Examining the adaptation of dance for people with Neurodevelopmental Disability:

A multiple-methods approach

by

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LIST OF ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
ADL	Activities of Daily Living
AS	Asperger Syndrome
ASD	Autism Spectrum Disorder
CP	Cerebral Palsy
DD	Developmental Disability
DMT	Dance Movement Therapy
DS	Down syndrome
DST	Dynamical Systems Theory
GMFCS	Gross Motor Function Classification System
ID	Intellectual Development Disorder
NDD	Neurodevelopmental Disability
PA	Physical Activity
Quasi	Quasi-experimental design

ABSTRACT

Dance has an ableist history that has defined who is a dancer, what dance looks like, and how dance is taught and performed. Dance can also enhance and promote physical and social development for persons with neurodevelopmental disability (NDD) when it is adapted to the capabilities of the individual dancer. However, dance educators are not required to complete training on adapting movement for persons who live with NDD, nor how to create inclusive and adaptive dance environments. I used a multiple methods approach to gain a deeper understanding of how adaptive dance programming and environments may impact dancers who live with NDD (dancers) and to make recommendations for practice.

This thesis includes three linked studies. The first study examined the literature specific to adults who live with NDD to determine the characteristics of, and common instructional strategies used in, dance interventions. The study synthesizes the outcome measures used and considers the relationship between outcomes and the characteristics of the dance interventions. The second study considers the perspectives of dancers through semi-structured interviews to better understand both the perspectives and experiences of dancers in dance. The third study used a Hybrid-Delphi technique to gather expert community, dance, and rehabilitation perspectives on adapting dance and dance environments to formulate a set of prioritized recommendations for dance educators.

The results of these studies are organized in a manuscript-style thesis. The results of the first study indicated that literature often focuses on reducing or changing of the behaviours and 'symptoms' related to NDD. The findings indicated that details of how dance interventions were adapted to dancers' functional levels and the specific details of interventions were scarce. In the second study the dancers shared that they gained a sense of purpose and belonging, as well as and interpersonal skills that apply to daily life when holistic approaches to dance instruction were used. The third study resulted in the formulation of a comprehensive list of recommendations that prioritizes the perspectives of the dancers and applies to a variety of movement settings. Based on these findings future research will evaluate the dissemination of the findings in the dance community broadly.

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Over the past 37 years I have had the privilege of teaching dance to children, youth, and adults across Manitoba. Each class and student have contributed to my motivation to pursue graduate school. Importantly, it is my work with youth and adults who identify as having a disability, and those who support them, who have been the driving force behind academic journey. Thank you for your energy, enthusiasm, trust, and understanding.

Finally, I gratefully acknowledge Research Manitoba, the Susan Bell Wright Award for research in developmental disabilities, and the University of Manitoba for their financial support throughout my graduate studies.

DEDICATION

This thesis is dedicated to the memory of my parents.

For their love, support, and encouragement.

J.V.L (1935-2012)

L.H.L (1929-2017)

CHAPTER 1

INTRODUCTION

1.0 INTRODUCTION

It has been estimated that worldwide 1.3 billion persons, including 8 million Canadians, 15 years and older live with disability (Statistics Canada, 2022; World Health Organization, 2022). Neurodevelopmental disability (NDD) references diagnoses involving alterations in neurological development during the pre-peri-postnatal stages of development (intellectual development disorder, Down syndrome, cerebral palsy, autism) (American Psychological Association, 2022). Occupational therapy (OT) and physical therapy (PT) are commonly prescribed throughout the lifespan of those who live with NDD. However, these therapies are not meant to be long term, nor should these therapies replace participation in recreational physical activity (PA) (Verschuren et al., 2016). Affordable opportunities for recreational and/or physical activities are often limited once an individual transitions, or 'ages out' of the 'system' (18-21years of age) (López-Ortiz et al., 2019). To this end, adults with disabilities often experience greater isolation due to accessible transportation difficulties, lower rates of employment, changing peer relationships and/or social networks, and participation in fewer leisure and social activities (Franklin et al., 2019; Nguyen et al., 2018; Palisano et al., 2017; Turcotte, 2014). A consistent challenge for individuals living with NDD is finding appropriate, personally meaningful, and safe physical activity opportunities with knowledgeable instructors (Fortin et al., 2021).

Dance has the potential to shift physical activity and movement instruction beyond the biomedical perspective of disability as abnormal or as body functions and/or structures to be 'fixed', towards a holistic inclusive approach to PA and recreation for persons living with NDD (Dhami et al., 2015; Goodwin & Connolly, 2022; Palisano et al., 2017). Specialized adapted dance programming may be a proactive means to promote continued motor development, social

engagement, and development throughout the lifespan in a way that may also support physical and/or occupational therapy goals. The aim of this thesis is to understand the ways in which dance instruction and dance environments may affect persons who live with NDD who participate in dance. The fundamental objectives of this thesis were to establish a foundation of understanding of the current dance and disability literature, understand the experience of dancers who live with NDD, and to gather expert recommendations for the creation of adaptive dance instruction and dance environments with the disability, dance, and rehabilitation communities.

As this thesis is situated in disability and both the research and writing of this thesis has been completed by a non-disabled student researcher, I will first address ableism and the language used around disability in the next sections.

1.1 **ABLEISM**

Disability scholar Simi Linton aptly describes ableism as both "formal and informal, the explicit and the tacit, the overt and covert that society works to divide up the human community" (Linton, 1998, p. 34). Ableism has been defined as an insidious language that exists across society, including in higher education, the arts, the discipline of kinesiology, and allied health professions (De Pauw, 2023; Jara et al., 2019). Over the course of history society has covertly deemed the non-disabled body as the "natural way of being and doing" (Janz, 2019). Through this lens humans have designed communities, transportation, recreation, and leisure activities to suit the corporeal standard of the non-disabled (Hansen & Philo, 2007). Consequently, the embodiment of disability has been deemed 'unnatural' or 'unacceptable' within non-disabled spaces (Hansen & Philo, 2007).

The biomedical model suggests that disability is a result of physiological and/or anatomical variations that differ from normative development and are to be corrected or cured

(Roush & Sharby, 2011). To this end, the model then upholds ableist practices through a deficit-based view of disability as it focuses on the reduction of behaviours, symptoms, and physical condition as characteristics to be 'fixed' to fit normative standards, rather than on improving the experiences of participants (Janz, 2019; Leadbitter et al., 2021). Society often holds the medical model as the 'gold standard' thus perpetuating ableist rhetoric across society including education, practice, policy, and policymakers (Janz, 2019). In the context of physical activity and recreation, the biomedical lens has shaped education related to medicine and healthcare including allied health, physical education, and kinesiology (Campbell, 2009; Janz, 2019; Jara et al., 2019). As a result, physical activities, and recreation available to persons with disability are often medicalized, and therefore limited by the lens of re/habilitation of an impaired body or cognitive function, rather than taking into consideration the dynamic experience of the person in relationship to the physical activity and the environment (Palisano et al., 2017). While outside of medical rehabilitation praxis, dance for persons with disability has become more commonplace (Dhami et al., 2015).

The presence of persons who live with visible or invisible disability in dance spaces challenges deeply entrenched perceptions of who is a dancer, what dance looks like, and how dance is performed (Albright, 2011; Aujla & Redding, 2013; Hansen & Philo, 2007; McCarthy-Brown, 2017). Thus, there is a discomfort with how to teach persons who live with disability and how to work with disabled bodies in dance (Fortin et al., 2021). Though the field of dance has begun to expand its reach to include programming for specific populations, programs are often described in therapeutic terms where the goal is rehabilitative, rather than for recreation, as those offerings designed for non-disabled persons.

1.1.1 LANGUAGE around DISABILITY

As language continues to evolve so does the terminology used in relation to disability. Presently there is an ongoing debate around person- or identity-first language in relation to disability (Best et al., 2022; Grech et al., 2023). Person-first language emphasizes the individual and their unique characteristics above the disability (e.g., persons who live with a disability), whereas identity-first language acknowledges disability as part of the identity of the individual (e.g., autistic persons; Grech et al., 2023). While the latter identity-first perspective has been promoted specifically by the autism and Deaf communities (C.A.S.D. Alliance, 2020; Grech et al., 2023), a recent literature review found that language preference across the disability community varies between individuals and communities, including within the autism and Deaf communities (Grech et al., 2023). In recognition of the fact that individuals and groups have differing preferences, the interchangeable use of language preferences is encouraged when writing about disability (Best et al., 2022; Grech et al., 2023; Dunn & Andrews, 2015). At the same time, academic journals may also have specific requirements around the use of language (e.g., Adapted Physical Activity Quarterly specifies the use of person-first language).

As a student researcher in the paradigm of dance and disability I believe it is important to demonstrate inclusion and work to address ableism through my language choices around disability and to consider the broader implications of language (DePauw, 2023). Throughout my teaching and research, including this thesis, I work to centre the individual (first) while simultaneously acknowledging disability as a part of the human experience and the lens through which persons who live with disability view the world. Thus, for the purposes of this thesis and the studies included therein I have chosen to use person-first language. To balance the preferences of the autism community I will also use identity-first language in relation to autism

and the autism community[1]. The preambles to studies two and three (Chapters 4 and 5) include a description of how language around disability was used in each study. To highlight the benefits of participation in dance specific to the characteristics that may arise in NDD the following sections provide a general overview of NDD and dance.

1.2 NEURODEVELOPMENTAL DISABILITY (NDD)

The umbrella term NDD refers to a group of medical diagnoses that share attributes including developmental onset (pre-peri-postnatal), differential diagnoses, and characteristics (physical, cognitive, and adaptive behaviours) (Ally et al., 2018; Jacobson et al., 2007; Leonard & Wen, 2002; Linehan, 2019; Lyall et al., 2017; Sadowska et al., 2020). The expected lifespan of individuals living with NDDs has lengthened due to improved neonatal care, nutrition, and socioeconomic conditions (Krahn et al., 2006).

Health disparities and challenging life transitions are also common among people living with NDDs. Between 18-21 years of age adults who live with NDD typically 'age out' of the education system and transition into adult care. This transition is a time of heightened stress and anxiety for both the individual and their family members as they typically receive more active guidance throughout childhood and adolescence (Ally et al., 2018; Nguyen et al., 2018; Young et al., 2009). When an individual transitions out of pediatric or school-based care into adult care, both the family or primary caregiver (often mothers) and individuals are left to seek out their own solutions for medical care, support, recreation and leisure activities, as well as living situations (e.g., living with family, living in a group home or shifting to independent living) (Ally et al., 2018; Nguyen et al., 2018; Young et al., 2009). For older adults living who live with NDDs functional capability may decrease, resulting in increased insecurity, isolation, and

[1] An exception to this choice can be observed in study one (Chapter 3) that has already been published. In this instance, the publisher specified the use of person-first language only.

loneliness (Sullivan et al., 2019). While there are commonalities between people living with NDDs, there are also clear differences between people with each of the diagnoses encompassed in this thesis (see Chapter Two of this thesis for further details). In the context of NDD the maintenance of functional movement is of particular importance as it supports functional independence across the lifespan.

