comfortable with large groups, bond with peers, and exhibit ameliorated social communication skills (Deng, 2016). Despite these positive outcomes, children with IDD also continue to experience barriers and stigmatization. Kulik and Fletcher (2016) found that children with Autism Spectrum Disorder (ASD) and their families experienced a sense of community when attending a fine arts museum but also frustration due to reactions from other visitors.

These data highlight the need to understand the factors affecting participation in informal settings for people with IDD. Only a small number of studies have looked at barriers and facilitators in informal education centres (Deng, 2016; Kulik & Fletcher, 2016; Leichtman et al., 2014; Linton, 2006; Lussenhop et al., 2016; Melber & Brown, 2008). To understand how to support inclusion and participation for individuals with IDD at a science centre, Leichtman et al. (2014) held focus group interviews with staff and parents of children with IDD (specifically, ASD). The staff members reported that they were unaware whether centre visitors had sensory processing difficulties, as is often the case with children with ASD, due to the shortness of visitor-staff interactions. Similarly, Lussenhop and colleagues (2016) found that individuals with IDD are likely to benefit from inclusive experiences in informal settings such as sensory-reduced evenings in which individuals with sensory challenges can also participate. It is through these facilitators of inclusion and participation that individuals with IDD can fully experience and engage.

Staff play an integral role in the inclusive practices at informal education centres. Given the integral role that staff of informal education centres play in the inclusion of children with IDD, it is necessary that staff and volunteers receive training for neurodiverse visitors to be able to both recognize and implement resources, supports, and strategies to achieve inclusive spaces (Coffey, 2018). Despite research that has been conducted on staff training, there continues to be a gap in understanding what staff training consists of, and staff perspectives on available training in support of children and families with IDD. For example, children with IDD, such as ASD, may not always be visually or behaviourally identifiable by museum staff and volunteers due to barriers in understanding or staff training (Kulik & Fletcher, 2016). Given the role and value of museum staff members, this lack of knowledge or training may result in uncomfortable visits for families of children with IDD who may feel judged or criticized for their child's behaviour, as it may be thought that the behaviour is a result of a child misbehaving or due to poor parenting strategies (Kulik & Fletcher, 2016). Additionally, a second study also found that museum staff members have difficulty identifying individuals with

disabilities due to lack of training and knowledge about the needs of individuals with disabilities (Chiscano & Jimenez-Zarco, 2021), which further impacts their availability to support a child's experience of inclusion and participation at informal learning centres. A study examining the facilitators and barriers to accessibility and inclusion for visually impaired individuals at a museum revealed that lack of knowledge and unavailability of museum staff hindered individuals' ability to engage meaningfully, while participants suggested that a way to improve this and use staff as a facilitator is through staff training and disability awareness (Argyropoulos & Kanari, 2015). Despite these barriers, staff strive to create environments in which individuals can learn and explore culture, art, heritage, and science by creating educational spaces (Roche et al., 2021).

The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) (WHO; 2007) is a conceptual framework for describing the functioning of children with disabilities across disciplines and settings (Simeonsson, 2009). The ICF-CY provides codes for various domains of functioning and interactions such as body functions and body structures, activities and participation and environmental factors (WHO, 2007). Participation is largely defined by the involvement within life situations while activities are the execution of tasks or actions of the person (WHO, 2007). Participation and activities share nine domains: learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas, and community, social, and civic life (WHO, 2007). The ICF-CY further examines participation through various tasks such as engaging in a daily routine, coping with stressful situations, and self-monitoring one's own behaviours (WHO, 2007). Given the ICF-CY's substantive understanding of an individual's ability to fully participate and be included, the ICF-CY was used as the conceptual framework for this study by both providing the framework of inclusion and participation and providing the narrative or lens through which the results were examined.

This study employs a qualitative descriptive methodology proposed by Sandelowski (2000). Sandelowski (2000) reports that qualitative descriptive studies are useful in providing comprehensive summaries of everyday events using everyday language and terms of those events. Through qualitative descriptive studies, the data is generally described, rather than interpreted, and provides a strong basis in describing phenomena. Using a qualitative descriptive methodology for this research is an attempt at describing if there are inclusive practices in place to enhance participation and engagement for children with IDD, and if so, how the practices are being executed or what may be standing in the way of practices being put in place. Using a qualitative descriptive study facilitates the understanding of what phenomena are directly taking place within these settings (Sandelowski, 2000).

Given the opportunities and challenges that large informal education settings have, such as museums, aquariums, zoos, and science centres (MAZSC) in providing informal learning for children with IDD, it is important to understand the nature of those inclusionary practices and methods most effective for engaging children with IDD. It is therefore central to explore what current facilitators and barriers are in place at MAZSC which may be impacting the participation and inclusion of children with IDD. Access to inclusive educational opportunities is a human rights issue and an ethical issue. Laws dictate that children with IDD be provided inclusive educational experiences regardless of ability.

3.2 Goals and Objectives

Although research has been conducted to determine the perceived needs of staff members working in informal educational settings, a study on the practices that are currently being used for children with IDD at MAZSC in Canada such that they may participate, and experience inclusion, had not been conducted prior to our study. Using a qualitative descriptive approach, the following objective guided our work: determine the practices that are currently being used for participation and inclusion for children with IDD at MAZSCs across Canada.

3.3   Methods

3.3.1   Research Design and Research Team

The research team consisted of JR, a female PhD candidate in the field of school and applied child psychology, Dr. NN (PhD), a female assistant professor with Western University, and Dr. AP (PhD), a male assistant professor at Western University. All three members of the research team have previous experience with research and have taken courses in statistics and research methods. The relationship with the participants controlled for bias as much as possible; no previous relationship with the participants existed, and the participants knew only that the interviewer (JR) was a doctoral candidate at Western University under the supervision of Dr. NN. No interviewer characteristics were provided to the participants.

This study employs a qualitative descriptive methodology (Sandelowski, 2000) by providing a comprehensive summary of everyday functioning and events within MAZSC in Canada. This study consists of collected data through interviewing staff members from multiple informal educational organizations, in which the interviews centered on the informal education setting. An interview protocol of predetermined and piloted interview questions was utilized. The interview questions were initially piloted, modified, then edited for clarity with a classroom schoolteacher, a faculty member, and a graduate student all of whom have considerable experience working with children with IDD and their families. Piloting the interview allowed for revisions based on the feedback received, as piloting increases the relevancy and validity of the interview questions and the interview process as a mode of data collection (Vogt et al., 2014). During this study, the primary researcher (JR) completed the coding and categorization of the data. Further, journaling was completed in an effort to reduce researcher bias, and frequent conversations with a research supervisor were completed to increase reliability. Emergent themes were reviewed and discussed, after which further coding and categorizing took place prior to the final themes emerging to ensure accuracy of results. Lastly, journaling was completed in an effort to reduce researcher bias, and frequent conversations with a

research supervisor were completed to increase reliability. Additionally, the interview questions were initially piloted, modified, then edited for clarity with a classroom schoolteacher, a faculty member, and a graduate student all of whom have considerable experience working with children with IDD and their families. Piloting the interview allowed for revisions based on the feedback received, as piloting increases the relevancy and validity of the interview questions and the interview process as a mode of data collection (Vogt et al., 2014).

To understand the complex social phenomena occurring within these settings, we conducted semi-structured interviews with a mid/senior staff member from each of the MAZSC. The ICF-CY (WHO, 2007) both informed the development of the research object and will be used as a lens through which the results are examined, given its strong advocacy and lens through which children are able to fully participate and be included.

3.3.2   Participants

Participants were recruited using purposive sampling. Participants met the following inclusion criteria: mid/senior level staff member working for a MAZSC in provincial capital cities, the national capital city of Canada, or cities with populations greater than 300,000 with knowledge of their organization's day-to-day and longer-term public facing programing matters. These cities were chosen in order to access major Canadian centers who are more likely to have policies, procedures, and practices in place to support children and families with IDD visiting their sites. Advertising e-mails were sent to e-mail addresses located on the websites of MAZSCs. A total of 32 sites were invited to participate via e-mail between April 12-May 11, 2021. Ten participants, each representing a different MAZSC, agreed to participate in the study. The positions held by staff within the MAZSC varied from curators and curatorial assistants to education officers, and program coordinators. One participant worked as a chief executive officer. Interviews were conducted as each participant was recruited; however, recruitment was completed once data saturation had been obtained during which no further interviews

would have provided additional categories and themes, and the study had become replicable (Creswell, 2011; Fusch & Ness, 2015).

Of the 10 informal sites, six sites were museums, two sites were science centres, one site was a zoo, and one site was an aquarium. Of the museums, a third of the museums were children's museums (33%, n = 2). Additionally, half of the sites were within Ontario (50%, n = 5), with the remaining sites located within British Columbia (n = 1), Alberta (n = 1), Saskatchewan (n = 1), Manitoba (n = 1), and Nova Scotia (n = 1).

3.3.3   Procedure

Institutional Review Board approval for the study was obtained on March 17th, 2021. All participants were e-mailed the consent forms for participation prior to the interviews. At the onset of the interview, the consent forms were reviewed, and verbal consent was obtained prior to the start of the interview.

Interviews with the 10 participants spanned between April 15, 2021 and June 16, 2021. The interviews were approximately 30-60 minutes in length and were composed of seven questions in total. Eight of the interviews were conducted over video conference (Zoom) and two interviews were conducted by telephone and were either video or audio recorded as appropriate. A semi-structured interview protocol was developed to explore the facilitators and barriers to participation and inclusion of children with IDD at MSZSC in Canada, including questions related to the site (e.g., *what aspects of your organization/services can create barriers for the child?*), staff understanding (e.g., *what is your understanding of intellectual and developmental disabilities?*), and staff experiences of facilitators and barriers within the informal education setting (e.g., *Tell me about an experience you thought was successful in terms of including a child with an intellectual or developmental disability – what elements contributed to the success of the experience?*).

3.3.4   Data Analysis

The recorded interviews were transcribed verbatim, re-checked for accuracy, and then coded using descriptive and *in vivo* coding (Saldaña, 2016) to identify categories and themes. In conjunction with descriptive and *in vivo* coding, the ICF-CY framework was also utilized as an analytic lens to the developed categories from the staff interviews. During descriptive coding (Figure 2), the data is summarized with a word or short phrase which summarizes and encompasses the subject of the interview while *in vivo* coding (Figure 3) uses the language of the interview itself to ensures the voices of the participants emerge in the codes and themes (Saldaña, 2016).

Figure 2: Example of Descriptive Coding Strategy

[The] process is that you want every	Process
exhibit to be engaging for anyone…what	Exhibit
we're really looking for is engaging	Engagement
everybody. So, it doesn't matter…what	
your [chronological] age is, it doesn't	Chronological age
really matter if your development is	Development
typical or not…everything is designed to	Design
have an entry point where everyone can	Entry point
access it.	Access

Figure 3: Example of *In Vivo* Coding Strategy

[The] process is that you want every	Want every exhibit engaging
exhibit to be engaging for anyone…what	
we're really looking for is engaging	Looking for engaging everybody
everybody. So, it doesn't matter…what	Doesn't matter chronological age
your [chronological] age is, it doesn't	
really matter if your development is	Doesn't matter if typically developing
typical or not…everything is designed to	
	Designed so everyone can access

have an entry point where everyone can

access it.

The first two interviews were manually transcribed by the first author (JR). The remaining eight interviews transcribed with the aid of transcription software Amberscript (2021) and Otter (2021). After the initial transcription, the first author then listened to all 10 recordings a second time and reviewed each transcript for accuracy. As each interview and transcription was completed, transcripts were uploaded to NVivo software (v.12.0) for data analysis. An initial analysis of each transcript was conducted prior to completing the next interview, as a means of preparing for subsequent interviews by reviewing the language in the interview questions and gaining the terminology used at each site. The interviews were analyzed using descriptive and *in vivo* coding (Saldaña, 2016) simultaneously. Upon completion of the interviews and data analysis, the interviews were examined further to ensure accuracy of codes and emergent themes and to confirm data saturation (Creswell, 2011; Fusch & Ness, 2015). The analysis was completed by the first author and then codes and themes were reviewed and discussed by the first and third authors (JR and AP). During each pass of coding, categorizing, and theme development, the first and third authors reviewed, merged, and collapsed categories until the emergent themes were true representations of the data.

3.4 Results

In line with the focus of the semi-structured interviews, the analyses revealed three themes exploring the facilitators and barriers to inclusion and participation for children with IDD: (1) Profiles of children's learning and engagement, (2) Facilitators toward participation and inclusion, and (3) Barriers to participation and inclusion.