1.2.1 **NDD and FUNCTIONAL MOVEMENT**

The multifaceted nature of dance makes it an ideal activity to support functional movement and independence. Functional movement refers to the biophysical, psychological, and sociocultural domains of function in relation to well-being and one's sense of a meaningful and healthy life (Cech & Martin, 2011; World Health Organization, 1989). In contrast, functional independence involves the independent execution of activities of daily living (ADLs), as well as the concept of personal autonomy or choice (Reindal, 1999; Rodrigues-Krause et al., 2019). In the context of disability, maintaining one's functional independence may delay or limit the need for support or home care as well as foster engagement in employment and community activities independently for a longer duration. Participation in meaningful PA such as sport, dance, recreation, and various leisure activities may also play a crucial role in maintaining functional movement and independence (Rhodes et al., 2017). Specifically, dance includes cognition, memory, rhythmic motor coordination, physical movement, physical expression of emotion, imagination, and social interaction (Dhami et al., 2015; Fancourt & Finn, 2019). The cognitive and physical benefits of participation in dance can enrich functional movement and support functional independence through the development of kinesthetic awareness (e.g., dynamic balance, postural control, proprioceptive awareness), cognition (e.g., memory), perception (e.g., interpreting sensory experiences to control complex movements), while promoting positive

mental health and increased self-efficacy (Blasing, 2014; Blasing et al., 2012; Karpati et al., 2016; Lopez-Ortiz et al., 2019; ParticipACTION et al., 2015; PHAC, 2018; World Health Organization, 2018). Additionally, it is often forgotten that persons with disabilities also reap the physical, mental, and health benefits of daily PA.

Adaptive dance programming has the potential to further broaden the lens of educators, clinicians, and society broadly, to see beyond the diagnosis and work with individuals who live with NDD. When adapting dance for this population it is thus important to engage a holistic approach, where the physical and emotional/psychological experience of the individual, the dancer, is placed at the centre of the approach (Getchell & Gagen, 2006; Palisano et al., 2020; Palisano et al., 2017). As a rhythmic, interactive, and cognitively engaging activity, dance encourages the freedom of physical expression through movement (Dhami et al., 2015; Lopez-Ortiz et al., 2019). Dance can therefore provide an opportunity for adults who live with NDDs to develop their functional movement in the domains of physical, psychological, and sociocultural development, and overall health and well-being.

1.3 **DANCE**

Dance is a performing art, as well as a form of celebration and expression engaged across cultural and socioeconomic contexts (Fancourt & Finn, 2019). Across the literature, the term ‘dance’ encompasses a vast range of genres and forms, from classical ballet to modern dance, improvisation and creative movement, culturally or historically based folk dance, traditional jazz and tap dance to hip hop, casual social dancing, as well as group cardio dance-based fitness classes (Aujla & Needham-Beck, 2020; DiPasquale & Roberts, 2022; Gutiérrez-Vilahú et al., 2016; Teixeira-Machado et al., 2017; Teixeira-Machado & DeSantana, 2019; Terada et al., 2017; Tsimaras et al., 2012). Common across cultural and formal genres of dance

is the act of learning sequences of dance movements and/or steps, rehearsing and performing sequences of movement, the use of musical accompaniment, and regular practice that occurs in group settings through which social interaction and a sense of community are developed (Dhami et al., 2015). These dance experiences can lead to multi-faceted benefits addressing physical, cognitive, psychological, and sociocultural domains (Blasing et al., 2012; Dhami et al., 2015; Lopez-Ortiz et al., 2019).

1.3.1 **REFLECTING ON DANCE**

All human movement has a rhythm, and human beings are meant to move and connect, to sense and respond, through movement (Kimerer, 2015). Dance engages an intentional rhythmic connection of movement to a musical cadence that forms the physical (non-verbal) communication of emotion, character, or narrative that, for some, can be the truest expression of the human experience. "[...] dancing exercises a fundamental sensory creativity whose nuance and range distinguishes humans from other living organisms." (Kimerer, 2015, p. 12). In professional, recreational, and cultural contexts dance requires the learning of complex whole body movement sequences including various technical and whole-body sensorimotor skills through the reproduction of observed movements (engaging visual information) and instruction (engaging verbal/auditory information) intertwined with musical accompaniment (auditory information) (Blasing, 2014; Blasing et al., 2018; Cross et al., 2006; Karpati et al., 2016; Kimerer, 2015). Dance is then the practice of finely tuned limb coordination, postural control, flexibility, and strength, with the additional cognitive, sensory, and proprioceptive requirements of learning sequences of movement that incorporate direction, spatial and body awareness, rhythm, speed, and physical expression of the self while also striving for a defined aesthetic (Blasing et al., 2012; Dhami et al., 2015; Lopez-Ortiz et al., 2019). Although group cardio dance-

based fitness classes do engage complex movement sequences and the reproduction of observed patterns, the intention of this approach does not typically engage a narrative, the explicit fine-tuning of movement through instructor to student communication, nor the goal of attaining a given nuanced aesthetic (Davies et al., 2012; Fancourt & Finn, 2019; Kimerer, 2015). Thus, the dance-based fitness approach is not included in the present definition of dance.

1.3.2 THE DEFINITION OF DANCE

For the present thesis the term dance references the cultural diaspora and formal genres of dance that involve the active engagement of an individual or group of individuals in the active expression of oneself through movement and music. Dance may also be described as highly structured as it requires the training of precise technical and artistic requirements. Likewise, dance can also be more exploratory where dancers move beyond the boundaries of technique and their physical relationship with the world to embody concepts such as space, time, relationship to others and objects in the space, and effort (Acarón, 2016). Whether structured or more exploratory in nature, these genres routinely require the communication of emotion and/or a narrative, the fine-tuning of movement through observation and instructor to student communication, the goal of attaining a given nuanced aesthetic, attending to a musical pulse (beat) and the intentional use of rhythm and phrasing (Blasing et al., 2018; Cross et al., 2006; Dhami et al., 2015; Leow et al., 2014). In addition to the many benefits of dance the combination of movement to music has been shown to engage the listener both cognitively and emotionally, encourage the perception of both the rhythm and quality of the music, resulting in the translation of these elements through measured steps, sequences, gestures, and expressions (Dhami et al., 2015; Fancourt & Finn, 2019; Teixeira-Machado et al., 2019). Thus, participation in dance

fosters cognitive, psychological, physiological, as well as social and behavioural benefits, all of which are inherently linked to functional capability.

1.4 **REFLEXIVITY**

The whole of this thesis is informed by my experiences teaching dance over the past thirty-six years, including my experiences developing and teaching adapted dance programming for and with individuals who have developmental and acquired disabilities over the past thirteen years. I locate myself in this research topic as an outsider and insider, a researcher who does not have a disability, and a dance teacher who creates programming for and with persons who live with NDD and acquired disability. As suggested by Holmes (2020), the role of the insider/outsider exists on a continuum rather than as a dichotomy. The outsider/insider perspective may shift in relationship to the focus of the research and the role of the researcher within a given study.

I identify as one who does not have a disability but who simultaneously holds the experience of working with dancers who identify as having a NDD (dancers), their families, and support persons. I also identify with the role of the caregiver as one who has witnessed close family members experience the acquiring of disability due to disease, specifically Parkinson's disease and end stage type-II diabetes. Reflecting on these experiences I have come to realize the importance of meeting the dancers where they are, rather than deciding where I feel they should be in relation to their dance experience and level of participation. To understand the lived experience of the dancers is to understand the breadth of their experiences including positive and negative experiences and perceptions. Here, I acknowledge the assumption that dance is a positive or enjoyable experience for all. However, the experience of dance as a whole or specific aspects of the dance experience, may hold negative associations for some individuals. I

acknowledge that the dancers and their support persons may have different understandings of my identity and perspective within this thesis. In contrast to the traditional role of the dance teacher who holds the knowledge and determines what knowledge is to be shared, and when, I recognize persons who live with NDD (studies two and three) and experts (study three) as the 'knowers', or those who hold the knowledge of the experience of disability, or of being an expert in a specific field (Stone & Priestley, 1996).

As I reflect on my previous quantitative and qualitative research experiences that engaged adults who live with NDD, I have come to understand that conducting research on, rather than with, persons with disability furthers the role of researcher as oppressor (Leadbitter et al., 2021; Stone & Priestley, 1996). Although the empirical knowledge I have gained through a positivist quantitative lens upholds this role, quantitative knowledge can provide information that may directly inform instruction and learning in dance. Likewise, the experiential knowledge gained through qualitative narratives can also provide critical insights towards growing our (my) understanding of the lived experience and further inform the development of instruction. My previous qualitative research experience demonstrated the feasibility of engaging persons with disabilities with a range of communication abilities and their support person/s in the interview process more directly (Moola et al., 2020). Further, these experiences fostered my appreciation for the critical narratives and understanding that can only be gained through the qualitative research process.

I recognize that the programming I teach is exclusive in that it is a space where the participants have the shared experience of disability. I recognize that for some individuals this approach may be perceived as ableist, where an integrated setting may be preferable. I also recognize that for some individuals the exclusive adapted setting where all the participants share

the experiences of disability may be considered a safe space and therefore provides more opportunity for instruction, movement, and pace of the class to be adapted to individual capabilities (Suppo & Swank, 2019). I also acknowledge the assumption that all members of the dance community are open to and seeking ways to create dance environments that are inclusive of dancers of all abilities and capabilities. For dance teachers a tension exists between the knowledge of disability and training in adapted dance, how much and what form of instruction is appropriate, the pace of the class, and maintaining the level of challenge needed for those who do and who do not have a disability (Nelson, 2015). In both scenarios the balance between knowledgeable, effective instruction and adapting the learning environment is crucial to creating an environment and culture that fosters the dance education of all dancers, regardless of ability or capability**.**

The intention of the present thesis is to examine how adaptive dance interventions are used and measured in the current literature, broaden our collective understanding of the experience of disability within the adapted and/or inclusive dance class, perspectives of adaptive teaching approaches, perceptions of inclusion, and to gather expert recommendations for teaching adaptive dance and creating inclusive dance environments. This thesis will inform and encourage a shift from adaptive and/or inclusive instruction being designed *for* persons who live with NDD, where the teacher is the holder of the knowledge, to the design being guided with the input and knowledge of the dancers.

1.5 **METHODOLOGY**

For this series of studies multiple methodologies are engaged to comprehend the ways in which dance instruction and dance environments may affect the dancers. According to Anguera et al. (2018) a multiple methods approach allows for different methodological approaches to

coexist within a larger project where each study may stand alone yet may also inform the other studies within the project. In contrast to a mixed methods approach where the mixing of the methods is required throughout the analysis, a multiple methods approach may engage both qualitative and quantitative methodologies, and each study is then analysed separately to fully examine a larger research question (Anguera et al., 2018; Plano Clark & Ivankova, 2016). This thesis will use a multiple methods approach by drawing on three separate methodologies: a scoping review (study 1), narrative inquiry (study 2), and a Hybrid-Delphi approach (study 3).

1.6 **RATIONALE FOR THESIS**

The following three studies will inform future dance interventions, training in adaptive dance for dance and physical educators, and the development of an adaptive dance approach. In the first study (see Chapter 3) the literature on dance and adults who live with NDD and the characteristics of dance programs and interventions for adults who live with NDD was assessed using a scoping review methodology. The findings of the first study directly inform both remaining studies. The purpose of the second study was to qualitatively engage adults who live with NDD who participate in dance through narrative inquiry to understand their experiences in dance and gain insight into the meaning of dance to them. The semi-structured interviews used photo elicitation as a tool to facilitate conversations around how adaptive strategies are received and what strategies were effective for the dancers, and to understand the meaning of dance for the participants. Informed by the findings of the previous two studies the purpose of the third study was to gather the recommendations of a range of experts on adaptive dance inclusive of community, dance, and clinical experts who identify as having, or support someone who has, NDD. Using a Hybrid-Delphi approach expert recommendations to guide what instructional strategies are best to engage in adapted dance were sought. The panelists were engaged in the

process of developing a set of prioritized recommendations that will guide the development of an approach to adapting dance, a training program for current and future dance educators, and an adaptive dance intervention.

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CHAPTER 2

THE CONCEPTUAL FRAMEWORK and BACKGROUND

2.0 THE CONCEPTUAL FRAMEWORK

This thesis is framed using the constraints model of development (Newell, 1984). I have chosen the constraints model of motor development as a framework because it captures the multidimensional nature of individual motor development, instruction, and the learning environment (Newell, 1984). This model and a brief overview of the background related to the model are described separately in the following sections.

2.1 CONSTRAINTS MODEL

For this thesis the adaptation of dance for persons who live with NDD is framed using the constraints-based model of motor development which incorporates concepts derived from the information processing and perception-action theories of motor control (Newell, 1984). The constraints model of motor development considers the physical and cognitive aspects of the individual and their diagnosis, as well as the affective and environmental factors that may encourage or discourage participation as equally important (Roush & Sharby, 2011). The constraints-based model is a valid pedagogical and instructional approach for the adaptation of movement for persons who live with disability (Gagen & Getchell, 2004; Getchell & Gagen, 2006). Newell's constraints-based model is a composite of dynamical systems motor learning theory and developmental perception-action theory (Gagen & Getchell, 2004; Gibson, 2014; Newell, 1984, 1986). From this vantage point motor development encompasses three categories of constraints to the development of movement throughout the life course: i) Individual; subdivided into physical and functional constraints, ii) task constraints, and iii) environmental constraints (Newell, 1984, 1986). Constraints are not inherently "bad", instead constraints are said to be dynamic in nature and may encourage or discourage movement at varying degrees of importance (Gagen & Getchell, 2004; Newell, 1984). Thus, constraints are said to shape our

development throughout the lifespan, where our physical and affective development is directly influenced by how and what instruction is given, opportunities to explore movement as they may expand or limit skill learning, and the societal, cultural, and familial influences and assumptions within our environments that may encourage or discourage participation. To contextualize the constraints-based model a brief overview of dynamical systems theory and the developmental perspective of perception-action are presented next.

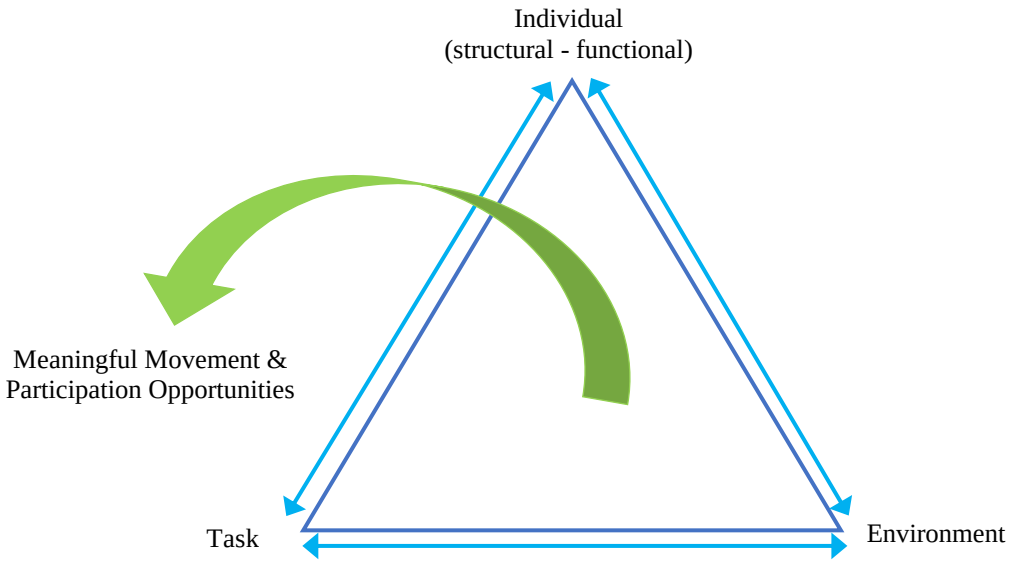

Figure 1. *A visual of the constraints model of motor development (adapted from Gagen & Getchell, 2004; Newell, 1984)*

2.1.1 DYNAMICAL SYSTEMS THEORY (DST)

For performers of all capabilities, at any developmental stage, coordination is essential to learning and performing movement. The dynamical systems theory (DST) highlights the relationship between how a task is learned and what is to be learned. A dynamical approach to motor learning includes the active process of discovering, and learning to exploit, the laws and mechanics associated with a task or skill (Bongaardt & Meijer, 2000; Vereijken et al., 1992). For instance, in the early stage of throwing an individual begins from a standing position and extends

two arms forward with minimal use of the hands, resulting in the ball dropping rather than being propelled toward the target. This process is described as 'freezing' of the degrees of freedom of the movement into larger movement (body) segments (Bongaardt & Meijer, 2000). With practice and growth, the individual learns to 'release', or exploit, the degrees of freedom to their advantage by using the articulation of the joints of the arm, adding a step forward in the direction of the target. Eventually the rotation of the torso is engaged to increase the force placed on the ball to achieve greater speed and distance. Practice then facilitates the process of learning how to reduce the muscular forces required for task performance, with consistency (Vereijken et al., 1992).

DST considers the emergence of the more mature skill as a process of 'self-organization', where task difficulty must be increased to a point where a disruption in the movement occurs and the motor system is challenged to exploit the degrees of freedom, without conscious control, to attain the most effective task performance ('self-organization') (Hofsten, 1989). Although this perspective challenges other traditional motor program perspectives, the strength of this perspective is that it goes beyond the learning process of the individual and takes into consideration the task/apparatus itself (e.g., the speeding up of a treadmill, the increase in the tempo of a metronome) and, perhaps most importantly, highlights the importance of the design of instruction pertaining to the task. However, it is important to acknowledge that this perspective also wholly disregards the role of the motor program or feedback in motor skill acquisition (Schmidt, 1975, 2003). Although DST has been found, and I agree, to oversimplify the learning and development of coordination and disregard the role of neuromotor processes, it does illuminate the importance of the interactive relationship between movement (coordination), how the task is presented/taught, and the environment (Hofsten, 1989).

2.1.2 **PERCEPTION-ACTION**

The constraints model of motor development also incorporates a developmental perspective of perception-action that is rooted in Gibson's perception action theory of vision (Gibson, 2014). Gibson suggests that relevant perceptual information from the environment is revealed through our intentions and active interactions with the environment (Gibson, 2014; Mossio & Taraborelli, 2008). Invariant sensory information is selected through these interactions, therefore from this perspective human perception is considered 'direct' and does not involve internal representations of the environment (Gibson, 2014; Mossio & Taraborelli, 2008). Broadly characterized, perceptual invariants are not limited to any one specific sensory modality (e.g., vision) but are multimodal in nature (somatosensory, vestibular, and sensory modalities) and are dependent on our interactions with the environment. Perceptual information is selected from the diverse sensory information made available through our physical interaction with the environment (Gibson, 2014; Mossio & Taraborelli, 2008). Motor equivalence refers to the motor systems ability to use the invariant information and how the motor system can adapt to the environment or to perform goal-directed movements (Mossio & Taraborelli, 2008). In other words, perceptions gained through invariant features are said to allow the achievement of specific movement goals. Thus, the constraints-based model recognizes that perceptual information from our environment is then considered to be transformation specific as information from the environment shapes the perceptual environment through our actions (Mossio & Taraborelli, 2008).

2.1.3 **INFORMATION PROCESSING AND THE MOTOR PROGRAM**

In the context of instruction, I feel it is important to acknowledge the role of information processing and the motor program. The information processing perspective suggests that our

motor performance draws on existing information stored in the primary motor cortex and is informed by sensory information including visual, auditory (including instruction), and proprioceptive information. Literature on goal-directed reaching considers the processes required for the initiation of reach, which involves the motor program and sensory processing, and the corrective processes required for limb-target control where sensory information guides the limb to the movement end (the target) (Elliott et al., 2020; Elliott et al., 2017). Schema theory suggests that discrete tasks engage the parameters of known motor programs that are stored in the motor cortex as a representation of the invariant features of a skill (Schmidt, 1975). This abstract representation (the motor program) is proposed to consist of a set of parameters that apply to a specific group of skills from which we can determine what type of movement is required for a specific task, such as sequencing of submovements, relative timing, and relative force that could be scaled according to the requirements of a related task (Schmidt, 1975; Shea & Wulf, 2005). Each time the motor program is accessed, and practiced, it is thought to be updated and strengthened with each movement performance. Two states of memory are involved in this process; recall is specific to attributes of previous performance, and recognition reflects sensory information such as proprioceptive and exteroceptive feedback (vision, audition, etc.) as it pertains to performance (Schmidt, 2003). At the same time, feedback is used to detect errors and to update the parameters of the schema each time it is accessed. Missing from the information processing perspective is the consideration of elements that constrain movement, as defined by dynamical systems theory.

In the context of adapting dance for adults who live with NDD, the constraints-based model and information processing are viewed as complementary, though historically have been counter to one another. The constraints model of motor development acknowledges individual

physical and affective development, the task considers how instruction is given and may be adapted, and the environment involves the influence of learning, cultural, and community environments. Whereas the information processing perspective recognizes the influence of the motor program, memory, and the processes of sensory integration on motor performance, in turn highlighting how instruction may influence these sensorimotor processes.

A limitation of the constraints model of motor development is that the assessment of constraints is typically based on the (outside) observations, rather than from the lived experiences of the individual. To address this limitation, in study two (Chapter 4) I chose to situate the constraints model of motor development in the lived experience of persons with disability. To accomplish this, I incorporated embodied knowledge theory into the constraints model of motor development (Lakoff & Johnson, 1999; Scully 2012). In study three (Chapter 5) I again chose to provide additional context to the constraints model of motor development by incorporating the social model of disability (Oliver & Barnes, 2012). The social model of disability was incorporated to focus on the ways in which the dance community and dance instructors might address the inclusion of persons with disability from a social and political perspective. This evolution is addressed throughout this thesis in the preambles to Chapter 4 and 5.

3.0 BACKGROUND RELATED TO DISABILITY

In the context of the constraints model of motor development (described in Section 2.1) and physical activity (e.g., dance, physical education, and adapted physical activity) disability is often viewed as negative or as preventing an individual's movement or participation (Getchell & Gagen, 2006). Importantly, the intention of the constraints model of motor development is not to judge an individuals' ability, but to simply consider what characteristics (physical, affective,

task, environmental) encourage different types of movement (Getchell & Gagen, 2006; Newell, 1986). A foundational understanding of the diagnoses included under the label of NDD provides an understanding of how a diagnoses may influence the ways an individual may physically and socially participate in a physical activity. The following section acknowledges and briefly describes both the unique and shared characteristics between and across NDD diagnoses. I recognise that presenting the following section creates a tension within this thesis specific to the discussion presented in Chapter One around the biomedical and the social models of disability. Specifically, some may view the presentation of the descriptions of each diagnosis as problematic, as this section may be perceived as using and/or supporting a biomedical view of disability. Using a model of constraints lens the common characteristics between and within diagnoses is presented as a frame of reference, rather than to stereotype or to generalize a diagnosis, as the characteristics of a diagnoses may (or may not) constrain an individual's participation in dance, or physical activity (Getchell & Gagen, 2006). Importantly, the recommendations arising from study three (Chapter 5) support the need for ongoing education opportunities for instructors and assistants around the characteristics of disability.