Theme 1: Profiles of Children's Learning and Engagement

The first theme was developed from the following codes: accessibility based on chronological and developmental age, providing alternative ways of thinking, challenging staff to think outside the box, focused/unique interests, individual differences, multi-

modal methods of learning, challenges experienced by children with IDD, benefits from accommodations, and excitement toward learning and participation. This theme explored the varying strengths, needs, and methods of learning of children with IDD identified by MAZSC staff (Table 6). Staff identified areas of overall strength in children with IDD, such as alternative ways of thinking and individual and unique differences, while they also identified areas of need or areas in which children with IDD may need additional support: with communication and language, focusing not on chronological age, but on developmental age, behavioural control, sensory needs, and transition times. For the staff at informal settings, children with IDD provide, and provoke within staff, alternative ways of thinking about the learning at informal sites. One staff member reported children with IDD *bring kind of a whole other perspective to something you know that they are learning about.* Furthermore, staff members recognize that each child has a unique profile, and these must be considered to enhance their learning experience. Acknowledging that *because somebody has an intellectual disability doesn't mean that it's a one size fits all,* a staff member at a museum described they would inquire directly to the individual or their caregiver to best serve them rather than taking a standardized approach.

Related to this, staff described that accessibility at informal educational settings is most effective when targeting developmental age in lieu of chronological age regardless diagnosis. A staff member a children's museum indicated that exhibits are designed to be engaging for all developmental levels to promote inclusion and participation. The staff member further stated that *it doesn't matter what your [chronological] age is...everything is designed to have an entry point where everyone can access it.*

Within MAZSC, the interviews revealed that children with IDD experience diversity in communication and language, diverse behaviour, diverse physical accessibility needs, social accessibility needs, and cognitive accessibility needs. As an example of a physical accessibility need, a staff member stated that *if it's someone who has wheelchair, and there [are] many small chairs that keep moving around...it's always going [to be] an*

obstacle for them. In this, the staff member highlighted the need for diverse physical accessibility options to accommodate the diverse needs of their visitors. Sensory challenges and difficulties with transitions were frequently cited across the interviews. To support the individual differences and needs of children with IDD visiting their sites, staff explained the benefits these visitors have when receiving accommodations, including using assists, routine and structure, scaffolding, and having an opportunity for unstructured programming and free play:

> In our experience [kids] who come with intellectual disabilities get the idea of…
> [the information we share]. So, it's just about accommodating their
> scaffolding…rather than changing the program altogether.

Another staff member at a participating site cited:

> I'd say most of our assists or resources…are for kids and their toys are play-based,
> either to facilitate a good learning environment or a good learning attitude
> atmosphere for the person, or something or another way to get them engaged.

When provided with the necessary accommodations or assists to participation and inclusion, staff indicated that children with IDD demonstrate excitement toward learning and further participation. Children with IDD visiting informal educational settings learn and engage with the materials at the sites in numerous and varied ways. Informal educational setting staff reported a variety of learning styles, including child-led learning and inquiry-based learning. This staff flexibility toward accommodating individualized needs encourages the individual with IDD to learn at their own pace which further increases participation and engagement with materials and learning. Additionally, when designing exhibits, staff members take into consideration numerous aspects for visitors including participation and inclusion:

> There [are] always multiple educational outcomes that [are] in our minds when
> we design the exhibits, but the kids always surprise us with how they use the

exhibits and it's all about free play and open-ended play and loose parts and using it however they want to use it, engaging however they want to engage.

Table 6: Profiles of Children's Learning and Engagement

Strengths	Needs	Methods
Alternative way of thinking	Targeting Developmental Age	Assists
Individual and unique differences	Communication and Language	Routine and Structure
	Behavioural Control	Scaffolding
	Physical, Social, and Cognitive Accessibility	Free Play and Child-Led Learning
	Sensory	Play-Based
	Transitions	Inquiry-Based Learning
		Learn at Own Pace

Theme 2: Facilitators toward Participation and Inclusion

This theme was developed from the following codes: additional staff available for camps, free admission for support persons, options for families, assists to facilitate participation, offering quiet space to families, providing choice to children with IDD, literacy accessibility, and receiving feedback. This theme explored the nature of facilitators to participation and inclusion for children with IDD found within the MAZSC setting (Table 7). At a systems level, staff reported that informal educational settings provide staff for added support when available, to speak with the child or caregivers directly about their needs and the ways the facility can meet their needs. Staff reported that with advance notice, MAZSCs can often tailor the experiences. For, example a staff member reported that *if there was a child who got overstimulated very easily, the interpreter would be able to offer less animated tour, maybe at a slower pace…talk a little with more [simplified] language.* On occasions where a child needs a calming environment because of a triggering experience or because of sensitivity to sensory stimuli, MAZSC staff indicated that they were able to offer a private room for support. This environment can help to decrease sensory overload for children and families. *So, if we see…the kid is having*

meltdown, we could …go to [their] parents, and [ask] 'there's a classroom right there, would you rather be in an enclosed room?'

Staff spoke of creating a positive learning environment, providing physical assists, and providing cognitive assists. For example, a staff member of a museum stated that to accommodate sensory overload, facilitators such as noise cancelling headphones, weighted blankets, tinted glasses, and fidget toys within a sensory kit are offered. Another staff stated that *if we knew in advance, there are lots of things that we could do to tailor the tours. So, for hearing impaired we have visual aids. We have microphones that can be worn. We have virtual tours that can be shown for areas that are physically inaccessible.* Additionally, the interviews revealed that many MAZSCs have a variety of materials available for children with IDD. As one staff member at a museum stated, *we do have lots of parts of the tour that are tactile…things that you can handle and touch and look at and inspect up close. But we can probably bring more out if we knew in advance.* Staff also reported that providing visual and tactile aids throughout the facility's physical spaces including exhibits and interactive learning areas. Additionally, a staff member reported that they enhance visitor experiences during interpretive sessions by appending the oral presentations with visual aids such as cards with pictures and artifacts. *And we'll show them a picture before we use it, or we can give it to them to use to show us what they need if they're non-verbal, because really you just give them an extra tool to be able to communicate with us.* Staff also reported that they have a variety of resources at hand to both alternatively engage children with IDD to the intent of the visit and calm them or act as a distractor when they are overwhelmed. In addition to more planned and structured facilitators, staff also spoke about in-the-moment experiences that they had with children with IDD and their parents to facilitate accessibility, participation, and inclusion. For example, one staff reported that they *print out pictures [or] visual schedules for the day for that child to know what's likely coming next* upon request from a caregiver of a child with ASD. Children with IDD frequently benefit from a support person. At all participating sites, support persons are not required to pay an admission fee for entry into the setting, and caregivers and families are further provided the opportunity

to engage in pre-visit tours to determine whether the site is suitable for their children with IDD.

Accessibility promotes learning and engagement with the materials at informal educational settings. Given that the needs of children with IDD are diverse, accessibility in promotion of learning is also diverse and requires adaptability and diverse resources. Additionally, accessibility from staff and the physical structures impacted the participation and inclusion for children with IDD. A museum staff member reported that:

> I think we're quite an open and welcoming place, there certainly are in our galleries um, you know organizations and families that come very regularly with their… with adults and children with intellectual disabilities but I think we're generally a pretty welcoming place.

Furthermore, there were reports from participants that indicated that the physical sites had previously undergone renovations, are currently undergoing renovations, or will be undergoing building renovations in the future to improve accessibility. This, in conjunction with researching methods of improving and increasing accessibility provides reassurance that MAZSCs are committed to creating a space of inclusion and opportunity for participation for children with IDD. Staff also reported seeking out feedback from agencies, families, and accessibility committees to further improve accessibility:

> One of the committees that helped us to…design our exhibits was an accessibility committee so that was really good…The sensory kits were one thing that came from that committee, and another thing that came [was] the distinction…that there's no need for you to put an age on [exhibits] because I shouldn't feel bad about bringing a child who's still having fun here if they're 16. If this is still the right place for them, then you putting the ages on there, it's going to make it the wrong place for them.

Moreover, staff expressed a willingness to make accessibility a continued goal and expressed a desire to continue improving upon current accessibility strategies both on the

site level and at the visitor level. In addition to improved accessibility, children with IDD benefit from accommodations. For some children with IDD, they exhibit externalizing or acting out behaviours due to various triggers. One such trigger that was often identified by staff was sensory overwhelm. To accommodate children with IDD experiencing overwhelm due to sensory stimuli, the following was stated:

> I remember someone actually came to see me and said, 'we're trying to find parking. My kid is on the spectrum. I don't even know if he's going to like it'. But the wait in line to have a ticket was an hour and a half. And I had these members tickets, and I just…said 'here,' and I just gave her the tickets to go inside the museum. And she just gave me this huge hug. [I told her], 'don't do the lines, just have fun and go and play'. And then because it's likely with all the noise that they won't stay for long anyway. And I didn't want the kid's first experience to be a bad one.

The staff willingness and flexibility to support children with IDD and accommodate their individual needs was rooted in a desire to make informal education settings fully inclusive regardless of ability level; however, conversations between staff and management regarding the definitions of inclusion or participation varied:

> So, I don't know a lot and I think that people in decision-making roles know even less, often, so like the education just [isn't] there so for me—of course we would try and make accommodations for everybody no matter who they are or what the accommodation is because we wouldn't question making an accommodation for a person with a physical disability, but when it came to you know intellectual disabilities it was a different conversation.

To best serve the visitors' needs, communication between the staff and the caregivers or support persons are integral. Furthermore, flexible accommodations provide individualized support to the visitor depending on their needs. Sites can provide multi-

modal accommodations for cognitive, physical, mental, and social domains of functioning.

Table 7: Facilitators for Participation and Inclusion

Facilitators	Example
Additional staff available for support	Extra staff to support children who are experiencing sensory overwhelm
Calming environment	Extra classrooms for a quiet space
Adaptability and diversification of resources	Partnering with community agency, diverse assists, or fidgets
Physical site improvements promote inclusion and participation	Signage with audio, braille, or written language
Staff attitudes and curiosities in creating accessible spaces	Staff curiosity about designing spaces that are accessible beyond physical accessibility
Communication between informal education setting staff and parents/caregivers	Visual aids, microphones, interpreters
Flexible accommodations	Key rings, visuals with pictures of washrooms, supporting non-verbally

Theme 3: Barriers to Participation and Inclusion

This theme was developed from the following codes: advertising focuses on physical accessibility, requiring a child to be present for admission, challenges in not knowing visitors, managerial barriers, employment barriers, inability to control sensory environment, lack of support staff, lack of facilitators, lack of developmentally appropriate programming, physical environment, high sensory environment, and finances. Although informal sites and their staff strive to provide an inclusive setting, barriers were noted throughout the interviews (Table 8). Some barriers identified include

physical site barriers, bureaucratic barriers, budget and administration barriers, and policies and/or attitudes toward policies as a barrier.

For examples, at times, sites are unable to control the sensory environment which leads to barriers to accessibility. Sites which have live animals on-site have challenges controlling the sensory environment:

> Our demonstrations happen in the aisle of a barn which aren't very wide so it's…a lot of people kind of all smooshed together in a small space all trying to hear the guide that is just speaking. We don't have a mic system or anything like that… it was a bit hard to hear guides just even with the fans going, the animals going, and then of course visitors.

Similarly, another staff member indicated that they have difficulty controlling the sensory overload for children with IDD the times when the facility is extraordinarily busy. The staff member stated that*, especially during like March break…people in the building…come in and then they've left right away or complained…that it's too busy for them.* This also prompted the staff member's facility to offer dedicated hours of quiet visit for children with IDD and their families.

Furthermore, for individuals for whom reading, or English is a barrier, it was noted that signage is a barrier due to it being unilingual or written without it being paired with either images or audio options. Both site and visitor finances were cited as barriers to inclusion and participation for children with IDD. Due to site financial barriers, hiring additional support staff and providing comprehensive training in working with individuals with IDD is an overarching barrier to inclusion and participation. *As much as we'd love to have a dedicated person on site that is specifically trained to work with people with an IDD [intellectual and developmental disability] or the resources to have someone even in the office to kind of consult on accessibility for people with IDD… and then just with our visitorship being down and the amount of programming that we can offer being drastically reduced, financially it's not something that's feasible.* Another MAZSC staff

noted that there are often hurdles and barriers to overcome with senior managers and administrators in offering additional services at no extra cost to the visitors, including children with IDD. The staff member stated that they *pushed up from the bottom and we actually faced a bunch of barriers about why [we] would offer specific programming for one specific group of people, are we going to charge extra fees for the amount of resources that we're spending.*

Lastly, site advertisements of accessibility and public awareness were described as a barrier to inclusion for children with IDD. Staff from all the sites noted that the informal educational site website had a description of physical accessibility, but that more information regarding programing and facilitators were not readily available on the website. As a result, parents or caregivers would be required to contact the site individually to inquire about facilitators or accommodations to inclusion and participation. A science centre staff member noted that further training is planned at the site which may improve accessibility advertising and public awareness:

> There's really not much. Like visiting our website or coming in – if they are coming in-person, we give them the opportunity to check things out on their own, but if they go to our website or find us through anything else, there's really nothing there other than I think it says we're wheelchair accessible. I think that's about all it says online, which is something with the training we're doing, we're hoping to work on that a bit more.