NDD is an umbrella term that describes a heterogenous group of diagnoses including intellectual development disorder, autism spectrum conditions, Down syndrome, and cerebral palsy. In Chapter One a general overview of NDD and the common characteristics such as onset and the challenges of transitioning into adult care, was provided. To highlight the diverse and shared characteristics NDDs, a brief outline of each diagnosis is presented.

3.1.1 **INTELLECTUAL DEVELOPMENT DISORDER (ID)**

ID has been defined as deficits in general cognitive abilities such as reasoning, planning, and abstract thinking, resulting in impaired adaptive functioning and onset during the

developmental period (American Psychiatric Association, 2013). The classification of function in ID has shifted from being based on IQ, where the focus was on the severity of the diagnosis, to adaptive function within the domains of conceptual (language, knowledge, and memory), social (empathy, social judgment, and ability to follow rules), and practical domains (self-care, organization, and daily living skills) (Krahn et al., 2006; Linehan, 2019; Marrus & Hall, 2017). The complexity of the diagnosis may also overlap with differential diagnoses including autism, language disorders or delays and epilepsy (Marrus & Hall, 2017). Twenty-five percent of children who live with ID experience behaviours described as tantrums/meltdowns and physical aggression (towards themselves or others) which may stem from communication capabilities that may limit one's ability to express themselves or to explain reasons for physical or emotional distress (Marrus & Hall, 2017). In comparison to those their neurotypical counterparts adults who live with ID may experience poorer health because of a complex matrix of individual factors such as genetics, contributing behaviours (e.g., nutritional habits), and environmental factors such as social circumstances (e.g., residential settings that promote inactivity), isolation, and inadequate access to healthcare (Krahn et al., 2006; Linehan, 2019).

3.1.2 AUTISM SPECTRUM CONDITIONS (AS)

The diagnosis of autism may occur in early childhood (from 6-18 months to 3 years) or later and has been described as involving impairments in social communication and interaction with accompanying repetitive behaviours or restricted interest in a topic or object (Croen et al., 2015; Fortuna et al., 2016; Lyall et al., 2017). Associated diagnoses may include ID, attention deficits, sensory sensitivity, seizure disorders, anxiety, depression, oppositional defiant disorder, and sleep disturbances (Croen et al., 2015; Lyall et al., 2017). Adults who live with AS share the experience of developing health conditions observed in neurotypical adults (e.g., hypertension,

hyperlipidemia, etc.) yet are often undiagnosed due to barriers to health care (Fortuna et al., 2016). Motor deficits may be observed as unique gait, walking on tiptoes, or clumsiness (American Psychiatric Association, 2013). PA levels for autistic persons also tend to be lower than their neurotypical counterparts (Healy et al., 2018).

3.1.3 **DOWN SYNDROME (DS)**

DS has been defined as an intellectual disability resulting from a genetic syndrome caused by the replication (in part or full) of the 21st chromosome (Jacobson et al., 2007). Moderate to profound cognitive impairment may be accompanied by distinct facial features and a range of characteristics such as hypotonicity, hyper-extensibility and poor behavioural responses. Delays in the language development along with attention difficulties, reduced inhibitory control, stereotypic and repetitive behaviour, stubbornness, impulsivity, agitation, and sensory dysregulation are commonly noted in DS (Korlimarla et al., 2021). Multiple age-related comorbidities including cataracts, hearing loss, hypothyroidism, congenital heart disease, and Alzheimer's disease, are correlated to premature aging (Jacobson et al., 2007; Korlimarla et al., 2021). The most common developmental characteristics affecting motor development in DS are hypotonia and ligament laxity (excessive joint flexibility). Tone (hypotonia) can be improved but developmental delays in motor function typically remain (Korlimarla et al., 2021). Due to reduced institutionalization and improved treatment of comorbid conditions, such as congenital heart disease, persons with DS are now living longer lifespans (~ 60 years of age) (Korlimarla et al., 2021).

3.1.4 **CEREBRAL PALSY (CP)**

The diagnosis of CP is non-progressive and affects motor function and posture throughout the lifespan (Eunson, 2012; Rosenbaum et al., 2007; Sadowska et al., 2020). It is an

umbrella term that encompasses disordered movement, posture, and/or motor function with an average prevalence between 1.5 and 3.0 per 1000 children (Eunson, 2012; Rosenbaum et al., 2007; Sadowska et al., 2020). Motor function disorders are often accompanied by dysfunctions of sensation, perception, cognition, communication, behavioural, epilepsy, and secondary musculoskeletal disorders (Sadowska et al., 2020). Life expectancy has improved due to improved neonatal care, nutrition, prevention and management of respiratory infections, and surgery for scoliosis (Eunson, 2012). Despite these changes, the prevalence of CP has not decreased over the past four decades (Eunson, 2012; Sadowska et al., 2020). It is known that reduced levels of PA and increased sedentary time are risk factors for chronic diseases such as cardiovascular disease and diabetes for neurotypical individuals; the same holds for persons with CP (Verschuren et al., 2016). Regardless of the functional capability of persons who have CP it is equally, if not more so, important to develop the practice of incorporating PA into one's life to maintain/improve cardiorespiratory endurance, muscle strength and flexibility, and to reduce sedentary behaviour (Verschuren et al., 2016).

3.2 **SUMMARY**

NDD has been described as a heterogeneous group of diagnoses that commonly involve an individual's cognitive, affective, and neuromotor capabilities. Arising from dynamical systems theory, the constraints-based model acknowledges the interactive nature of the individual, the environment, and the task. It recognizes that the opportunity to participate in PA is a key requirement for developing, and maintaining, motor skills and coordination across the lifespan for all individuals. Here, information processing and the motor program are recognized as motor development is also dependent upon related motor programs and how sensory

information from the environment is integrated for the planning, and guiding, of accurate and efficient movement.

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PREAMBLE TO CHAPTER 3

I chose to begin with a scoping review (Chapter 3) to establish the foundation for the two subsequent studies of this thesis. While the objectives of this review could be viewed as engaging a biomedical lens of disability, the viewpoint of this review reflects the literature identified in the scoping review. In fact, one of the findings of this scoping review is that the literature often engages a medicalized view of disability. When writing this scoping review, I framed the analysis and interpretation using the constraints model of motor development (as described in Chapter 2).

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CHAPTER 3

STUDY 1: A synthesis of the characteristics of dance interventions engaging adults with neurodevelopmental disabilities: A scoping review

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J.L. designed the protocol for the current study and led the review procedure, analysis, and interpretation of the data. E.B. assisted with the review process as the second reviewer. C.G. acted as a third reviewer. All authors critically revised the draft of the manuscript for intellectual content and approved the final draft for submission to *Adapted Physical Activity Quarterly* on September 12, 2022.

ABSTRACT

Purpose: Dance can encourage physical activity and promote physical, cognitive, and social development for adults who live with neurodevelopmental disabilities (NDD). Dance is defined as a form of expression that may be structured, exploratory, and/or cultural. Current literature supports the benefits of participation in dance for persons who live with NDD, however less is known about what characteristics support participation in dance.

Materials and Methods: A scoping review was conducted to synthesize the characteristics of dance interventions, teaching strategies, and outcome measures used to assess the efficacy of dance interventions. Searches were conducted across six databases and the results were screened according to: i) adults ≥18yrs of age with a diagnosed NDD, and ii) the program incorporated activities that fall within our definition of dance.

Results: A range of dance forms and NDDs were represented across the fourteen studies reviewed. Few provided explicit details of the dance interventions, nor how instruction was adapted. All studies that measured fitness, mobility, balance, posture, and functional activity showed significant improvement. Studies that measured psychosocial and well-being focused on autistic characteristics and showed mixed results.

Conclusions: Details of interventions, instructions, measures of movement performance, and the relationship between outcomes and the interventions require further development and research.

IMPLICATIONS FOR REHABILITATION

- Dance is a multimodal activity that can improve aerobic capacity, postural control, passive ROM, and strength in adults with neurodevelopmental disability at all levels of function.
- Participation in dance may be recommended as an option for recreational physical activity as current evidence supports dance as an effective physical activity, and/or supplement to therapeutic goals, with physiological as well as psychosocial benefits.
- When considering dance as a recreational activity it is important to consider the program and instructors approach, as well as the experience and training of the instructor, to best match the goals of the dancer with the goals of the specific program.

4.0 INTRODUCTION

Worldwide approximately 785-975 million persons aged 15 years and older live with a disability; of those, 110-190 million are classified as having a severe, or more complex, disability (Committee, 2011). The term neurodevelopmental disability (NDD) references a group of diagnoses that occur during the developmental period and includes intellectual disability (ID), Down syndrome (DS), cerebral palsy (CP), and autism spectrum disorder (ASD) (American Psychological Association, 2013). Similar across NDDs are the: i) category of risk pertaining to parental and social function of the family unit across biomedical, social, behavioural, educational domains occurring during pre-peri-post natal periods (Linehan, 2019), ii) differential diagnoses, and iii) physical, cognitive, and adaptive behaviours (Jacobson et al., 2007; Sadowska et al., 2020). The characteristics of NDD are also heterogeneous in nature, varying between individuals and across the lifespan. These can include changes in cognition and adaptive behaviours, such as communication, self-care, functional mobility, and socialization (Gardiner et al., 2018). Between 18- 21 years of age, persons who live with NDD typically 'age out' of the education system to adult services. Families are often left on their own to find social opportunities and medical care for family members (Franklin et al., 2019). Combined with a lack of adaptive or integrated physical activity (PA) opportunities this transition often increases isolation, anxiety, depression, and sedentary behaviour, resulting in poor health outcomes (Croen et al., 2015; Lopez-Ortiz et al., 2019; Sullivan et al., 2019). Participation in PA is critical for adults who live with NDD as they are vulnerable to social isolation, respiratory, and cardiovascular disease at an earlier life stage than their neurotypical counterparts (Liptak, 2008). Available PA opportunities often welcome individuals who identify with a broad definition of disability rather than limiting

participation to a specific population. To better reflect PA opportunities in community we chose to focus on NDD broadly.

Dance is a multidimensional performing art that engages participants through rhythmic motor coordination tasks, the activation of sensory and perceptual-motor systems broadly, imagination, and social interaction, in relation to musical accompaniment (Dhami et al., 2015; Fancourt & Finn, 2019). Consistent participation in dance may encourage further participation in PA for enjoyment and health benefits as it promotes physical, cognitive, and social development, and supports the management of mental health (Cairney et al., 2019; Dhami et al., 2015; Palisano et al., 2020). Despite the growing evidence for the benefits of dance for persons with disabilities, the availability of programs designed for persons who live with NDD remains limited (Pontone et al., 2020).

Dance is also an expression of self, emotion, and heritage across most cultural and socioeconomic contexts (Fancourt & Finn, 2019). The term ‘dance’ can encompass a range of genres such as formal, highly structured (e.g., classical ballet, jazz), exploratory (e.g., creative dance), street dance and cultural dance, as well as dance-based fitness. Each of these genres requires learning complex whole body movement sequences including technical and whole-body sensorimotor skills through the reproduction of observed movements and instruction with musical accompaniment (Blasing, 2014; Cross et al., 2006; Karpati et al., 2016). Formal, exploratory, street, and cultural genres of dance routinely require the communication of emotion and/or a narrative, the fine-tuning of movement, the goal of attaining nuanced aesthetic, and the intentional use of the musical pulse, rhythm, and phrasing (Blasing et al., 2018; Cross et al., 2006; Dhami et al., 2015; Leow et al., 2014). In contrast, the goal of dance-based fitness is to challenge aerobic and physical fitness through continuous movement and does not typically

engage the previously described characteristics. Therefore, dance-based fitness interventions were excluded from this review (Davies et al., 2012; Fancourt & Finn, 2019; Kimerer, 2015).

Systematic reviews and meta-analyses examining the effects of dance and physical activity interventions for adults with disabilities span genres of dance and encompass both developmental (CP; (Lopez-Ortiz et al., 2019), ASD; (DeJesus et al., 2020; Takahashi et al., 2019), ID; (Hackney et al., 2012; Martínez-Aldao et al., 2019), and acquired diagnoses such as Parkinson's disease (Berti et al., 2020; Carapellotti et al., 2020) and fibromyalgia (Bravo et al., 2019). Overall, this evidence indicates that dance and movement to music may improve physical function (i.e., body awareness, postural stability, balance), mobility (i.e., gait, walking, strength of lower limbs), health, and health related quality of life. Although the evidence supports the benefits of participation in dance for persons who live with NDD broadly, less is known about what specific program characteristics and instructional strategies are most beneficial, nor how efficacy of the dance programs/interventions have been measured. We chose to focus this scoping review on adults who live with NDDs because there is a need to understand program characteristics and instructional strategies that are specific for adults who live with NDDs (Pontone et al., 2020).

The guiding framework for this scoping review was the constraints model of motor development. This model proposes that both motor and perceptual development are driven by the interaction of the individual, the task, and the environment (Gagen & Getchell, 2004; Getchell & Gagen, 2006; Newell, 1986). In this review the environment is defined as the characteristics of the dance class and instruction, if/how adaptations are provided in relationship to the individuals' physical and affective characteristics, and, in a research setting, which outcome measures were used. The constraints model of motor development posits that instruction should consider the

capabilities of the participants and is a key factor in both motivation and motor development (Gagen & Getchell, 2004; Getchell & Gagen, 2006). Instruction can include a variety of forms of augmented feedback, including strategies, cues, directions, or the posing of questions to encourage creativity and group interaction. The outcome measures used across the literature are considered in the present review as the variety of measures used suggest how the efficacy of dance interventions have been evaluated and which of the ecological domains (the individual, task, or environment) have, or have not, been considered and evaluated.

In alignment with Arksey & O'Malley's (2005) reasoning for engaging a scoping review methodology, the primary objective of this review was to determine and summarize the characteristics of, and common instructional strategies used in, dance interventions for adults who live with NDDs. The secondary purpose was to synthesize the outcome measures used to assess the efficacy of dance as an intervention. The tertiary purpose was to consider the relationship between the reported outcomes and the characteristics of the dance interventions. The findings from this scoping review will deepen our understanding of how dance has been used as an intervention, what instructional strategies have been engaged, and what outcome measures have been used specifically with adult dancers.

4.1 **METHODS**

A scoping review was conducted using the five-stage framework (Arksey & O'Malley, 2005) informed by Levac (2010) and Colquhoun (2014). Specifically, we conducted the scoping review using the five stages proposed by Levac (i.e., the identification of the research question, relevant studies, the study selection, charting the data, and collating, summarizing, and reporting of the results). The review process was iterative, with continued refinement of terms and definitions, as well as explicit documentation of the review process (Colquhoun et al., 2014). The

review is also reported according to the PRISMA-ScR reporting guidelines ((Tricco et al., 2018); see Appendix D). The following research questions were considered: i) What are the characteristics of, and instructional strategies used in, dance interventions for adults who live with NDDs (e.g., type, structure and form of the class, teaching strategies, use of music, duration)? ii) In what ways has the efficacy of dance interventions for adults who live with NDD been measured? And iii) How do the instructional strategies and outcome measures used relate to the reported outcomes of the dance interventions for adults who live with NDDs?

4.1.1 IDENTIFICATION OF RELEVANT STUDIES

A librarian from the University of Manitoba was consulted to establish broad search terms (Arksey & O'Malley, 2005). To retain a broad scope of the search no limits were set for study design. Relevant studies were sought using three approaches: i) using the search terms related to the aim of the study (danc* AND disabilit*, dance* AND autis* and the combined queries of both combinations were used in each database search), ii) hand searching of reference lists of relevant reviews to identify any further studies related to the objectives of this review, and iii) a citation chasing search was conducted by hand searching the citation lists of three relevant articles of interest. Three populations were identified in the original search and therefore one article of interest was selected from each population that was: published within five years of the original search, fit the definition of dance for this study, and focused on either ASD, ID, or CP (Martínez-Aldao et al., 2019; Stamou et al., 2019; Teixeira-Machado et al., 2017). Searches were conducted in Scopus, Pub Med, ERIC, APA Psych Info, Academic Search Complete, and Cochrane databases. Additional searches were also conducted using the search terms danc* and autism, ASD, intellectual disability, cerebral palsy, Down syndrome, DS, and developmental disability (separately). A sample search strategy is provided in Appendix C. An additional eight

articles were identified using a citation chasing strategy. The original search was conducted in March of 2020 and updated in July of 2022.

4.1.2 STUDY SELECTION

The search results were uploaded into EndNote 20 reference manager software (The EndNote Team, 2013) and duplicates were removed. Two primary reviewers (JL and EB) conducted an independent screening process, and a third reviewer was available in case of any disagreements (CG). Articles were screened for eligibility using Rayyan (a web-based systematic review platform that facilitates blinded review of articles) (Ouzzani et al., 2016). Each study must have evaluated dance as an intervention, rather than as a dialogue on the experience of dance performance, or a discussion of a dance company or performance experience. Specific eligibility criteria for articles to be included were: i) studies engaged adults (≥18yrs of age, or if the mean age of all study participants was ≥18yrs) diagnosed with NDD; ii) dance interventions or programs that fit the definition of dance; iii) original articles were written in English and published in peer-reviewed journals; and iv) articles were available through database subscription or interlibrary loan.

4.1.3 CHARTING THE DATA

All data were extracted by the two primary reviewers and input into a spreadsheet in Microsoft Excel® (version 6.15). Extracted data included: (i) title, (ii) author name/s and year published, (iii) population, (iv) age and number of participants and participant characteristics, (v) purpose of the study, (vi) the form of dance used in the intervention, (vii) description and duration of the dance intervention, (viii) training or qualifications of instructor and location of intervention, (ix) measures used, (x) study results and significance. Each study was then

categorized for sorting purposes according to the dance form and the details of the intervention provided.

4.1.4 COLLATING, SUMMARIZING AND REPORTING THE RESULTS

The data was synthesized using two approaches: i) a numerical summary and description of the types of interventions and instructional approaches, and ii) items were organized and summarized qualitatively to consider the outcomes and implications of each study (Colquhoun et al., 2014).

4.2 RESULTS

From the initial search (n= 2,287) a total of seventy full text articles were screened and a total of 14 studies met the inclusion criteria (see Figure 1).

4.2.1 INTERVENTION CHARACTERISTICS

The range of diagnoses reported by participants included ASD (*n* = 4; 29%; (Hildebrandt et al., 2016; Koch et al., 2015; Mastrominico et al., 2018; Mateos-Moreno & Atencia-Doña, 2013)), CP (Gross Motor Function Classification System (GMFCS) III-V; *n* = 3; 21%; (Teixeira-Machado et al., 2017; Teixeira-Machado & DeSantana, 2019; Terada et al., 2017)), ID (*n* = 3; 21%; (Barnet-López et al., 2015; DiPasquale & Kelberman, 2018; Tsimaras et al., 2012)), DS (*n* = 1; 7%; (Gutiérrez-Vilahú et al., 2016)), and clusters of diagnoses (ID and/or ASD, *n* = 1; 7% (Kim & Hong, 2019); NDD, *n* = 2; 14%; (Aujla & Needham-Beck, 2020; DiPasquale & Roberts, 2022)). Intervention durations ranged from one session per week over the course of seven weeks to two or more sessions per week for twelve months. The dance interventions engaged dance movement therapy (DMT; *n*= 5; 36%; (Barnet-López et al., 2015; Hildebrandt et al., 2016; Koch et al., 2015; Mastrominico et al., 2018; Mateos-Moreno & Atencia-Doña, 2013)), contemporary (*n* = 5; 36%; (Aujla & Needham-Beck, 2020; DiPasquale & Kelberman, 2018; DiPasquale &

Roberts, 2022; Teixeira-Machado et al., 2017; Teixeira-Machado & DeSantana, 2019)), mixed forms (*n* = 1; 7%; (Gutiérrez-Vilahú et al., 2016)), folk (*n* = 1; 7%; (Tsimaras et al., 2012)), ballroom (*n*= 1; 7%; (Terada et al., 2017)), and creative movement (*n* = 1; 7%; (Kim & Hong, 2019)). Ten studies (71%) used a quasi-experimental design and four (29%) were randomized control trials. Five studies (36%) provided examples of the type of instruction (e.g., cues, strategies) used in the intervention. Five studies (36%) reported the role of dance assistants in the intervention and two of these studies reported that the assistants were trained pre-intervention. See Appendix A, Table 12 for a summary of the included studies.

4.2.2 **OUTCOME MEASURES**

Across the studies reviewed the primary outcome measures were grouped into three main categories: physical fitness, balance, and mobility (n = 6, 43%; (DiPasquale & Kelberman, 2018; DiPasquale & Roberts, 2022; Gutiérrez-Vilahú et al., 2016; Teixeira-Machado & DeSantana, 2019; Terada et al., 2017; Tsimaras et al., 2012)), psychosocial and behavioural (n = 7, 50%; (Aujla & Needham-Beck, 2020; Barnet-López et al., 2015; Hildebrandt et al., 2016; Kim & Hong, 2019; Koch et al., 2015; Mastrominico et al., 2018; Mateos-Moreno & Atencia-Doña, 2013)), and disability and health (n = 1, 7%; (DiPasquale & Kelberman, 2018)). Three (21%) studies engaged measures explicitly designed to assess individuals who live with NDD, five (36%) studies applied measures validated for related diagnoses such as stroke, and five (36%) studies used measures validated for neurotypical individuals.