Table 8: Barriers for Participation and Inclusion

Barriers	Examples
Bureaucratic and administration	Barriers in offering specific programming due to costs
Site and visitor finances	Reliance on government funding, cost of attending MAZSC

Advertisement	Inclusion advertising lacking; focus on physical accessibility alone
Communication through signage	Signage primarily in English; disadvantaging individuals who are deaf or hard of hearing, or who are English Language Learners
Sensory overload	Crowds, lighting, loud sounds

3.5 Discussion

This study was a qualitative descriptive study of the facilitators of barriers to inclusion for children with IDD at MAZSC across Canada. The study revealed three themes: *profiles of children's learning and engagement; facilitators toward participation and inclusion;* and *barriers to participation and inclusion.* Each of the participants from all informal sites shared the methods of learning for children with IDD, their individual differences in both strengths and areas of need within an informal education setting, and the facilitators and barriers to full inclusion and participation within the sites. The ICF-CY (WHO, 2007) uses a two-level classification which examines participation which examines body functions and structures, activities and participation, and relevant environmental factors. Body functions and structures, and activities are participation are classified within the components of functioning and disability while environmental factors are further positioned with the components of contextual factors (WHO, 2007). Within this study, theme one of the *profiles of children's learning and engagement* falls within components of functioning and disability, while themes two and three fall within the components of contextual factors. For example, although the themes within this study were not mapped directly onto the one-level or two-level classification within the ICF-CY (WHO, 2007), *profiles of children's learning and engagement* overlaps with body functions (i.e., mental functions, sensory functions, voice and speech functions), and activities and participation (i.e., learning and applying knowledge, general tasks and demands, communication, mobility, self-care, interpersonal interactions and relationships, major life areas, and community, social and civic life). Themes two and three, *facilitators toward participation and inclusion;* and *barriers to participation and*

inclusion, fall within the contextual factors, or environmental factors (i.e., products and technology, natural environment and human-made changes to environment, support and relationships, attitudes, and services, systems, and policies). The ICF-CY (WHO, 2007) was utilized as the framework through which this research questions and interview questions were developed, through the understanding of inclusion and participation through the lens of the ICF-CY; however, it was not utilized for specific coding purposes within this study. Given the results of the study, however, staff may have adopted the ICF-CY's model of inclusion and participation through their own experiences, training, or personal experiences which demonstrates that the cultural within MAZSC and potentially other informal educational settings is changing to provide more inclusive spaces for individuals with IDD.

Children with IDD have diverse needs in accessing MAZSC, including challenges in the following domains: (1) accessibility and mobility challenges, (2) communication challenges and nonverbal needs, (3) externalizing behaviours including impulsivity or disruptive behaviours, (4) challenges transition between tasks, (5) challenges with social cues or sitting still during quieter times, and (6) sensory challenges. The ICF-CY (WHO, 2007) outlines that accessibility, communication, social life, and relationships are integral in experiencing inclusion and participation. Given the diversity of these needs at MAZSC for children with IDD, numerous and diverse facilitators provide a higher degree of inclusion and participation. The facilitators found within this study are congruent with other factors found to facilitate inclusion within the literature. For example, facilitators are factors which increase inclusion and participation and ranges from family support, peer involvement, improved opportunities, availability of skilled staff, improved access to information and its dissemination, attitudes toward acceptance and inclusion, physical sites or objects, and adaptable approaches and accessibility of sites (Shields et al., 2012; Shields & Synnot, 2016).

Assists to facilitate play-based opportunities, a positive learning environment, prompts and interpretive assistance, and individual puzzles or fidget tools provided children with

IDD the opportunity to participate more inclusively at informal education settings within this study. Specifically, for support in sensory challenges, some sites offered noise-cancelling headphones, sensory kits which included facilitators such as weighted blankets or tinted glasses, to name a few. Some sites were able to provide quiet spaces to families to provide calming environments, light reduction in spaces, or reduced sensory hours of operation to decrease sensory overload. To facilitate literacy accessibility, sites offered facilitators such as nonverbal supports, visual assists, scribes, or video and/or audio signage. Given the diverse communication needs of children with IDD, study participant described barriers in signage at MAZSC. For example, some sites presented monolingual signage, while other sites have exhibits which require visitors to read to consume the information. In support of challenges with transitions, facilitators included providing breaks, visual schedules, and flexibility in staff attitudes and approaches to provide choice and individualized opportunities for children with IDD. Additionally, some sites were able to provide additional staff to support children and families with IDD when funding was not a barrier at the site. In an inclusion study examining the facilitators and barriers of inclusion at a university, similar facilitators were found; providing space with attention to students with disabilities, the positive attitude of employees within the university, and providing training opportunities to increase knowledge of supporting individuals with disabilities (Sanchez-Diaz & Morgado, 2021).

To further support inclusion and participation, advertising accessibility played a role in communication with parents and caregivers of the inclusion opportunities for IDD. Sites offered website advertising, social stories, and pamphlets to communicate the diverse opportunities offered from the site. However, some sites also had gaps in advertising accessibility and noted that some advertisements focused on physical accessibility. To overcome this barrier, front desk staff at the sites are the individuals who provide information to parents or caregivers wishing to know about inclusive opportunities within their site. Further, some sites provide pre-visit tours for families who wish to determine if the site is suitable for their child with IDD. Lastly, to continue supporting families of children with IDD, numerous sites were undergoing or had undergone renovations to

improve accessibility and had received input from accessibility committees and families of children with IDD to increase inclusion capabilities.

Although full inclusion and participation is a human right (United Nations, 2020), barriers continue to exist for children with IDD in being fully included at informal education settings. A study examining social inclusion within Egyptian museums found that, although laws require accommodations in support of individuals with disabilities, political stances and public discourse continue to serve as barriers to accessibility (Zakaria, 2020). Furthermore, despite anti-discrimination legislation within the United Kingdom and the United States, attitudes continue to be a barrier toward inclusion for individuals with disabilities (Walters, 2009). Within this research, this was particularly highlighted in a museum in which managerial staff and administration pushed back against staff members wanting to provide specific programming. While this was, in part, due to lack of resources and financial burden, the attitudes of the administration and managerial staff also served as barriers toward inclusion. Additionally, Bedell and colleagues (2013) discussed that children with disabilities are less likely than their typically developing peers to participate in unstructured community activities and therefore would benefit from opportunities for social participation. As such, opportunities for children with IDD to participate and experience inclusion through facilitators is paramount. Although the ICF-CY (WHO, 2007) views community engagement through education and recreation as a necessity for inclusion and participation for children with IDD; barriers to participation also continue to exist at informal education settings across Canada. For example, language barriers, physical barriers, and financial barriers continue to exist. Participants identified that site and visitor finances could be a barrier at times, depending on government funding, seasonal demands, budget and administration, and admission costs. Although support persons at all sites are not required to pay for admission, the cost of admission for children or families was viewed as a potential barrier.

Staff members are pivotal facilitators at informal educational settings and play a substantial role in both inclusion and facilitation of learning and engagement. Children with IDD, when visiting a MAZSC, may not be easily identifiable by staff members depending on the individual (Kulik & Fletcher, 2016). When individuals with IDD are not identifiable, either through lack of knowledge or lack of training, families of children with IDD may feel misunderstood, excluded, or potentially even judged if their children's behaviour is not on par with the expected behaviour of a child that age (Kulik & Fletcher, 2016). A qualitative study with individuals with invisible disabilities at public libraries revealed that participants suggested that posters, signs on doors, or allyship messages on name badges would provide support for individuals without the need to self-disclose their need for assistance due to disability (Muir et al., 2019). For families to experience acceptance and inclusion, staff and volunteers require training, would benefit from opportunities for learning and access to resources specific to IDD, and could better serve families of children with IDD at their centres through signage indicating awareness about disabilities.

Some sites identified that additional support staff at the sites would provide greater opportunity for inclusion and participation of children with IDD; however, budget and administration acted as barriers. Furthermore, while all sites identified facilitators to participation, not all participating sites had a policy to support accessibility or inclusion of children and families with IDD. Lack of policies also presents as a barrier. Sites which had a policy on inclusion often centred around physical accessibility. The lack of policy focusing on inclusion and participation, and policies focusing exclusively on physical accessibility, further led to managerial barriers when staff sought to seek changes in support of children with IDD in accessing their site. For example, for some staff members at sites, the desire to implement specific sensory-reduced hours received pushback from managerial staff due to concerns regarding costs of changes in programming to accommodate these needs, and due to a lack of policy on how to implement such changes.

Despite the barriers present at MAZSC across Canada, staff expressed the desire for learning and change to create informal education sites which are fully inclusive and accessible for children with IDD. Furthermore, staff spoke of hopes for the future which included improved communication strategies through audio, video, or digital signage, staff hiring, increased physical spaces for improved programming, and the development of more available quiet spaces in support of children and families with IDD. A relevant note is that individuals responding to this research may also represent the staff members with the greatest interest and knowledge of inclusive practices within the MAZSC. The staff members discussed the facilitators, barriers, and methods of learning and engagement of children with IDD visiting their sites; however, despite individual desire or knowledge of current practices, staff members also implicitly discussed institutional barriers present at the sites. Results of this study demonstrate that staff members work hard to provide inclusive opportunities despite institutional barriers which are present. While staff identified facilitators toward inclusion and participation, there remains opportunities to implement facilitators at the institutional levels which may further provide inclusive opportunities, such as advanced ticket purchases, front of line passes, and companion restrooms. Walt Disney World (2022), as an example, provides both services and strategies for guests who have cognitive disabilities who otherwise may not be able to have a meaningful or enjoyable experience. Presenting options such as these at MAZSC provides greater opportunities and eliminates some barriers to participation which may otherwise exist for children with IDD.

3.6 Implications

The interviews with staff demonstrated a genuine desire and enthusiasm to continue removing any barriers for children with IDD in accessing informal educational opportunities. The implications of this research point to the strides that have already been taken to remove barriers for children with IDD in accessing informal educational settings and the progress which still needs to be made before sites can be considered fully inclusive and participatory.

All MAZSC can provide fully inclusive spaces by conferring with other sites to determine what facilitators have been successful, or to understand what barriers remain in place which need to be removed. Indeed, during the conversation with the staff it was common to hear that the conversation itself generated ideas for the informal site to be able to implement. Staff desire to implement new ideas and strategies in support of families and children with IDD was evident.

Lastly, more research is needed to examine the specific role that policies can play on providing a more inclusive space for children with IDD at informal settings to participate in. These policies can enhance the practices and procedures in place at inclusive education sites in breaking down the barriers that otherwise may be experienced by this population.

3.7 Limitations

There are several limitations associated with this study. First, this study centred on MAZSC at provincial and national capitals, as well as cities with populations greater than 300,000 individuals. As such, informal sites such as camps, or MAZSC in cities outside of capital cities or cities with less than 300,000 people were not included at the study. This, then, omits cities which may have smaller populations, but higher foot traffic at these informal education settings. A more diverse study including various programming options, such as day camps or other recreational settings which may provide informal educational opportunities is recommended for further research studies. Second, informal education settings outside of Canada is recommended to provide a more diverse understanding of the facilitators and barriers to participation internationally. A third limitation is that the participants of the study were staff members of MAZSC in Canada. Therefore, information regarding managerial barriers may be better addressed from staff at that level within the organizations. Furthermore, the study relied on one staff member per site to gain information and an understanding about the methods of engagement, facilitators, and barriers to participation and inclusion. Interviewing more than one staff member could provide more corroborating evidence and potentially provide additional

information for future studies. Recommendations for future research also include interviewing site visitors such as families and children with IDD to gain further perspectives on learning and engagement, facilitators, and barriers to participation, as well as site visits by the researcher.

3.8 Conclusion

The findings of this study illuminate the facilitators and barriers to inclusion of children with IDD at MAZSC in Canada. Understanding the facilitators and barriers provides a platform for continued research into providing a human right for children with IDD in accessing informal educational opportunities more fully. This study provides context to the diverse facilitators which are currently providing a fully inclusive opportunity for this population and provides an understanding as to the barriers which need to be addressed. The findings of this research can be used to identify barriers and ways to reduce or eliminate these barriers so that children with IDD can engage more fully in an inclusive educational experience.

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Chapter 4

4   Staff Training at Informal Learning Settings to Support
     Children with Intellectual and Developmental
     Disabilities and their Caregivers

Informal learning settings such as museums and aquariums play an integral role in the

educational experience of children. The staff of informal learning settings have

responsibilities in creating accessible sites in which all children can participate. This

study examines the nature of staff training at informal learning settings to support

children with intellectual and developmental disabilities (IDD) and their caregivers

during visits. Ten staff members of informal learning settings across Canada completed

semi-structured interviews revealing three principal themes: leveraging staff diversity in

supporting families and children with IDD, staff training opportunities, and staff training

barriers. Findings support the diverse backgrounds of staff members at informal learning

settings. Barriers to staff training for this population were illuminated, indicating the need

for further research and support in this area.