Figure 2

Flow Chart of the Search Process and Results

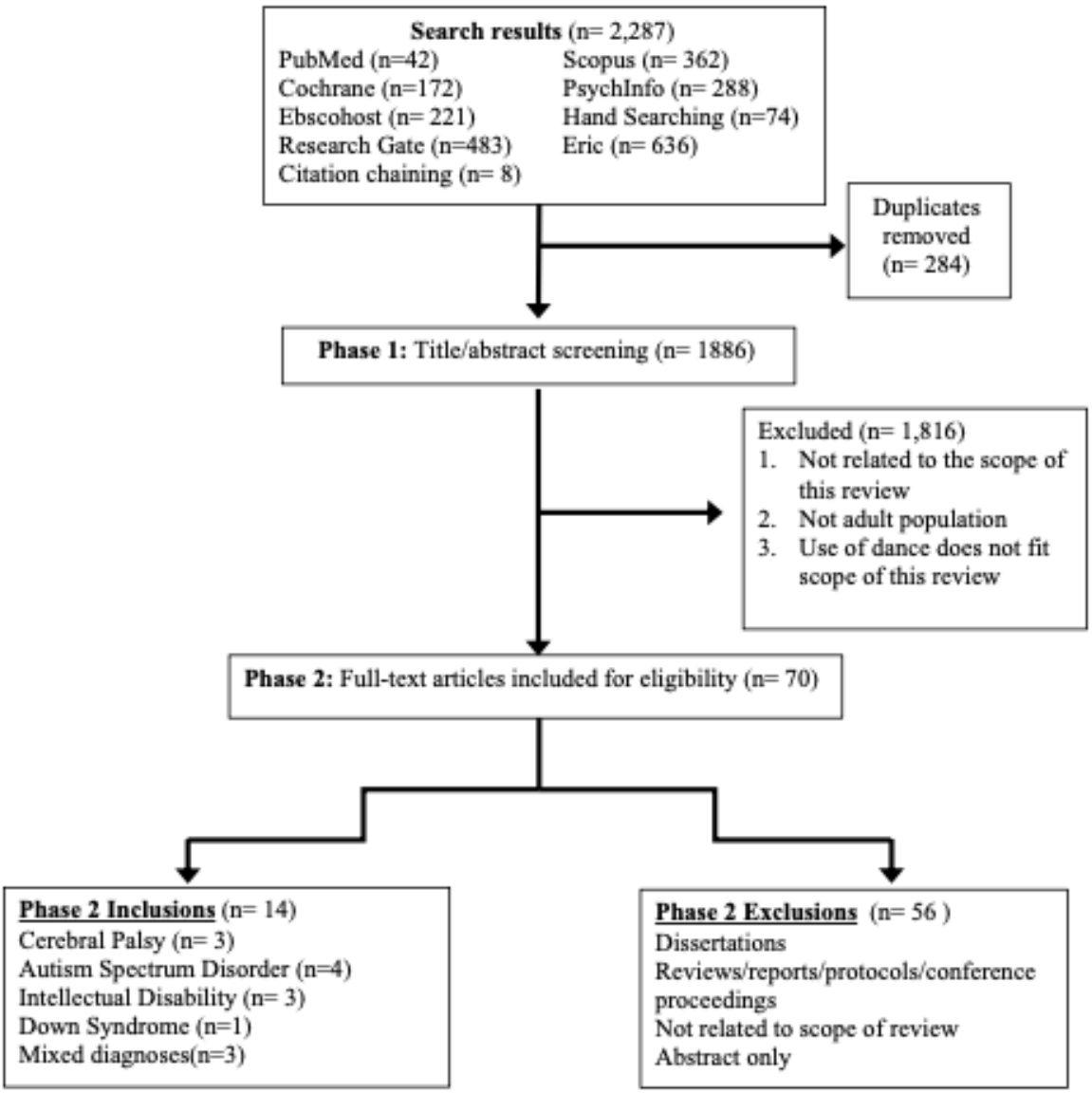

Table 1

Physical fitness, balance, and mobility measures

Population	Measures
ID	Dynamic balance (using a stabilometer); measured at 30-45-60s intervals
ID	Postural stability (static) and Centre of Pressure (both using a Wii balance board)
DS	Centre of pressure (using a force plate)
CP (GMFCS V)	Peak O_2 (O_2 P; a calculation of participant oxygen uptake (VO_2)/ participant heart rate (HR))
CP (GMFCS III-V)	Passive range of motion of the hip, knee, and ankle joints (using a pendular fleximeter)
CP (GMFCS II-V)	World Health Organization Disability Assessment Schedule (WHODAS), Gross Motor Function Classification System (GMFCS), Functional Independence Measure (FIM)
NDD	Strength (using dynamometer), Knee extension test, Timed-up-and-Go (TUG), 30s Sit-to -stand test, Functional Reach Test (FRT)

Note. None of the studies used DMT as an intervention.

*4.2.2.1 **PHYSICAL FITNESS, BALANCE, AND MOBILITY MEASURES***

Seven of the fourteen studies (50%) included physiological and balance measures or assessments of functional activities (DiPasquale & Kelberman, 2018; DiPasquale & Roberts, 2022; Gutiérrez-Vilahú et al., 2016; Teixeira-Machado & DeSantana, 2019; Terada et al., 2017; Tsimaras et al., 2012). All seven studies support improvements in the assessment of physical fitness, balance, mobility, and functional activity with participation in dance. While a range of NDD were considered in this category of physical measures, none of the studies that included measures of physical performance included autistic dancers (see Table 1). Notably, three studies did specifically engage adults with more complex CP diagnoses (GMFCS level III-V (Teixeira-Machado et al., 2017; Teixeira-Machado & DeSantana, 2019; Terada et al., 2017)). Overall, the seven studies in this category demonstrated that for a range of NDD, participation in dance can influence significant changes in upper and lower body strength and flexibility (NDD; (DiPasquale & Kelberman, 2018)), aerobic capacity and lower leg joint ROM (CP; (Teixeira-Machado & DeSantana, 2019; Terada et al., 2017)), both dynamic (DS and ID (Tsimaras et al.,

2012)) and static (DS; (Gutiérrez-Vilahú et al., 2016)) balance, and independent function, self-care, mobility, and communications (CP; (Teixeira-Machado et al., 2017)).

Table 2

Psychosocial and Behavioural Measures

Population	Measures	DMT
ASD	• The Revised Clinical Scale for the Evaluation of Autistic behaviour (assesses behavioural symptoms as a measure of efficacy of the intervention)	*
	• (Psychological well-being) Bipolar 12-item "Heidelberger State Inventory" • (Body awareness) Subscale Body Awareness of the Bipolar 15-item "Questionnaire of Movement Therapy" • (Self–other awareness) a self-constructed scale • (Empathy) a short form of the Emotional Empathy Scale • (All self-reported measures)	*
	• Scale for Assessment of Negative Symptoms (SANS); 24 items divided into 5 subsets: blunted affect, alogia, abulia avolition, anhedonia, diminished attention	*
	• Cognitive and emotional empathy questionnaire (CEEQ) • Subscale Empathic concern of the Interpersonal Relativity Index (IRI) questionnaire • (All self-report measures)	*
ID/ASD	• PaMA - perceptual and motor ability (for children 4-6 yrs of age); • Emotional experience assessment tool (teacher observation & assessment) • Facial emotion recognition ability assessment tool	
ID	• Human Figure Drawing: participants were asked to draw a whole person (timed task;15min.)	*
NDD	• Personal wellbeing index for intellectual disability (PWI-ID) questionnaire (self-reported)	

Note. (*) indicates the Dance Movement Therapy interventions (DMT).

*4.2.2.2 **PSYCHOSOCIAL AND BEHAVIOURAL MEASURES***

Seven of the fourteen studies included measurement of psychological, social, or behavioural aspects with inconsistent results. Five studies (36%; (Hildebrandt et al., 2016; Kim & Hong, 2019; Koch et al., 2015; Mastrominico et al., 2018; Mateos-Moreno & Atencia-Doña, 2013)) engaged persons with ASD, one study focused solely on ID (14%; (Barnet-López et al., 2015)), and another on NDD broadly (14%; (Aujla & Needham-Beck, 2020)). Four studies (29%) included observational measures and three studies (21%) included self-report measures. Overall, the measures of behaviour, including symptoms and body knowledge, did demonstrate significant effects of participation in dance on cognition, body knowledge, the ability to regulate

emotion and behaviour, instinct, and self-adaptive behaviours (see Table 2). However, psychosocial measures that centred on empathy, personal well-being, perceptual motor ability, or emotional experience had inconsistent results.

4.2.3 RELATIONSHIP BETWEEN INTERVENTION DELIVERY AND OUTCOMES

To better understand why dance may or may not be an effective and meaningful form of PA in relation to each category of outcome measure, any improvements (or lack thereof) in the reported outcome measures were reviewed in relation to each specific dance intervention. Five of the fourteen studies reviewed (36%) did not provide a transparent or comprehensive description of the dance intervention and/or clear links between the results and intervention (see Appendix B, Table 13). The remaining nine studies are presented in more detail below.

4.2.3.1 PHYSICAL FITNESS AND MOBILITY OUTCOMES

Of these nine studies, five used unique dance methods and engaged physical fitness or mobility measures or assessed functional activity. The level of detail provided ranged from low to medium (see Appendix B, Table 13). Two separate groups of authors linked the significant improvements in dynamic balance and postural control of individuals who have ID (Tsimaras et al., 2012) and DS (Gutiérrez-Vilahú et al., 2016) in Greek folk-dance and mixed dance (classical, modern, and creative dance) interventions to the integration of sensory stimuli through the vestibular, auditory, and visual systems during the interventions. In one case, a contemporary dance intervention that engaged locomotion and body mobility was linked to improved physical fitness, balance, posture, and coordination (Teixeira-Machado et al., 2017). Improved cognition was also linked to the processes of learning and memory, and the refining of sequential movements in relation to the rhythmic musical accompaniment (Teixeira-Machado et al., 2017).

The authors of another study, using the same intervention, linked the intentional movements used in the intervention to the cognitive engagement in dance, as well as the use of the upper and lower limbs, resulting in enhanced kinesthetic awareness, musicality, and the physical expression of emotion (Teixeira-Machado & DeSantana, 2019). These enhanced concepts are suggested to be a result of engaging the processes of movement control, providing distraction from physical pain and/or daily stressors, a change in emotional state, and the practice of building awareness of self through movement (Teixeira-Machado & DeSantana, 2019).

4.2.3.2 ***PSYCHOSOCIAL OUTCOMES***

Four of the nine studies used psychosocial measures to assess change; in all cases these studies used a DMT approach. The level of detail provided in these four studies ranged from Medium-High to High (see Appendix B, Table 13). The use of DMT-music therapy intervention that engaged rhythmic activities such as music, singing and rhythm, as well as a range of body movements and imagery is suggested to have led to improved impulse regulation, improved attention, and emotional self-control in individuals with ASD (Mateos-Moreno & Atencia-Doña, 2013). A mirroring strategy often used in DMT was suggested to have elicited improvements in the self-reported outcomes of decreased negative affect and expression of emotion (Hildebrandt et al., 2016), body awareness, self-other awareness, psychological well-being, and social skills, as well as therapist observed self-other distinction and enjoyment in adults with ASD (Koch et al., 2015). The effect of (DMT) mirroring strategies that pair individuals with ASD together did not have a significant effect and was linked to persons with ASD often having difficulty expressing themselves in social situations (Mastrominico et al., 2018).

4.3 DISCUSSION

This scoping review focused on the literature pertaining to dance interventions that engaged adults who have NDD. The specific aims of this review were to: i) identify the characteristics of, and strategies used in, the dance interventions, ii) summarize which measures have been used, and iii) consider the explicit relationship between the reported outcomes and the characteristics of the dance interventions as discussed in each study. The constraints model of motor development was a guiding framework as it considers both motor and perceptual development to be shaped and driven by the interaction of the individual, the task, and the environment (Gagen & Getchell, 2004; Getchell & Gagen, 2006; Newell, 1986). How the learning environment is designed, including how instruction is provided or structured, is directly relevant to performance improvements, motivation, and learning (Gagen & Getchell, 2004; Getchell & Gagen, 2006).

4.3.1 CHARACTERISTICS

Overall, the lack of detail and transparency of the intervention descriptions was identified as a concern for replication in research or applications in communities. Four of the fourteen studies shared the same approach (DMT) and provided enough detail to facilitate replicability of the study (Koch et al., 2015; Mastrominico et al., 2018; Mateos-Moreno & Atencia-Doña, 2013). In contrast, those studies that engaged other adapted dance approaches, such as Greek, ballroom, classical, modern, and creative movement dance forms, were described inconsistently. In addition, of the studies that engaged dance assistants (n=5), only three of these indicated that training was provided for the assistants. Even if training was indicated, details on the form and frequency of training, and the level of involvement of the assistants in how instructions and/or movements were adapted to suit the capabilities of the dancers, were not reported. It is of interest

and encouraging that three studies did include individuals with more complex CP (GMFCS IV and V) (Teixeira-Machado et al., 2017; Teixeira-Machado & DeSantana, 2019; Terada et al., 2017). However, details of how instructions and/or movements were adapted to suit the capabilities of the dancers were not reported. Overall, information regarding the adaptation of movement, and how dance assistants were instructed to engage with the dancers, are needed to address how, and if, the environment was adapted. More specific details about the instructional techniques are important to include for both the replication and application of the studies.

4.3.2 CONFLICTING DEFINITIONS

DMT is described as a primarily psychological intervention that uses dance as a psychotherapeutic tool to achieve clinical goals rather than dance as solely a recreational activity (DiPasquale & Roberts, 2022; Mastrominico et al., 2018). Thus, DMT takes a biomedical approach to adapted dance, and therefore conflicts with the definition of dance used for this scoping review (i.e., where participation in dance is supplemental to therapies). For this reason, the remainder of the discussion will not include the DMT studies (n = 5), thus reducing the number of studies reviewed to nine. This shift further highlights the need for research on dance as a recreational intervention to i) provide greater descriptions of dance interventions directed to adults who live with NDD, ii) develop guidelines and/or training that are applicable to a range of dance forms, and iii) engage the broader dance community through knowledge translation.

4.4 MEASURES

Three areas of concern arose regarding the types of measures used: i) in many cases the measures were not validated for NDD, ii) the psychosocial measures often required comparison to a normative scale, or were self-report measures, and iii) assessments of movement quality

were not included. The physical fitness and mobility measures (see Table 1) did provide objective assessment of how participation in dance could benefit overall physical function and, apart from ASD, appear to relate to common issues reported with each diagnosis. Although the physical fitness and mobility measures were not validated for NDD, they did assess pre to post change, rather than compared to normative scales. The psychosocial measures used (see Table 2), although not always validated for NDD, do provide insight into perceptual and motor ability, emotion, and well-being. The latter measures were predominantly used in dance intervention studies that focused on ASD. These measures were administered as either a scale where a rank or score described a level or category of behaviour, or as a self-report measure where the participant completed a questionnaire. Although the language used in self-report tools, such as the Personal Wellbeing Index for Intellectual Disability, have been modified for the ID population (Cummins & Lau, 2005), the nature of the self-report tool inherently assumes a level of participant understanding and comprehension.

Absent from the literature are measures of movement performance. Using movement performance and kinematic measures to assess changes in temporal and spatial characteristics would allow researchers to track any improvement in movement control without labelling change as "good" performance, or in relation to normative definitions. To demonstrate how movement performance might be improved through dance it is recommended that measures such as the reciprocal Fitts' task, reaching or choice reaction time tasks, and movement kinematics be considered (Elliott et al., 2020; Foster et al., 2020). Because of the heterogeneity of the physical characteristics in NDD and the influence of environmental factors on learning, it is also recommended that movement effectiveness be assessed through measures that are validated for NDDs and/or that consider the relationship between the individual and their environment

(Leadbitter et al., 2021). For example, to address the diversity of individual characteristics (e.g., autonomy, quality of life) and inter-related concepts (e.g., anxiety, communication) within neurodiverse populations the International Classification of Functional, Disability and Health (ICF) Core Sets have been developed for Autism, ADHD, and Cerebral Palsy (Branch, 2017; Leadbitter et al., 2021).

4.4.1 THE INTERVENTION-OUTCOME RELATIONSHIP

To understand this relationship the details of the dance interventions (non-DMT) were reviewed. Four studies provided clear links between the study outcomes and intervention characteristics but provided minimal intervention details (see Appendix B, Table 13). For example, reflecting on the group nature of Greek folk dances, the bilateral support provided when holding hands in circle dances is proposed to enhance dynamic balance, cooperative group work, and proprioceptive input (Tsimaras et al., 2012). This characteristic is suggested to have played a role in strengthening the integration of vestibular, auditory, and visual information (Tsimaras et al., 2012). However, details about how, when, and how often the circle and partner work was used throughout the intervention was not reported. Likewise, Gutiérrez-Vilahú et al. (2016) linked improvements in static-stance stability to how a mixed dance intervention was explicitly designed to focus on core strength, proprioception, and balance (with and without vision). The explicit use of visual cues was found to be an effective strategy for the development of balance control. The authors do provide an outline of the intervention and the intention of each section without reporting explicit detail.

4.5 LIMITATIONS

While we worked to conduct a comprehensive scoping review, there are limitations that must be acknowledged. First, our specific definition of dance may differ from others' definition,

thus the literature captured may be considered by some to be less inclusive than other literature (Bidonde et al., 2018). We chose to focus on dance as recreation as opposed to therapy because the focus of this review was on adults who live with NDD who have expressed a desire to have meaningful activities that are not medicalized (Fortin et al., 2021). That said, we acknowledge that it is possible to use a Hybrid approach where dance could be both recreational and therapeutic. Second, while the focus of this review was to capture the scope of available research, the searches were limited to peer-reviewed journal articles published in the English language. Third, the heterogenous nature of the included populations (ASD, ID, DS, CP) may limit the specificity to certain physical, sensory, and cognitive differences unique to each population. At the same time, it is critical to recognize the additional heterogeneity within a given diagnosis, as well as the commonalities across NDDs.

4.6 RECOMMENDATIONS AND CONCLUSION

Details of the dance interventions and adaptations of dance, measures of movement quality, and the linking of outcomes in relationship to the characteristics of the dance interventions were areas found to be lacking in the reviewed studies. In addition, studies engaging autistic persons were focused on psychosocial constructs such as behaviour and empathy rather than on physical fitness or mobility. The addition of detailed intervention descriptions that include examples of instruction, strategies, and cues, will improve the clarity of the interventions, and enhance both the reproducibility and transferability of the findings to applied settings. Given the heterogeneity of NDD, and the range of functional and communication abilities inherent across NDD, it is recommended that future studies engage a person-centred approach, examine ways to adapt the dance environment, and explicitly address how and in what ways dance instruction has been adapted (Getchell & Gagen, 2006; Palisano et

al., 2017). It is also recommended that future studies examine which specific aspects of dance and dance instruction (e.g., mirroring, holding hands, interacting with music) might influence changes in physical fitness, mobility, quality of movement, or psychosocial constructs. The addition of measures of movement quality will provide a deeper understanding of how dance may produce meaningful change in movement performance. Further, examining the relationship between specific characteristics of the dance interventions and study outcomes will provide a better understanding of what characteristics are key for observed changes. A more direct link between intervention details and observed improvements will also provide meaningful information for the application of specific approaches to inclusive adaption of dance instruction. The application of these recommendations across NDD populations will inform theory and practice of inclusive and adaptive pedagogy, specifically, the culture and praxis of teaching inclusive dance in adaptive settings.

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5.0 PREAMBLE TO CHAPTER 4

Chapter 4 (study two) used narrative inquiry to gain insight into the dancers' experiences with the goal to better understand both the lived experience and the meaning of dance for the participants. In study two I intentionally chose to challenge the ableist perspectives around dance and disability and to centre the perspectives and experiences of the dancers.

Two strategies were incorporated in the methods to actively support the dismantling of ableism in the research: i) the language around disability and ii) using a trauma-informed approach during the interview process (Grech et al., 2023; Isobel, 2022). First, as each participant with NDD also participated in dance within their own community, I chose to use the term 'dancers' when referring to this specific group. Second, as this research is situated in the disability community, I believe it is imperative that I recognize that trauma is often a part of the experience of the disability community. Trauma-informed strategies were used in the interview process including face-to-face (virtual) participant screening to support familiarization, understanding of the study purpose, and the interview process, the provision of the interview questions in advance to the participants, the option to prepare answers in advance of the interview, and the option for participants to read their answers during the interview (Isobel, 2022).

As indicated in Chapter Two, here the constraints model of motor development informed the analysis and discussion of study two. Importantly, the constraints model of motor development is thought to consider each category of constraints (individual, task, environment) as equal rather than prioritizing one constraint over another (Getchell & Gagen, 2004; Newell, 1984). To prioritize the lived experience of the individual and ground the constraints model of

motor development in the experience of the individual I chose to incorporate embodied knowledge theory into the model (see Figure 2; Lakoff & Johnson, 1999; Scully, 2012). Embodied knowledge theory is described in the next section.

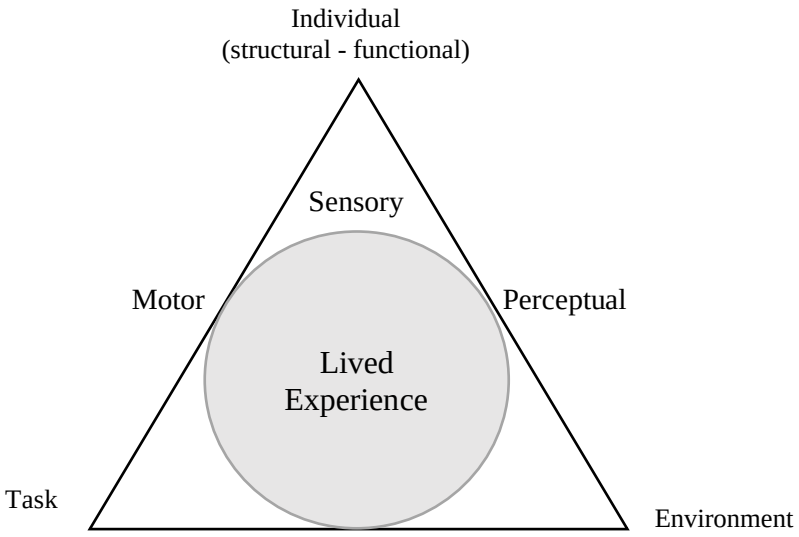

Figure 3. *A visual depicting how embodied knowledge theory was incorporated into the constraints model of motor development (Getchell & Gagen, 2006; Newell, 1986)*

5.1 **EMBODIED KNOWLEDGE THEORY**

"People perceive in order to move and move in order to perceive. What, then, is movement but a form of perception, a way of knowing the world as well as acting on it?" (Thelen, 1995). Embodied knowledge theory proposes that the human (lived) experience engages both perception and movement (Lakoff & Johnson, 1999). More specifically, to understand the lived experience of the individual is to also recognize the interdependence of sensory, perceptual and motor experiences of the individual (Scully, 2012). In relationship to disability, Scully further suggests that embodied knowledge then acknowledges the tendency of conventional philosophy to treat the disabled body as a barrier rather than a source of knowledge (2012). This perspective dissolves the philosophical separation of the body and mind, and recognizes the role of perception as not only how we receive information sensorily, but also how the body inhabits

the world (Scully, 2012). Knowledge of the world is then "mediated through the corporeal expressions of action and competencies" which evolve with each interaction with and within our environments (Scully, 2012). Our motor and sensory experiences (a combination of visual, auditory, tactile, and kinaesthetic components) collectively provide context for, and enhance our understanding, of abstract thought (Scully, 2012). In study two the combined lens' of embodied knowledge theory and the constraints model of motor development centred the voices of the dancers with disability to understand their experiences in dance.

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CHAPTER 4

STUDY 2: "When We Dance It's Never Just Dancing...": Understanding the experiences and perspectives of adult dancers with neurodevelopmental disability.