4.1   Introduction

Large informal learning settings, such as museums, aquariums, zoos, and science centres

(MAZSC), are institutions in which learning occurs outside of formal educational

classrooms (Spencer & Maynard, 2014). Informal education experiences play an

important role in developing children's interests and career aspirations. For example,

literature suggests that the way in which families and caregivers interact with and discuss

the educational components of MAZSC can improve a child's learning in areas such as

science, technology, engineering, and mathematics (STEM; Haden et al., 2014; Haden,

2010). Family interactions which take place in these informal settings are also associated

with STEM achievement in formal educational settings (Duncan et al., 2007; Tenenbaum

& Callanan, 2008; Tenenbaum et al., 2005).

MAZSCs are increasingly recognizing the importance of inclusion of people with disabilities. For example, Inclusion 2025 is a guide in which individuals are introduced to the principles of diversity and inclusion, provided with resources for diversity and inclusion, and provided with examples of museums within Ontario, Canada which are considering what inclusive practices look like (Ontario Museum Association, 2022). Similarly, the University of Toronto Libraries Research Guide (2022) provides resources within museum studies which support equity, diversity, inclusion, and accessibility. Additionally, the American Alliance of Museums provides resources for diversity, equity, accessibility, and inclusion through a working group which strives to examine museum practices toward inclusion (2022). Despite this, although MAZSCs have made strides in the areas of diversity and inclusion, children with IDD continue to experience barriers engaging with and learning from exhibits, programming, or general visits at MAZSCs.

Intellectual and developmental disabilities (IDD) are characterized by limitations in intellectual and adaptive functioning within the conceptual, social, and practical domains, and in varying levels of severity (American Psychiatric Association, 2013). It has been well documented that individuals with IDD experience social exclusion (Amado et al., 2013; Brown et al., 2013; Linton, 2006) and studies also indicate children with IDD often experience barriers at MAZSCs (Kulik & Fletcher, 2016; Langa et al., 2013; Lussenhop et al., 2016). For example, Kulik and Fletcher (2016) found that children with Autism Spectrum Disorder (ASD) and their families experienced frustration due to interactions with other visitors. Others report the novelty, unfamiliarity, noises, and crowds act as barriers to visiting MAZSCs for people with IDD (Langa et al., 2013). However, despite these challenges, other MAZSC have sought to implement practices which prevent these barriers toward inclusion, such as hosting sensory-friendly opportunities for individuals with sensory needs (Lussenhop et al., 2016).

Staff members present in community settings play an important role in the inclusion of people with IDD. In a review of environmental factors influencing community participation of people with IDD, Verdonschot (2009), found support from staff

influenced social engagement of people with IDD. People with IDD themselves also indicated the importance of people in the community in supporting inclusion. Abbott and McConkey (2006) conducted focus groups with 68 individuals in supported living or within shared group homes. They identified four barriers to experiencing social inclusion: personal abilities and skills, staff and management, the location of the supported living or shared group homes, and further community factors such as lack of amenities or external attitudes. They noted that people in the community may not respond or talk to them or make them feel included. Further, the lack of support staff and volunteers acted as a barrier to inclusion. Moreover, given that parents of children with IDD experience stigma, they may not receive the necessary supports from the community to feel included (Duran et al., 2018).

There is also evidence of the important role that staff play in inclusion of people IDD at MAZSCs. In a study including 32 individuals with disabilities (including IDD), it was found that staff-visitor relationship acted as a barrier to participation; staff may not consider access and communication needs or may treat people with disabilities differently (Chiscano & Jimenez-Zarco, 2021). Participants felt having to explain their disabilities resulted in exclusion. Further lack of training and knowledge on the needs and wants of individuals with disabilities among managers prevented them from designing inclusive experience (Chiscano & Jimenez-Zarco, 2021). A study investigating the barriers experienced by families of children with ASD visiting a fine arts museum found that responses from staff members were split between staff who expressed a desire to learn more about ASD to ameliorate the experiences of family members visiting and staff who did not feel able to participate in new projects on this topic (Kulik & Fletcher, 2016). It was found that 60% of staff and volunteers within the study had not received any training for working with children with ASD or other needs, while 80% of these participants expressed a desire for training in this area (Kulik & Fletcher, 2016). Despite these gaps in training, staff and volunteers expressed a belief that participation and engagement within the museum setting is important for children with ASD and were desirous of training in topics such as identification of a person with ASD, communication styles, behavioural-

management strategies in support of a person with ASD, and methods of engagement for this population (Kulik & Fletcher, 2016). For staff and volunteers who expressed not wanting to be involved in inclusion programs, it was found that it was due to fear or hesitation in taking on new projects rather than a lack of desire for inclusion, noting that these projects would provide support where there is currently a gap which could be addressed through specific training (Kulik & Fletcher, 2016).

Interventions and resources provided by staff members at MAZSC in the forms of facilitators could assist children and families with IDD in empowering the individual with IDD to have an inclusive experience free from, or with reduced, barriers to participation and accessibility. Only a handful of studies have investigated the experiences of staff as they relate to people with IDD in informal education settings. For example, staff members of a science centre reported a desire for more information regarding ASD, sensory processing challenges, and behavioural management strategies to improve engagement, participation, and inclusion for children with IDD (Leichtman et al., 2014). In a study of parents and caregivers of children and young adults with ASD or Attention Deficit/Hyperactivity Disorder accessing leisure activities or facilities, diverse experiences and concerns were noted, including concerns about staff training, public attitudes, and accessibility (Thompson & Emira, 2011). Leisure activities within this study included activities such as visiting the cinema, going swimming, accessing sport facilities and clubs, or engaging in interest groups and activities (Thompson & Emira, 2011). It was noted that staff training within leisurely activities and facilities could be strengthened through disability equality training in which staff members developed improved awareness of the needs of individuals with disabilities while also challenging assumptions regarding individuals with disabilities (Thomspon & Emira, 2011). These findings are also consistent with other studies (Coles, 2001; Tregaskis, 2003), indicating a need for further research examining the role of staff in supporting individuals with IDD at informal settings.

Tran and King (2007) suggest that lack of professionalization of museum staff members through a recognized set of best practices and body of knowledge limits their ability to interact with all visitors in ways to promote and foster engagement, participation, and inclusion. To address this, Tran and King (2007) provide a framework of six elements for describing the professional work completed by museum staff. These elements include context, choice and motivation, objects, content, talk, and theories of learning (Tran & King, 2007).

To classify disability through the lens of the interaction between an individual and their environment, the World Health Organization (WHO) (2001) published the International Classification of Function, Disability and Health (ICF). Subsequently, the International Classification of Functioning, Disability and Health Child and Youth (ICF-CY) was published and guides assessment and intervention for children and youth with disabilities (Simeonsson, 2009; WHO, 2007). The ICF encompasses two domains: (1) Components of Functioning and Disability which is further broken down into body function, body structures, activities, and participation, and (2) Contextual Factors which is further divided into environmental factors and personal factors (WHO, 2007). Given the importance of participation and inclusion of children with IDD in informal learning settings, the ICF-CY (WHO, 2007) was used as the conceptual framework for this study, with a specific focus on the activities, participation, environmental, and personal factors provided within the assessment tool for children and youth.

4.2 Aim

Although there exist some studies examining the importance of supporting staff for individuals with disabilities (Bates et al., 2020; Chicano & Jimenez-Zarco, 2021; Clifford et al., 2018), a study examining the nature of MAZSC staff training in Canada that supports children with IDD and their caregivers' visits to MAZSC had not yet been conducted prior to our study. Given the important role that MAZSC staff have in providing inclusive learning to children with IDD, understanding staff profiles, backgrounds, and the nature of training they undertake helps to recognize both site

specific and broader MAZSC-wide resources, opportunities, and barriers for professional development related to supporting children with IDD. Therefore, the aim of the study was to explore the nature of training that MAZSC staff receive to support children with IDD and their caregivers during their visits to MAZSC. The following objectives guided our data collection:

A. Describe how staff profiles and backgrounds can be used in support of children with IDD at MAZSC

B. Describe staff training opportunities and gaps at MAZSC in Canada to support children with IDD and their caregivers

These objectives were explored using a qualitative descriptive methodology (Sandelowski, 2000). Qualitative descriptive studies are valuable for describing phenomena which are directly occurring with settings (Sandelowski, 2000). By describing and understanding the general staff profiles and backgrounds pertaining to the support of children with IDD and their caregivers and current staff training opportunities, we may be able to better equip staff members with the resources they need to facilitate a fully inclusive and participatory experience for families of children with IDD.

4.3 Methods

4.3.1 Design

A qualitative descriptive study (Sandelowski, 2000) was used to describe MAZSC staff profiles and the current staff training opportunities related to support of children with IDD and their families. Information was collected through semi-structured interviews. Ethics approval was gained through Western University's Human Ethics Non-Medical Research Ethics Board (March 17, 2021).

4.3.2 Participants

We used a purposeful criterion sampling to recruit participants. From March – June 2021 we recruited participants who were staff members working for a MAZSC in capital cities

within Canada, both provincial and national, and in cities with populations greater than 300,000 individuals with knowledge and experience of the agency's day-to-day organizational structure and programming. These cities were selected for recruitment in order to access larger sites in major cities who are more likely to have supports, policies, and practices in place for individuals with IDD when compared to smaller, or more rural sites. Advertising was sent to 32 MAZSCs using email addresses listed on their public website and via the Canadian Association of Science Centers newsletter. Ten staff members, each representing a different MAZSC, were interviewed. Staff members from six museums, two science centres, a zoo, and an aquarium participated in the study. Regional/provincial representation included British Columbia ($n = 1$), Alberta ($n = 1$), Saskatchewan ($n = 1$), Manitoba ($n = 1$), Ontario ($n = 5$), and Nova Scotia ($n = 1$). Participants were provided with compensation for participation in the form of a $25.00 gift card. The staff members included within the staff worked for the agency in a variety of roles, including curators and curatorial assistances, education officers, and program coordinators. One participant worked in the position of chief executive officer for the agency.

4.3.3 Data Collection

Data were collected through semi-structured interviews conducted by the first author (JR). The interview protocol was initially piloted with three separate professionals with extensive experience working with, and supporting, children with IDD: a classroom schoolteacher, a universal faculty member in occupational therapy, and a graduate student. The pilot occurred six weeks prior to the submission for ethical approval to ensure time for revisions. From this pilot, interview items were modified to ensure inclusive language, excluded if items were not applicable to answer the research question, or included if appropriate to the study. Table 7 provides details of the interview questions pertaining to MAZSC within Canada which explore the general staff profiles, educational backgrounds, and staff training opportunities in support of children with IDD and caregivers during visits to MAZSC settings across Canada.

Following recruitment, an interview date and time was arranged. Consent forms were e-mailed to the potential participants. Prior to the start of each interview, consent forms were reviewed, and verbal consent was obtained. Interviews were completed with participating staff members through videoconferencing or through the telephone and were approximately 30-60 minutes in length (mean = 43.15 minutes).

Table 9: Interview Questions and Prompts

Primary Interview Questions	Probing Questions
What is your understanding of IDD?	Tell me about your perspectives on the strengths and needs of someone with IDD.
Tell me about an experience you thought was successful in terms of including a child with an IDD.	What elements contributed to the success of the experience? What aspects of the environment supports a positive experience for a child with IDD? How would you improve the experience?
Tell me about an experiencing you thought was challenging in terms of including a child with an IDD.	What elements contributed to the challenges of the experience? What aspects of the environment created barriers for the child with IDD? How would you improve the experience?
Imagine a parent or caregiver who has a child labelled with an intellectual or developmental disability is visiting your site to see if it would be suitable for the child or not. How would that person know if your program is an inclusive program which has facilitators to participation for children with IDD?	What facilitators do you have available that you could provide to parents/caregivers of children with IDD?
What aspects of your organization/services can create barriers for the child?	What could be done differently in eliminating these barriers?
Tell me about the training opportunities staff can access to be able to support children with intellectual and developmental disabilities.	
Tell me about your perspectives on the current policies in place and whether you feel the policies serve the needs of the children with IDD who visit your organization.	Do you feel the current policies are sufficient in supporting children with IDD? If not, what could be implemented to ameliorate the policies?

4.4   Data Analysis

Thematic analysis was used, via descriptive and *in vivo* coding (Saldaña, 2016). During the interviews, journaling was completed as the researcher reflected on the data being obtained. The interviews were recorded and then immediately transcribed. The first author transcribed the first two interviews directly, with the remainder interviews being transcribed with Otter.ai or Amberscript transcription software (Amberscript, 2021; Otter, 2021). After the production of the initial transcripts, the first author then listened to the interviews a second time, ensuring the transcriptions matched the interviews accurately. Following a secondary review of the transcripts by the first author, the transcriptions were then uploaded to NVivo software (v.12.0) for analysis (NVivo, 2018). This process was repeated with each interview and transcript. After each interview, an initial analysis of the interview was conducted to prepare for remaining interviews by reviewing the wording of the interview questions and probes to ensure clarity and orient the interviewer to the specific language of the staff members at the MAZSC. Data analysis using both descriptive and *in vivo* methods was completed (Saldaña, 2016). Descriptive coding was completed such that a word or short phrase was utilized to capture the topics found within the interview, while *in vivo* coding utilized the language of the interview itself such that the voices of participants were captured, identified, and expressed (Saldaña, 2016). As codes emerged, repetitive codes were then collapsed, and codes were organized into categories. Following the completion of the interviews, transcripts, and data analyses, the interviews were again examined for accuracy of codes and emergent themes with both the first and second authors to confirm data saturation in which no further data would contribute to new categories or themes, as well as to ensure replicability (Creswell, 2011; Fusch & Ness, 2015).

4.4.1 Trustworthiness

To ensure rigour of research, Lincoln and Guba's (1985) criteria of credibility, transferability, dependability, and confirmability were utilized. Within this research, credibility was achieved by piloting the interview prior to interviewing staff members,

taking notes throughout the interviews and during transcription analysis, and through continued discussions regarding the interview process, reviewing the eligibility criteria, and reviewing the emerging codes and categories with the research team. To achieve transferability, the emerging themes provided thick descriptions which became transferable to other contexts. Third, to confirm dependability within this research, the methods have been documented in rich detail such that repeatability can be ensured. Lastly, to achieve confirmability, the researcher practiced reflexivity and bracketing through journaling and team discussions to minimize researcher bias during the study.

4.5 Results

Three central themes were identified: (1) Leveraging staff diversity in supporting families and children with IDD, (2) Staff training opportunities, and (3) Staff training barriers.

Theme 1: Leveraging Staff Diversity in Supporting Families and Children with IDD

The general profiles and backgrounds of staff members were found to be highly diverse. Within this study, job titles and descriptions ranged from education officers, working with the board of relations, working with management, working as a chief executive officer (CEO), all aspects of visitorship including overseeing the gift shop, general information, cleanliness of the site, supervision of hospitality staff, looking after exhibits, public and school programming, supervision of interpreters, exhibit staff, and more. One staff member stated, *our staff run things like our camps, our programs, our traveling programs, our drop-in programming here on site. So, talks and anything they would do, animal encounters and things they would do out here at the zoo.* Some staff members began working at the MAZSC directly out of post-secondary education, while other staff identified working in previous fields prior to switching to their current position. Some educational backgrounds identified included staff with bachelor's degrees in biology, history, and education, and master's degrees in history and museum studies.

Furthermore, some staff members began working with full-time employment at MAZSC after completing summer employment at the site in between academic semesters, after

completing practicum experiences at the site as a part of their educational program, or after being a volunteer at the site. For other staff members, working at a MAZSC was a continuation of other work opportunities which supported children and families. For example, *I decided to move into something that was a little bit more about capacity building…within [the] family and not-for-profit sectors.* This staff member identified having previously been employed in a family responses/crisis intervention area and was looking to support children and families in a more preventative and capacity building context, rather than working in field dedicated to response or crisis intervention. This staff member's experience of capacity building with children and families with IDD was built on the premise of both developing and strengthening the skills of the individual they are supporting through resources, support, and facilitators within the MAZSC.

Staff members described an excitement across all levels of staff including volunteers, staff, supervisors, and upper management. One staff member described, *I think my supervisor would be on board and really excited. So that's also good that I don't think that I'll reach any pushback or barriers from my supervisor, which is the head person trying to implement these [accommodations]. It's part of where her heart is and where her background, her previous organization comes from.*

Adding to the diversity of staff at MAZSC, volunteers were also noted to play a pivotal role in the running of the organization and inclusion of families and children with IDD. Volunteers were also described as having diverse educational and employment backgrounds, with some sites noting that they make efforts to provide volunteering opportunities for individuals with IDD themselves. As such, inclusion extended to not only visitors with IDD, but also to volunteers with diverse IDD:

> I think that's been a really great thing in our volunteer program in that it's very welcoming that we've been able to find a place for many volunteers with intellectual disabilities and that they need a different type of support or specific kind of job for them.

Staff members also described the positive attitudes and perspectives of both staff and volunteers at MAZSC. It was further noted that despite positive attitudes and inclusive perspectives, the outcomes may not always be linked with best practices:

> I would say that individuals who work here care and strive. And that's everybody; that's from frontline staff to management. [We] care about all of our visitors and want everybody to have a good time. I think sometimes that doesn't translate into the best practice or the best result.

This desire for change and positive outlooks appeared universal across staff members and sites, where it was further stated that, *so, we're always looking for ways to do better, for ways to improve both our physical site but also our offerings in terms of programming.* Lastly, it was remarked that there will always be room for growth and improvement until full inclusion is reached for children with IDD:

> So, I think [with] the basic museum experience we're doing good, but I think that …if our staff were trained better and if we made it, and if we redesign some of our programs and the accessibility of our programs would be a lot better. I think there's still ground to be made. Like yes, we have an inclusive environment and yes, we have accessibility designed into our exhibits and their families can enjoy and engage, but until we reach that point where for all of the services that we offer are designed to be equally accessible then we still have ground to make up.

The relationships and the importance of consistency between staff members and visitors with IDD was further discussed. Several staff members described how staff strive to provide a consistent experience for visitors, noting that this can be both within the MAZSC exhibits, programs, or at the gift shops within the sites. It was described that, often, children with IDD and their families will attend the sites frequently and often become familiar with staff and, similarly, the staff become familiar with the strengths and needs of the visitors. However, it was noted that when specific accommodations are made to meet the needs of the individuals, in the absence of the regular staff members, this can

further create disruption as new staff or volunteers may not be aware of the accommodations provided for specific visitors. As such, while staff have positive attitudes and have desire to contribute to inclusion and participation, newer or inexperienced staff members may not know what to provide or how to provide for these frequent visitors. Without a standard of practice or policy in place, then the absence of these specific, informal, accommodations can become detrimental and may become a barrier to participation and inclusion.

When asked about personal knowledge of IDD, staff members varied in their knowledge and comfort level. One staff member identified living with an individual with IDD while another stated, *I am definitely ignorant in that I don't know a lot about [it].* Similarly, another staff member explained, *my understanding comes[from], I guess, a lot of how [children with IDD] think.* An additional staff member stated that their understanding of children with IDD pertains more to inclusion, stating, *my understanding of it, I think, is…in terms of inclusive education.*

While efforts are made to hire staff and volunteers, it was mentioned that due to varying backgrounds, not all individuals had the experience needed to support individuals with IDD at the sites. One staff cited, *we hire summer students and many of them are wonderful, but they don't often have that experience [of working with a child with IDD].* However, despite the diverse background of experiences and education, staff continue to work towards improving sites and creating accessibility and accommodations for individuals with diverse needs. For example, at the physical site through building renovations or through improving behavioural management strategies in support of children with IDD:

> Like at many organizations, we are looking at our approach to diversity and
> inclusivity…so that, of course, represents a huge spectrum of people and abilities
> and particular perspectives…bringing in new perspectives to the museum world. I
> want to make sure that we don't forget about…people with other accessibility

needs. We've just gone through a whole process here…of renewing our [exhibits] and so it's sort of an exciting time.

Staff members, including managerial staff and volunteers, provide a wealth of diverse employment and educational backgrounds, abilities, knowledge, and comfort levels of support children and families with IDD. Staff members across all sites expressed a desire for positive change, noting a commitment toward growth and improvement to achieve full inclusion for children with IDD. The diverse background experiences and education of staff members and volunteers were discussed as a medium for the desire for continued improvement in accessibility and examination of the approaches of diversity and inclusion. Lastly, although positive attitudes and excitement were expressed from staff members, it was also noted that despite efforts, best practices in full inclusion and participation may not always be achieved when attempting to support children and families with IDD

Theme Two: Staff Training Opportunities

Staff training is an integral part in creating an inclusive space for children with IDD to fully participate at informal learning settings. Staff members identified areas of strengths and opportunities in staff and volunteer training specifically in support of children with IDD. One staff member cited that training and professional development had clarified methods of supporting an individual with an IDD:

I just finished [attending] a virtual conference…they were talking about how [to] handle temper tantrums when kids were on the way out [of the site] and how that can be embarrassing but can also be very pressurizing for the adult and the child and the staff and how staff can be helpful by stepping in. Because others around us are always judging, right, and so just stepping in and trying to alleviate some of the pressure.

Although gaps in formal training were identified, staff demonstrated a willingness and desire to learn from each other and recognize the value of informal training through communication with parents, caregivers, and school support staff for children with IDD:

> But there's also a lot of, "if you don't know – ask," and then we bring it up. So, if they're just unaware of how to handle situations, like don't try to invent something, bring it up, and then go and handle it. Often, we just find that that's the best way is to talk directly with the parents, instructors. And just being really upfront, even before they come about what do they want? What do they expect how we normally work? So, like really establish a good line of communication.

To best support the training endeavours of staff, sites have offered training in various formats including online and in-person training, as well as the option to receive training from community organizations specializing in support individuals with IDD:

> We do have a set of online training seminars that …different staff can take and some of them do focus on working with children, some are just working with children in general, [and] some of them are specifically targeted to working with people with IDD.

Additionally, some staff have received training to ask caregivers or teachers about the needs of the child with IDD to ensure that pertinent information toward the care and the support of the child is provided:

> Staff are trained to ask if there's anything they need from us to support in terms of when they confirm the program. They'll go "[are] there any needs or anything that you need from us or anything we should be aware of?" So, like, if we need to know that a child might be wearing headphones the entire time. That way...we don't have to ask them to take something off, right, like we may ask for that.

Staff further identified that sites are working toward governmental standards that are required, *I don't know if it's provincially or nationally, but there's been new standards*

for accessibility that have come out recently that we've worked to comply with. Additionally, some sites have also connected with community agencies to support staff training considering training gaps identified:

> We are working with another organization…and we're working on putting stuff together right now [as] we don't have a particular training already in place. All of our staff are really good at asking each other, and people ask questions with each other, and they share information they have. We don't have a set [training] just yet, but we are working with a group right now.

These community organizations have positively impacted the MAZSC, with one site remarking, *we did have one training session…that was a really great training. It really talked about a different approach to integrating a child within a group that has IDD.* In addition to community training and informal learning for staff, some sites offer shadow training in pairing new staff or volunteers with others who have been with the MAZSC for longer:

> [Training is] mostly site training. It's often a lot of shadowing, shadowing other educators. And so, we not only do the shadow training, we try and improve over time. So, the new person learns from the person who's already there but [we] recognize that everyone has a little bit…to give. So, we try and do a lot of sharing or scenario and sort of brainstorming and talking through different ways we could do it.

Staff training was noted as an important aspect for increasing the opportunity for full inclusion and participation for children with IDD, particularly in understanding the various methods that an individual with IDD can be supported. Staff members noted some opportunities for both training and professional development; however, gaps in training were also identified. Staff members described a strong willingness and desire to learn from each other and recognize the informal training which occurs through communication with parents, caregivers, and school support staff for children with IDD.

While informal opportunities for learning exist for staff members, formal training opportunities have also been afforded at some sites in various modalities including online training, in-person training, shadow training, training from community organizations which specialize in supporting individuals with IDD, and training specifically in interacting with child caregivers. Lastly, staff members identified that through training opportunities and continued learning, sites are persisting in working toward meeting governmental standards for accessibility.

Theme Three: Staff Training Barriers

While staff training opportunities are integral to an inclusive space, barriers within staff training opportunities at MAZSC were also identified. A staff member at a museum suggested that improved training would also improve accessibility which would then increase participation:

> With better training we could probably make…programs more accessible and design programs that would be maybe even specific for kids that have intellectual disabilities…. So, I think the basic museum experience we're doing good, but I think that…if our staff were trained better and if we…redesigned some of our programs [then] accessibility of our programs would be a lot better.

Furthermore, despite the helpfulness in receiving training, gaps were identified in receiving adequate training and an over reliance on school staff to support children who have specific needs:

> So, we very, very briefly, as a supervisory team, do training with [staff]. Pre-COVID…we would do a weeklong summer training. So that's all the training they need to have on site. And it might have a brief section about working with people with intellectual or developmental disabilities. But it's usually fairly brief because our school programming, which is what we run first, tends to not be our heaviest

season in terms of what they would have to do as a site facilitator, because most
of them are field trips with schools where the school would come with the
supports that a child needs.

This demonstrated gaps in pedagogical approaches due to the brevity of focus on
supporting children with IDD and lack of teaching strategies which could facilitate
greater understanding and awareness of the needs of individuals with IDD. However,
despite there being some opportunities for training specifically in support of individuals
with IDD, these training opportunities were infrequent:

I believe in the past, that there was a training session for the front-line staff, so our
guides, and then as well our admission staff on working with people with IDD
and specifically with…how to provide an accessible and inclusive space and
experience for them. But that would have been probably over three years ago.

At times, there are gaps in staff being able to access training or resources in order to
increase understanding of IDD and how to create a fully inclusive space: *in terms of
training…no, there aren't any resources that are available to us as staff for that, without
us going to find it from somebody.* Lastly, it was identified that training is not only useful
as a staff tool, but also helps to identify the gaps in providing service and accessibility to
individuals with IDD:

Without the right training I don't know how I would say what needs to change or
what we need to do differently, but it's clear to me that there [are ways to
improve]. We just… we aren't seeing the enrollment [for children with IDD] so
there is some barrier there that we need to identify and work through.

Staff barriers were noted as an important aspect for potentially hindering opportunities
for full inclusion and participation for children with IDD, due to gaps in understanding or
knowledge, or gaps in providing inclusive opportunities for this population. Improved
training was identified as a method in which accessibility and participation would further
be improved through the identification of facilitators for accessibility and re-designed

programming. Furthermore, it was found that gaps in training due to brevity, duration, or frequency has led to overreliance on other supporting staff such as school staff during school visits to MAZSC. Furthermore, although staff have demonstrated a desire and willingness to participate in more frequent or intensive trainings, some staff identified that resources or professional development are not available creating doubt and unsurety regarding what changes or modifications need, or could be, put into place to best support children and families with IDD.

4.6 Discussion

Staff working within MAZSC play an integral role in the inclusion of children with IDD at MAZSC. The ICF-CY (WHO, 2007) examines inclusion and participation through the lens of body functions, body structures, activities and participation, and environmental factors. Within activities and participation, the ICF-CY further examines the impacts of community, social, and civic life (WHO, 2007). Additionally, the environmental factors within the ICF-CY examine support and relationships, attitudes, and services, systems, and policies (WHO, 2007). This interconnection between inclusion and participation with environmental factors, activities, and participation through the lens of the ICF-CY (WHO, 2007) demonstrates the necessity for improved, standardized, and evidence-based best practices when it comes to staff and volunteer training. MAZSC staff and volunteers provide a supporting role in both the inclusion and participation of children with IDD, and in supporting their parents or caregivers with whom they are accompanied at the site. Three central themes were identified within this study, specifically illuminating the diversity of staff and volunteers supporting families and children with IDD at MAZSC, and the opportunities and barriers to staff training opportunities in supporting this population.

While staff and volunteers have varying academic and workplace histories, their desire for working in capacity building and in informal education and teaching was universal across all sites. Given the diverse backgrounds experiences and education of IDD, staff identified that it is this diversity which is a contributing factor in the desire for continued

improvement in examining their approaches toward diversity and inclusion. Staff and volunteer attitudes were one of a willingness to provide a supportive environment for children with IDD while striving to do better with future practices. This also highlighted their desire to engage in continued capacity building, through developing and strengthening their own skills through resources or further community supports. Relationships between staff members is an important pathway to social inclusion (Simplican et al., 2015). In an ecological pathway to and from social inclusion for individuals with IDD, Simplican and colleagues discuss the importance of individual factors, interpersonal factors, organizational factors, community factors, and socio-political factors (Simplican et al., 2015). Within this study, staff members expressed the importance of interpersonal factors through the relationships between staff members and children with IDD visiting the MAZSC while also highlighting organizational factors such as access to community services. Through continuing to strengthen the interpersonal and organizational factors at MAZSC, staff members are able to continue engaging individuals with IDD into inclusive settings.

Furthermore, while personal staff experiences varied from having family members with IDD to having no personal experience with IDD, staff expressed a commitment to providing person-centred approaches in creating and implementing visions for the future. Staff members identified variability in their knowledge and comfort levels of IDD and spoke of the disconnect between possessing a positive outlook versus having best practices as an outcome when supporting children and families with IDD. In a 2012 study examining social inclusion of children with ASD in community groups, leaders in the community and volunteer sector were provided with a two-hour introductory training course (McConkey et al., 2012). This study highlighted that that staff were appreciative to learn more about ASD and strategies to support children with ASD while in their care (McConkey et al., 2012). They further noted that the programming provided insight into the challenges that individuals face who experience ASD, such as communication challenges (McConkey et al., 2012). The results of this current study align with the findings by McConkey and colleagues, in that the staff at MAZSC are appreciative of

training opportunities to learn more – whether formally or informally—but have found that in the absence of these opportunities, staff do not always feel equipped or comfortable supporting individuals with IDD. Lastly, while staff expressed a desire for change and a positive outlook toward inclusion and participation for children and families with IDD, it was further noted that there remains room for growth and improvement until fully inclusive opportunities exist for this population.

Tran and King (2007) propose that gaps in professionalization of staff members through a recognized set of best practices limits their ability to interact with visitors in ways which foster engagement, inclusion, and participation. At this time, across all sites, there are no formalized or professionalized ways of offering training related to supporting children with IDD. And while there are current staff training opportunities, when staff members and volunteers experience gaps in training in support of children with IDD, these gaps present challenges for full inclusion for these individuals as they lack theory-based or communication-based standardized training options. Holistic pedagogy encompasses the physical environment of an informal or formal learning setting while also incorporating social relationships, cognitive, emotional, and spiritual elements in the development of a child (Tirri, 2011). In the context of MAZSC, a holistic pedagogy may be directly linked with a full participatory and inclusive experience for children with IDD; however, when training gaps and barriers are identified in staff training in support of children with IDD, further barriers toward participation and inclusion are created for this population.

Staff identified that training is an important facet for increasing participation and inclusion of children with IDD and found that opportunities for training and professional development clarified the various methods, accommodations, and modifications which may be helpful in supporting individuals with IDD. Some training opportunities were identified and were described as opportunities for online and in-person training, as well as shadow training and training from community organizations specializing in supporting individuals with IDD. Notably, some staff identified that sites are working toward governmental standards for accessibility. Additionally, staff demonstrated a willingness

to learn from each other and recognize the value of informal training occurring through interactions with parents, caregivers, and school support staff, with some staff members having received formal training in asking caregivers or teachers about the needs of the child with IDD to ensure needs are supported during their visits to MAZSC.

Despite the training opportunities provided, formal training gaps and barriers to staff training were also identified. While each MAZSC staff member receives some training, the trainings were infrequent and brief. This presented gaps in the overall professional development of staff and volunteers who demonstrated a willingness to learn and a desire to support families and children with IDD. Staff training was presented through various modalities including online training, in-person training, and also on-the-ground informal training in the moment with families. However, despite improved staff training leading to improved accessibility, participation, and inclusion for children with IDD, the depth and breadth of training did not appear to be sufficient given the variety in academic and employment backgrounds of each staff member and volunteer. These findings are consistent work completed by McConkey and Bhlirgri (2003) who also found that staff members within the Greater Belfast area working with children with ASD were committed to enrolling children with ASD within schools; however, felt that they had not receiving any training – or felt their training had been inadequate – in supporting these children. Further, they reported that a lack of knowledge and skills to support the needs of children with ASD within the school settings (McConkey & Bhlirgri, 2003).

An additional barrier to training was frequently found within the gaps in a formalized training standard at the sites. And although these gaps were present at the system level, the staff members within this study clearly demonstrated that their own attitudes and their colleagues' attitudes were one of willingness and desire for inclusion and change. This points to changes being made within the individual levels with hopes that changes can also be made at the system level for improved training opportunities. Further, given that children with IDD and their families can experience exclusion due to disability, staff training that helps to support children with IDD so that they are not removed or excluded

is paramount. When children with IDD are supported by staff members at informal learning settings, they are supported at the levels of community, social, and civic life through the lens of the ICF-CY (WHO, 2007). McConkey and Collins (2010) found similar results in their study examining the role of support staff in promoting social inclusion for individuals with intellectual disabilities. Their study demonstrated that, while some staff in certain settings (i.e., in individualized support arrangements) provide greater priority for social inclusion for individuals with IDD, that variability of inclusion as a priority varied greatly between settings and staff members (McConkey & Collins, 2010). This highlighted that, although attitudes and willingness toward inclusion may have existed at the individual level, service managers were encouraged to provide a greater emphasis on leadership, training, and resources with respect to social inclusion for this population. In this way, greater support at the organizational and community levels will provide greater opportunities for social inclusion for individuals with IDD across settings.

Identification of barriers to staff training in support of children and families with IDD can further identify gaps in services and accessibility for this population. Improved training may further lead to improved accessibility, with increased inclusion and participation as the consequences of these opportunities, noting that infrequent or brief training sessions or gaps in training creates an overreliance on school staff which may be remedied by filling the gaps in pedagogical approaches at MAZSC. However, the lack of resources or professional development can be ameliorated in creating more facilitators to staff training to better support their visitors with IDD. Pedagogy within the context of staff training, which encompasses not only a set of instructions, but which also enables learning to take place (Kapur, 2019), could enable MAZSC staff members to provide a greater learning opportunity and support for children with IDD and their families within not only knowledge acquisition, but also in their attitudes toward this population.

4.7   Implications

The findings of this study highlight various implications for practice and procedure within informal learning settings as it pertains to children with IDD and their families. The findings of this research point to training gaps in pedagogy, communication, and theory-based training. Given the impacts of reduced or insufficient training of staff members in support of families and children with IDD, the implications of such can result in reduced inclusion and participation options for this population. Therefore, with improved training practices, or a standardized or evidence-based approach, these barriers may be alleviated or reduced such that this population may have full and equal access to informal educational experiences as their peers without disabilities. The implications of this research point to the efforts being made at the individual level, including attitudes, efforts, and desires of staff members at MAZSC, while also demonstrating areas of need at the system and service levels.

4.8   Limitations and Future Directions

Two major limitations are associated with this study. First, this study was a study centering on capital Canadian cities and cities within Canada of populations of 300,000 and more, and thus eliminated smaller city centers as well as cities outside of Canada. Studies including smaller cities, cities internationally, and informal learning centres stretching beyond MAZSC such as day camps and other programming is recommended. A second limitation centres on a small sample size with which to represent all staff and volunteers at MAZSC across Canada. Therefore, interviewing multiple staff members of various backgrounds, including management staff or staff members responsible for training could provide further information for future studies.

4.9   Conclusion

The findings of this study highlight the staff and volunteer profiles at MAZSC as well as the opportunities and barriers to staff training in support of children with IDD and their parents/caregivers at informal learning settings. Understanding the current practices of

staff training and the current gaps in place, as well as understanding how those gaps may be impacting inclusion and participation for children with IDD and in support of their parents and caregivers provides further insight into how those gaps may be preventing participation and inclusion for children with IDD, a direct human rights issue. This study provides context to the current practices in place which may both be supporting and hindering full inclusion due to challenges at the system level in supporting families and children with IDD. The gaps and barriers currently highlighted need to be addressed in future research and in practice. The findings of this research study can thus be used to begin establishing best practices to staff and volunteer training at MAZSC in support of parents and caregivers of children with IDD so that they may engage in a fully inclusive informal education.

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Chapter 5

5   Discussions and Conclusions

For this dissertation, I completed a scoping literature review for study one, and completed interviews for studies two and three with staff members of museums, aquariums, zoos, and science centres (MAZSC) within Canada. The dissertation addressed the following aims: (1) examine the existing body of literature, including grey literature, and determine the current practices informal education settings (IES) use to promote participation, (2) determine the facilitators and barriers to inclusion and participation for children with intellectual and developmental disabilities (IDD) at MAZSCs across Canada; and (3) determine the gaps and barriers to staff training at MAZSCs across Canada in support of children with IDD and their parents/caregivers. The contributions of each of these studies adds to the current body of literature by examining the practices which exist both within the literature and within current MAZSC in Canada. The research findings support what is currently in the existing body of literature in that there are current facilitators and barriers to informal educational opportunities for children with IDD, and also contributes to these findings by outlining the system-level barriers that continue to exist in preventing a fully inclusive educational opportunity. This dissertation therefore provides continued indication that further research and continued community support in reducing and eliminating such barriers is paramount to providing children with IDD opportunities for full inclusion and participation at IES.

5.1   Contributions of Each Paper

Each paper provided a novel, in-depth examination of practices, facilitators, and barriers to inclusion. Paper one contributed to the existing body of literature by examining the practices of inclusion for children with neurodevelopmental disorders at IES internationally. By understanding the characteristics of the studies in the literature base and examining the practices used for inclusion and outcomes measured, it was found that inclusion was explored through the lens of the ICF-CY (WHO, 2007) in body structures

and functions, activities, and participation, and through environmental factors. These facets of practices used to promote inclusion, in turn, contributed to an increased sense of belonging, self-esteem and self-perception, improved social and cognitive skills, improved skill development, increased social acceptance, improved quality of life, and the connection between increased self-efficacy and improvement in self-perception. In understanding what the current practices are for children with neurodevelopmental disorders at IES, further progress can be made in ameliorating the practices and rooting them within theoretical frameworks in an effort to increase full inclusion and participation.

Study two presented a qualitative descriptive study which examined the facilitators and barriers to inclusion and participation for children with IDD at MAZSC within Canada. Prior to completing this study, no national study on the specific facilitators and barriers at MAZSC had been completed. This study uniquely contributes to the current body of research in many ways: through completing a national study, through understanding the distinctive profiles of learning and engagement for children with IDD at MAZSC, and through examining what facilitators and barriers exist at MAZSC. This study highlighted the immense work and progress which has been made toward inclusion of children and families with IDD at MAZSC and the progress that continues to be made.

Lastly, study three presented a qualitative descriptive study which examined the unique profiles and backgrounds of staff members at MAZSC within Canada and the training opportunities and barriers which exist specifically in support of children and families with IDD. This study provided an understanding as to the diverse backgrounds of individuals working or volunteering at MAZSC across Canada and how these diverse backgrounds either support, or hinder, full inclusion and participation for children and families with IDD. Similarly, when examining the training opportunities and gaps at participating sites, there was evidence to suggest that, while sites have made both efforts and strides to complete training in support of children and families with IDD, current gaps in training may be contributing to barriers for participation and inclusion.

While each study presents unique contributions to the literature, the overarching theme across each study illuminates the progress and advances which have been made toward fully including children with IDD at informal educational settings. And while barriers were also identified, it would be unjust to disregard the current efforts being made. With the illumination of the barriers which do exist, however, future research is required to examine the contributing factors to the barriers which remain and to focus on how such barriers can be broken down, reduced, and eliminated altogether.

5.2   Overall Findings and Themes

5.2.1 Changes toward Inclusion

Individuals with IDD are a historically marginalized population and research focusing on participation and inclusion continues to be lacking. All three studies demonstrated that, though some changes toward inclusion are occurring, there remain challenges and barriers toward inclusion. Study one demonstrates that efforts toward inclusion and participation are occurring, though smaller IES such as camps, for example, developed specific programming options specifically for children with neurodevelopmental disorders, rather than in an integrative or community way in which all children can experience inclusion. These results are not unlike the results found within the review completed by Verdonschot and colleagues (2009) which found a lack of research on community participation for individuals with IDD. Further, Verdonschot et al. (2009) also found that individuals with IDD have lower participation than their typically developing peers which is similar to the results within study one. Study one found that some research is being done in the area of practices toward participation; however, the studies currently within the body of literature are smaller studies which have broad definitions of participation. As such, further research with larger studies examining the practices for both participation and inclusion for children with neurodevelopmental disorders at IES is necessary. Study two demonstrated that efforts towards inclusion using facilitators has changed, while barriers continue to be identified and either changed, or removed. For example, unlike previous studies of museums and disability in which

attitudes were found to be a barrier (Walters, 2009), our study found that staff attitudes were generally positive and desirous toward creating inclusive spaces and creating change, which may be indicative that progress in this area is being made. The participants both in studies two and three expressed a desire to complete initiatives and create inclusive spaces; however, we continue to see gaps in those desires being translated into research in this area. Study three noted that staff play an integral role in supporting children with IDD at MAZSC and can further serve as facilitators and barriers toward inclusion through staff attitudes, staff knowledge, and staff training. There remains little evidence that individuals with IDD are providing feedback or engaging in participatory research to provide first-hand experiences or viewpoints of the changes being made toward inclusion. In study two, one staff member identified that in the development of exhibits at their centre, families of children with IDD came to see the spaces being developed to offer feedback and insight – through these experiences, greater changes toward inclusion can be made. When opportunities for autonomy and decision-making exists on the part of staff, policymakers, stakeholders, and visitors with IDD at IES, a culture is created in which practices for inclusion and participation can be ameliorated for this community which is at-risk for experiencing exclusion.

5.2.2 Variety of Facilitators

All three studies discussed the variety of facilitators of inclusion. In study one, this was demonstrated in the practices used to promote inclusion, through offering both traditional and modified versions of physical activities, modifying the language of questionnaires and surveys, through receiving 1:1 support and modifying methods of administrations. Study two further illustrated the diversity of facilitators of participation at MAZSC, such as having additional staff to support children with IDD, providing a calming environment, improving physical sites through flexible signage (i.e., use of audio, braille, or written language), using flexible accommodations through visual aids, microphones, or interpreters and staff attitudes. Study three also endorsed the variety of facilitators by examining staff willingness and attitudes toward inclusion. These diverse facilitators reflect the diversity of needs children with IDD can experience and points to the need of

flexibility both with material facilitators, but also in programming facilitators (i.e., hosting inclusive opportunities at different times of day), and flexibility within staff members (i.e., staff being flexible in providing opportunities in-the-moment when needed).

5.2.3 Continued Barriers

Another theme which emerged across studies was continued barriers to inclusion and participation. While barriers were not explicitly discussed in study one, barriers were clear. Many of the practices designed to promote inclusion and participation occurred in segregated settings for children with neurodevelopmental disorders (e.g., camps for children with neurodevelopmental disorders). While studies two and three discuss inclusion within public settings in which all children can participate, the majority of IES within study one was specifically designed for participating children with neurodevelopmental disorders. As such, one could debate whether these truly were practices for promoting inclusion and participation. Study two explicitly described barriers to inclusion and participation at MAZSC for children with IDD, including being unable to offer specific programming due to costs, site and visitor finances, lack of inclusion advertising (noting that advertising currently focuses on physical accessibility), and potential sensory overload due to crowds, lighting, and loud sounds. Study three also highlights continued barriers, in the context of lack of knowledge and lack of available staff training in support of children with IDD. An overarching theme across all three studies is that institutional barriers to inclusion and participation for children with IDD remain, despite staff commitment to inclusion and attitudes toward inclusion.

5.3 Future Directions and Implications for Practice

Children with IDD, like all children, thrive when they are provided with opportunities and ways in which they can both participate, and experience inclusion. While all three studies demonstrated areas in which progress has been made toward inclusion and participation, work and research in this area continues to be needed. All three studies highlight that accommodations have been made so that children with IDD can participate;

however, rather than creating accommodations for individuals, this research suggests that truly inclusive spaces are necessary so that segregation or "othering" of this population does not happen. For example, while it is helpful for sites to provide specific camps for children with IDD or sensory nights specifically for children with sensory concerns, these are examples of accommodations made, versus inclusive spaces in which all children can participate. One participant in study two identified that doing a walk-through of exhibits with families who have loved ones with IDD provided information in understanding that chronological age is not equivalent to developmental age. As a result, this site removed advertisements which specified an age limit to increase inclusion for all individuals wanting to participate. This is an example of both the need for participatory research and approaches in which the voices of individuals with IDD are heard. It is also important to build inclusive spaces right into the IES or MAZSC so that children with IDD are included *within* the space, rather than have to participate within a *separate* space. The Universal Design for Learning framework (CAST, 2022) is used as a framework and tool which creates equitable learning opportunities and outcomes. While participatory research is invaluable, particularly with individuals with IDD who so often do not have their voices heard, but also in other participatory approaches such as in conversation about design, equitable learning opportunities, and through multiple methods of engagement, representation, and action and expression as per the Universal Design for Learning framework (CAST, 2022). As such, the first recommendation is that informal educational settings engage in participatory opportunities for families of children with IDD to visit the sites and offer feedback about existing facilitators and barriers for participation and inclusion. When families of children with IDD are involved in the process of designing programming and inclusive spaces, true inclusion as both a process and a goal can be achieved.

The second recommendation from this research is that staff members have access to comprehensive training opportunities to continue gaining knowledge about the diverse needs and strengths of individuals with IDD. Muir and colleagues (2019) suggested that, rather than individuals with disabilities needing to self-identify, that posters, signs on

doors, or allyship messages on name tags provide indicators that staff members are knowledgeable and allies for individuals with disabilities. As staff receive comprehensive, in-depth training that extends beyond the minimum legal requirements set out at the provincial, state, or national levels, knowledge, insight, and awareness into the unique needs and strengths of individuals with IDD can be better understood. Consequently, this would contribute to a reduction of barriers toward participation and inclusion.

The United Nations (2016) and Simplican and colleagues (2015) both offer definitions for inclusion which have been examined throughout this dissertation. While the United Nations (2016) describes inclusion as both a process and an outcome, Simplican's (2015) model of inclusion for individuals with IDD discusses the interaction between interpersonal relationships and community participation. All three studies examine components of these models, though some areas are being met, other areas continue to need further work. Notably, study one found that often it was the *outcomes* that were focused upon in the literature, but that the *process* of inclusion remained lacking. For example, participants highlighted outcomes in which they felt greater sense of belonging (Aggerholm & Moltke Martiny, 2017) or demonstrated improved cognitive skills (Langa et al., 2013). Throughout the studies, though practices toward inclusion were in place, the process of inclusion and the interaction between interpersonal relationships and community participation were generally not discussed. Arguably, community participation in study one remained scarce, as literature on the practices for inclusion centred upon IES which were largely designed specifically for individuals with IDD, rather than the inclusion of individuals with IDD into the community itself. In studies two and three, inclusion was often discussed through accommodations and through ways in which accessibility were improved; however, inclusion as a process was often lacking. Throughout all three studies, true community participation and integration within the community was lacking. As such, the third recommendation from this research is for individuals with IDD to continue receiving support for community participation that extends beyond accommodations to accessibility. For example, having individuals with

IDD sit on a board of directors, be employees at MAZSC and IES, or being a part of planning exhibits in which individuals with IDD can participate during typical community hours, rather than during segregated or separate times.

Lastly, throughout the research, it was found that the terms *inclusion, participation,* and *accessibility* were often used interchangeably, despite being three distinct terms. Study one examined practices to promote participation, and although inclusion and participation were at the forefront of studies two and three, when asked about inclusion, participation, and accessibility, participants generally discussed accessibility for children with IDD, rather than discussed opportunities in which children could experience inclusion and participation. This may be, in part, due to provincial or federal legislature in which accessibility is required by law. For example, the Ontarians with Disabilities Act (2001) mandates standards for accessibility to reduce and/or prevent barriers which would otherwise prevent participation for individuals with disabilities. Accessibility generally refers to the ability to *access* versus the ability to be included and participate. Therefore, it is possible that staff member's focus on accessibility is due to legal requirements, rather than thinking about active social involvement for this population. The ICF-CY uses a common language when documenting the influence of the environment on the developing child and adolescent, specifically in terms body structures and function, activities and participation, and relevant environmental factors (WHO, 2007). As such, the final recommendation from this research is the development of a more universal language in which to discuss accessibility, inclusion, and participation. Common language is beneficial so that, like the ICF-CY (WHO, 2007), it can be used to improve services, policies, practices, and research across disciplines. This may be done through the above-mentioned recommendations, through altering the culture of IES through continued conversations about participation and inclusion, and potentially through modifying the mission and vision statements of IES to reflect inclusive settings for children with IDD.

5.4   Conclusion

The purpose of this dissertation was to explore the facilitators and barriers of inclusion and participation for children with IDD in IES. A scoping literature review (Tricco et al., 2009) and two qualitative descriptive studies (Sandelowski, 2000) completed. Overall, it was found that IES utilize multiple methods to facilitate inclusion and participation, though barriers in both language and practice continue to exist. Utilizing a scoping literature review for the first study provided a backdrop into what practices are currently being used globally to promote inclusion for children with neurodevelopmental disorders, while utilizing the qualitative descriptive methodology for studies two and three illuminated the current practices being utilized by staff at large IES across Canada. Using the qualitative descriptive methodology provided a description of what is occurring in everyday language in terms of facilitators and barriers to inclusion and participation for children with IDD. Based on the results of this dissertation, children with IDD continue to experience barriers toward participation and inclusion, although efforts are being made by staff members to reduce or eliminate barriers. Staff members provided relevant examples of key barriers which continue to be experienced, such as finances or attitudes by administration or management; however, facilitators such as the willingness and attitudes of staff members were also noted. Despite the facilitators in place, children with IDD continue to be at risk for exclusion and therefore efforts need to continue being made to include this population in all areas of functioning so that they may not only be physically present at IES, but that they may experience meaningful inclusion along with their typically developing peers. Disability awareness continues to be an area of need which will further support inclusion for children with IDD. The results within this dissertation contribute to the body of literature on inclusive education for children with IDD and provides researchers, staff members, and clinicians with opportunities and recommendations for educational practices – either through physical practices, policies, or through language – in support of children with IDD at IES worldwide.

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Appendices

Appendix A: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

Section	Item	PRISMA-ScR Checklist Item	Reported on Page #
Title			
Title	1	Identify the report as a scoping review.	30
Abstract			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	30
Introduction			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	32-33

Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements or other relevant key elements used to conceptualize the review questions and/or objectives.	32-33
Methods			
Eligibility criteria	5	Specify characteristics of the sources of evidence used as eligibility criteria and provide a rationale.	35
Information sources	6	Describe all information sources in the search as well as the date the most recent search was executed.	33
Search	7	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	33-34
Selection of sources of evidence	8	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	34

Data charting process	9	Describe the methods of charting data from the included sources of evidence and any processes for obtaining and confirming data from investigators.	34
Data items	10	List and define all variables for which data were sought and any assumptions and simplifications made.	34-35
Synthesis of results	11	Describe the methods of handling and summarizing the data that were charted.	35-36
Results			
Selection of sources of evidence	12	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	34
Characteristics of sources of evidence	13	For each source of evidence, present characteristics for which data were charted and provide the citations.	35-36
Results of individual sources of evidence	14	For each included source of evidence, present the relevant data that were charted	36-47

		that relate to the review questions and objectives.	
Synthesis of results	15	Summarize and/or present the charting results as they relate to the review questions and objectives.	36-47
Discussion			
Summary of evidence	16	Summarize the main results and link to the review questions and objectives and consider the relevance to key groups.	48-52
Limitations	17	Discuss the limitations of the scoping review process.	52-53
Conclusions	18	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	53-54

Appendix B: Email Script for Recruitment Advertisement

<u>**Subject Line: Invitation to Participate in Research on Inclusion in Informal Education Centres**</u>

Hello,

My name is Nicole Neil and I am an assistant professor at the University of Western Ontario. I have received your email address from your organization's website. You are being invited to participate in a study assessing the barriers and facilitators to participation for children with intellectual and developmental disabilities within informal learning organizations. This information will be collected by researchers via an online survey as well as individual interviews which will take place over video conferencing or telephone.

To participate, you must be an English-speaking staff member (directors, curators, administrators, or other staff) of your organization. During the study, staff members will be provided a link to the online survey to complete assessing the barriers and facilitators to participation for children with intellectual and developmental disabilities. Participants will be given the opportunity to provide their email address if they are interested in participating in an individual follow-up interview. The online survey will take approximately 15-20 minutes to complete and the interview will take approximately 30-60 minutes and will occur through OWL Collaborate. Participants who enter the interview portion of the survey will receive a $25.00 honorarium.

If you would like to participate in this study please click on the link below to access the letter of information and survey link:

https://uwo.eu.qualtrics.com/jfe/form/SV_6nDvtC0tKLwAYkJ

If you would like more information about this study, please contact my graduate student, Julia Ranieri, at jranieri@uwo.ca.

Thank you,

Nicole Neil, PhD, BCBA-D, Assistant Professor, Faculty of Education

Julia Ranieri, Graduate Research Assistant

Appendix C: Interview Protocol/Guide

Name of interviewer:
Name of person being interviewed:
Date of interview:

Section A.

The purpose of this study is to explore informal programming and policies in the science, technology, engineering, and mathematics areas for children with intellectual and developmental disabilities in informal educational settings across Canada and to draw a comparison between the policies currently being implemented to what policies are currently found in the literature worldwide.

PROJECT SCRIPT

My name is Julia Ranieri and I am a doctoral student at Western University. This research is being supervised by Dr. Nicole Neil. The purpose of this study is to explore the programming and policies that are taking place at informal education settings, particularly in the areas of science, technology, engineering, and math. Before we begin, I want to make sure that we have gone through the informed consent and that you have an opportunity to have any of your questions answered.

Have you received and read the Information Letter and Consent Form for Interview? (Circle Response) YES   NO

If yes, have you signed and returned the consent form?

Do you have any questions at this time?

If no,

I would like to take a moment to review the consent form with you.

Prompt: Review the consent to participate in research form.

If you are in agreement with this, please send an email to which states "I have read and understood the letter of information and agree to participate in this interview."

With your permission, I am going to audio record this interview for transcription purposes only. The audio recording will be destroyed at the end of the study.

Do I have your permission to record this interview?   YES   NO

If yes, turn on recorder. Thank you.

If no, will it be possible to reschedule this interview? If the interview is not recorded, we require two research assistants to be present so one person can conduct the interview and the other person can take notes to ensure accuracy. YES   NO

This interview will take between 30 minutes to an hour to complete. You are free to withdraw from the interview at any time. If we run out of time, and you wish to complete the interview, do I have your permission to contact you at a later date to complete the interview?

(Circle response) YES   NO

Thank you.
I'm now going to ask you some questions about the participation of people with intellectual and developmental disabilities at your organization.
Intellectual and developmental disabilities, or IDD, are a group of diagnoses that are defined by the limitations they experience in functioning. Examples of this can include limitations in their social interactions, in their intellectual abilities, in their academics or the way they can function and adapt to daily living. Some examples of an IDD include autism spectrum disorder, fetal alcohol spectrum disorder, Down syndrome, Tourette syndrome, and intellectual disorder, or what used to be called 'mental retardation'. Do you have any questions about what IDD is or means?

Section B.

1. I would like to start off by getting to know you a little bit. What made you interested in participating in this study?

2. What is your job title?

3. What does your role as [job title] entail?

4. What interested you in working in your role as [job title]?

5. How long have you been doing work related to [job title]?

I'm now going to ask you some broad questions about your perspectives of individuals with IDD, and the policies, procedures, and practices of your organization for providing services to individuals with intellectual and developmental disabilities.

1. What is your understanding of IDD?

   Probing question:

   a. Tell me about your perspectives on the strengths and needs of someone with IDD

2. Tell me about an experience you thought was successful in terms of including a child with an IDD

   a. What elements contributed to the success of the experience?

   b. What aspects of the environment supports a positive experience for a child with IDD?

   c. How would you improve the experience?

3. Tell me about an experiencing you thought was challenging in terms of including a child with an IDD

   Probing questions

   a. What elements contributed to the challenges of the experience?

   b. What aspects of the environment created barriers for the child with IDD?

   c. How would you improve the experience?

4. Imagine a parent or caregiver who has a child labelled with an intellectual or developmental disability is visiting your site to see if it would be suitable for the

child or not. How would that person know if your program is an inclusive program which has facilitators to participation for children with IDD?

    a. What facilitators do you have available that you could provide to parents/caregivers of children with IDD?

5. What aspects of your organization/services can create barriers for the child?

    a. What could be done differently in eliminating these barriers?

6. Tell me about the training opportunities staff can access to be able to support children with intellectual and developmental disabilities.

7. Tell me about your perspectives on the current policies in place and whether you feel the policies serve the needs of the children with IDD who visit your organization

    Probing questions

    a. Do you feel the current policies are sufficient in supporting children with IDD?

    b. If not, what could be implemented to ameliorate the policies

My final question for this interview is the following:

Is there anything that you would like to talk about that we didn't cover in the interview?

This concludes the interview process. Do you have any further questions? Concerns?

Thank you for participating in this research.

Appendix D: Letter of Information and Consent Form

Western

Project Title
An Exploration of the Facilitators and Barriers of Inclusion and Participation for Children with Intellectual and Developmental Disabilities in Informal Educational Settings

Document Title
Letter of Information and Consent – Study 1

Principal Investigator + Contact
Principal Investigator
    Nicole Neil, PhD, BCBA-D, Faculty of Education
    Western University,

Graduate Research Assistant
    Julia Ranieri

1. Sponsor/Funder Information
This project is supported in part by funding from the Social Sciences and Humanities Research Council.

2. Invitation to Participate
You are being invited to participate in this research study about approaches in informal educational settings to increase participation in science, technology, engineering, and mathematics (STEM) for children with intellectual and developmental disabilities in Canada because you are an organization which engages children in STEM.

3. Why is this study being done?
Researchers are interested in understanding how current programming is being conducted in informal settings across Canada to increase participation for children with intellectual and developmental disabilities who may otherwise be unable to access informal educational opportunities. This information will be helpful in developing future programming and accessibility policies.

The purpose of this study is to explore informal programming and policies in the STEM areas for children with intellectual and developmental disabilities in informal educational settings across Canada and to draw a comparison between the policies currently being implemented to what policies are currently found in the literature worldwide.

4. How long will you be in this study?

It is expected that you will be in this study for a maximum 30-60 minutes for an interview.

5. What are the study procedures?

Participants must be English-speaking staff member (directors, curators, administrators, or other staff) of informal learning centres (e.g museums, zoos, aquariums, science centres) in a Canadian city with a population greater than 300,000.

If you agree to participate you will be asked to:
1. **Complete an 30-60 minute phone or video-conferencing interview.**

We will be asking questions regarding the background information of the informal educational setting you work at and information regarding accessibility, inclusion, and participation.

During the interview, you will be video or audio recorded. The recording of sessions will be used to create a transcription for analyzing your perspectives on accessibility and inclusion. Video recordings will be viewed by project staff only and will be kept in a locked office.

6. What are the risks and harms of participating in this study?

The risks within the current study are no different than any other day to day activities in which you would be involved with in your workplace.

7. What are the benefits?

While you may not directly benefit from participating in this study, the information that is gathered may benefit informal educational organizations and the families of children with intellectual and developmental disabilities who access these organizations by providing information which may enhance inclusive policies and practices

8. Can participants choose to leave the study?

If you decide to withdraw from interview portion of the study, you have the right to request (e.g., by phone, by email, etc.) withdrawal of information collected about you. If you wish to have your information removed please let the researcher know and your information will be destroyed from our records. Once the study has been published we will not be able to withdraw your information.

9. How will participants' information be kept confidential?

All information from interviews about you will be coded with a number (participant number) so that your name is not associated with the information collected. All information (participant numbers and corresponding recordings) will be kept in a locked file cabinet in the principal investigator's office. Electronic files with be stored on a password protected device. Access to all data will be limited to the study personnel. In the dissemination of results, all participant information will be de-identified and de-

identified quotes will be used. If the results of the study are published, your name will not be used.

Representatives of The University of Western Ontario Non-Medical Research Ethics Board may require access to your study-related records to monitor the conduct of the research.

While we do our best to protect your information there is no guarantee that we will be able to do so. Since your name will not be linked to your assigned participant number it is unlikely that someone would be able to link the data and identify you. Video recordings will not be used if the results of the study are published.

The principal investigator will keep any personal information about you in a secure and confidential location for a minimum of 7 years. It will be kept by the researcher in a secure place, separate from your study file.

Anonymized data from this study may be published in an open -access repository. All identifiable information will be deleted from the dataset collected so that individual participant's anonymity will be protected. The de-identified data will be accessible by the study investigators as well as the broader scientific community. More specifically, the data may be posted on an open-access data set OR made available to other researchers upon publication so that data may be inspected and analyzed by other researchers. The data that will be shared will not contain any information that can identify you.

10. Are participants compensated to be in this study?
Compensation will be provided for participation in the interview in the form of a $25.00 gift card.

11. What are the Rights of Participants?
Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate you have the right to not answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study at any time it will have no effect your employment status.

You do not waive any legal right by signing this consent form.

12. Whom do participants contact for questions?
If you have questions about this research study please contact the Principal Investigator: Nicole Neil

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics.

This letter is yours to keep for future reference.

13. Consent

Verbal Consent

Has the Letter of Information been read to you or have you read the Letter of
Information?
 ☐No
 ☐Yes

Have all of your questions been answered?
 ☐No
 ☐Yes

Do you consent to participate?
 ☐No
 ☐Yes

Name of Participant   Date of Participant Verbal
            Consent

Name of person obtaining   Signature of person obtaining   Date verbal
verbal consent   verbal consent   consent obtained

Curriculum Vitae

Name: Ranieri Julia

Post-secondary Education and Degrees:
Western University
London, Ontario, Canada
2018-2022 (expected) Ph.D., School and Applied Child Psychology

University of Lethbridge
Lethbridge, Alberta, Canada
2016-2018 M.Ed., Counselling Psychology

University of Guelph
Guelph, Ontario, Canada
2005-2010 B.Sc., Biological Sciences

Honours and Awards:
Western Graduate Research Scholarship
2021

Western Graduate Research Scholarship
2020

Western Graduate Research Scholarship
2019

Western Graduate Research Scholarship
2018

Alberta Graduate Student Scholarship
2018

Queen Elizabeth II Graduate Scholarship
2016

Related Work Experience
Psychology Resident
Ottawa Catholic School Board
2021-2022

Psychometrist
London Psychoeducational Assessment Centre
2020-2021

Student Clinician
2019-2021

Practicum Student, Psychological Services
Thames Valley District School Board
2019-2020

Practicum Student, Mary J. Wright Research and Education Centre
Merrymount Family Support and Crisis Centre
2018-2020

Housing First Liaison Worker/Youth Support Counsellor
YWCA Lethbridge & District
2018

Publications: Azzam, M. B., Ranieri, J., & Puvirajah, A. (2022). Interprofessional education in prelicensure health and social care professions education: A systematic review. *Health Interprofessional Practice and Education, 4*(3), 2186. Doi: 10.7710/2641-1148.2186.