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CONTRIBUTIONS OF AUTHORS TO THE MANUSCRIPT:

J.L. designed the protocol for this study and led the interviews, analysis, and interpretation of the data. E.B. assisted with the interviews when participants were known to the first author. J.R. assisted with the initial analysis process and discussion regarding saturation. All authors critically revised the draft of the manuscript for intellectual content and approved the final draft for submission to *Research in Dance Education*.

ABSTRACT

Dance is an activity that engages the physical, cognitive, and social dimensions of movement and health. Research in dance and disability is often focused on reducing symptoms and behaviours, rather than individual experiences. Using a constructionist lens, we explored the meaning of dance as shared through personal narratives from adult dancers who live with neurodevelopmental disability (NDD) and aimed to deepen our understanding of their experiences and perspectives on instruction. Interviews were conducted with twenty-one dancers. Through an iterative thematic analysis, we identified three main themes and contextualized them using the combined constraints model of motor development and embodied knowledge theory: i) dance is who I am, ii) dance provides skills for life, iii) inclusive instruction and environment. Collectively the dancers' gained a sense of direction and belonging that fueled their motivation to interact socially. We also found that through strengths-based and person-centered approaches the dancers' experienced greater purpose, direction, and gained skills applicable to dance and daily life.

6.0 INTRODUCTION

Dance is a unique physical activity that brings together physical, cognitive, and social skills in what can become a meaningful lifelong pursuit. The rhythmic and adaptable environment of dance has been found to make positive contributions to the physical, cognitive, and social dimensions of health for persons with disabilities (Cherriere et al., 2019; Dhami et al., 2015; Teixeira-Machado et al., 2017). Current perspectives on accessibility and inclusion reinforce that individuals of all abilities be welcomed into dance and physical activity opportunities and urge us to create accessible and inclusive environments, opportunities, and educational approaches centred on the experiences of persons with disabilities (Canada, 2023; Franits, 2005; Svendby, 2016). In the context of dance, the constructs of accessibility and inclusion challenge Eurocentric and Western perspectives of who is a dancer, how dance is taught and performed, and how the dance environment and culture are constructed and nurtured.

Adaptive (i.e., classes tailored to a specific, or group of, diagnoses) and/or inclusive (i.e., dancers with and without disability within the same class) dance opportunities have been made available in a variety of settings including universities, arts organizations, and commercial dance studios. However, the inclusion of the personal experiences and perspectives of dancers with disabilities in the design and delivery of dance programs is scarce (Nelson, 2015; Purcell Cone, 2015; Suppo & Swank, 2019). The disability rights movement mantra “nothing about us without us” reminds us that those without disability cannot fully understand the experience of and the societal issues which impact persons with disability (Franits, 2005). The development of an adaptive dance approach specific to neurodevelopmental disability (NDD) requires that as researchers and dance educators we grow our understanding of experience of disability and examine our assumptions of who is a dancer, what dance looks like and how it is performed, and

how the dance environment impacts the individual experience (Shmulsky et al., 2022). The present study lends the experiences and insights of dancers who live with NDD to the literature and will inform the development of future adaptive approaches to dance.

6.1 BACKGROUND

In the context of sport and leisure activities, individuals who have the common experience of a NDD often participate together (e.g., Special Olympics). NDD is a broad label that references a range of diagnoses including cerebral palsy, Down syndrome, intellectual disability, and autism (Ally et al., 2018; Linehan, 2019; Sadowska et al., 2020). Recent research indicates that adults who identify as having a NDD participate in fewer sport and leisure activities as compared to adults without disabilities (Hassett et al., 2021). There are multifaceted benefits associated with participation in sport and leisure activities, including enhanced autonomy and competence, experiences of social approval and support, and fun (Farrell et al., 2004). That said, not everyone enjoys sport and the availability of inclusive and accessible opportunities that are not sport-centric are limited (Lopez-Ortiz et al., 2019). Opportunities to participate in physical activity (PA) and leisure that are designed primarily for fun and recreation, are equally as important as activities designed with a rehabilitative focus.

Research in disability and dance is often viewed through a biomedical lens and is primarily focused on the rehabilitation of the symptoms of NDD rather than on individual strengths and capabilities (Ladwig et al., 2023; Leadbitter et al., 2021). The literature is overwhelmingly focused on children with limited consideration of the lifelong participation of adults. Our recent scoping review found that adaptive dance opportunities were more often directed to those who are physically independent, can communicate independently, and require minimal physical assistance to move throughout their daily lives (Ladwig et al., 2023). In other

words, movement-based opportunities are directed to individuals who can participate with a fair amount of physical independence. While inclusive opportunities should be available, some suggest that fully inclusive opportunities may not be the best fit for every individual that lives with NDD (Shirazipour et al., 2020). Shirazipour and colleagues reported that participation with peers who also have a disability may improve the experience and quality of participation (2020). In the context of dance, it is important for the dance community to understand the experience of persons with disabilities in the dance environment. The purpose of this study was to engage the dancers in semi-structured interviews to understand and appreciate their experiences in, and perspectives of, dance. The objectives of this study were to understand: i) the experiences of adult dancers engaged in inclusive/adapted dance programming, ii) the dancers' perspectives on instruction, and iii) the narratives of the dancers broadly.

6.2 **THE FRAMEWORK**

The present study was informed by the constraints model of development and theory of embodied knowledge (Gagen & Getchell, 2004; Lakoff & Johnson, 1999; Newell, 1984). The constraints model recognizes that our movement experiences across the life span are shaped by the relationship between the individual (physical and emotional), task (instruction and the action/movements), and environment (physical, social, and cultural) (Gagen & Getchell, 2004; Newell, 1984). Notably the influence of societal and cultural norms, as well as role of the instructor, are seen as integral to shaping skill development. Embodied knowledge theory acknowledges that an individuals' lived experience reflects how the body inhabits the world inclusive of their sensory, perceptual, and motor experiences (Lakoff & Johnson, 1999; Scully, 2012). The incorporation of embodied knowledge theory into the constraints model of development grounds the model in the experience and perspectives of the dancers who live with

NDD as only the ‘knowers’, I.e., dancers who live with NDD, can know the experience of disability within the dance community and that their experience of dance and disability is inherently linked to their interactions within a social (learning) environment (Newell, 1984; Scully, 2012). To develop an adapted approach to dance that is informed by the experiences of the dancers, researchers and dance educators must acquiesce to being the learner rather than the ‘knower’. When we create space to intentionally engage the narratives of the dancers our understanding of the experience of disability (in dance) will be nurtured (Stone & Priestley, 1996). This study received ethical approval from Research Ethics Board 1 at the University of Manitoba and adhered to the tenets of the Declaration of Helsinki (2013).

6.3 **METHODS**

6.3.1 **DESIGN**

The study was conducted using a constructionist lens that recognizes that knowledge and meaning are developed through the context of our interactions within our homes, communities, and society (Crotty, 1998). Ontologically the experiences of the dancers were each considered to be an authentic reflection of their constructed reality (Denzin & Lincoln, 2011). The dancers’ personal narratives were collected through virtual or in-person semi-structured interviews. Photo-elicitation was used as a tool to stimulate engagement, direct and foster attention, and conversation around each interview question (Danker et al., 2019; Ewing & Hughes, 2008; Lumia et al., 2021). Following consent, the interview questions were shared with the dancers to encourage thoughtful consideration of the questions along with the invitation to select two web-based or personal images that related to each of their responses (Barone & Eisner, 2006; Danker et al., 2019; Jacob, 2012; Lumia et al., 2021). The dancers were encouraged to prepare their responses in advance of the interview. During the interview, the dancers could choose to read

their responses out loud. A selection of generic images was made available to those who chose not to select their own images. The generic images were presented with each interview question and the dancers could select the image/s that they felt reflected their response. This approach allowed for rich and descriptive data to be gathered that highlighted the dancer's experiences (Harrison et al., 2017; Orum et al., 1991).

To capture and understand the experiences of the dancers it was important to recognize the diverse communication capabilities that exist within the continuum of NDD (Barton, 2005; May et al., 2019; Mietola et al., 2017). Previous literature endorses the inclusion of persons who work with and/or for dancers such as support persons provided through day programs or those hired by families and carers such as parents or siblings to support communication and comprehension (e.g., rephrasing the researchers' questions) and reduce potential anxiety (Moola et al., 2020). When invited by the dancers the voices of the support persons aided the contextualization of the dancers' narratives and selected images and provided support during the interviews (Danker et al., 2019; Lumia et al., 2021). These partnerships encouraged a shared dialogue where the perspective of the dancer was central and the support person was able to provide contextual information, and at times provided translation of physical responses such as eye and head movements (Leadbitter et al., 2021; Moola et al., 2020).

*6.3.1.1 **THE INTERVIEW***

To ease any potential anxiety or concerns of the dancers the interviews began with an introductory question that provided some background detail regarding activities they enjoy outside of dance, as well as of their current dance program or class. Conversations were initiated by introducing the images selected by the dancers for each question. A series of prompts were used to foster the conversation and deepen understanding (see interview guide; Appendix E). All

natural silences, or pauses, in the conversation were embraced to encourage thoughtful responses, conversation, and support a comfortable interview pace (Kvale & Brinkmann, 2015; Rabionet, 2011). All interviews ranged from 45-75 minutes in length and were video recorded using the Zoom© platform. Field notes were taken to process and debrief how each interview unfolded noting moments of expression (e.g., laughter, eye contact, gesturing with eyes, hands, or head) (Birks et al., 2008). An audit trail was kept that included raw data, field notes, transcripts, analysis iterations, and a reflexive research journal (Lincoln & Guba, 1985; Nowell et al., 2017).

6.3.2 **POSITIONALITY**

As qualitative researchers we reflected on our preconceptions, assumptions, and biases throughout the research process (Holmes, 2020; Tracey, 2010). The interviews were conducted by the primary author who is a doctoral candidate and a research assistant, both who identify as dancers. The primary author has taught dance for over thirty years and has taught adaptive dance for over a decade. The research assistant has danced for twenty-six years and has assisted in an adaptive dance program for four years. During the pre-interview (before consent was attained) the interviewers shared their relationship and interest in the paradigm of dance and disability with the dancers. A third researcher who has an extensive research background in disability and rehabilitation was engaged in the coding process. The third researcher provided a different perspective to the analysis process as their relationship to disability is primarily in research and rehabilitation. We recognize that our perspectives of the meaning of dance for persons with NDD is based on our previous interactions with persons who participate in adaptive dance in the context of dance, research, and as rehabilitation; an outsider/insider perspective that lacks the direct insight of the individual lived experience of the dancers. Collectively we recognize that the

lived experiences of disability and dance cannot be extracted from the physical experience of the person as the experience of dance may hold negative associations for some individuals. In this study the dancers are recognized as the 'knowers' or as those who hold the knowledge of the experience of disability in dance (Stone & Priestley, 1996). Thus, we have chosen to use the term 'dancers' when referring to the participants who live with a NDD who participate in dance.

6.3.3 **RECRUITMENT**

A purposive sampling process was undertaken through disability organizations across Canada who then shared the information across social media (Potts & Brown, 2005). Eligibility criteria defined that participants must have been: i) 18 years of age or older, ii) diagnosed with a form of neurodevelopmental disability, and iii) have participated in adapted/inclusive dance programming within the last 3 years. Participants were also given the option to invite a support person to participate with them in the interview (in this case, both were considered participants). Recognizing the prevalence of trauma in the disability community, we engaged a trauma-informed practice to foster rapport and trust between each participant and the researcher (Isobel, 2021; Keen et al., 2022). Individuals who expressed interest in the study were asked to attend a pre-interview where the interviewers shared their background, an overview of the study, the interview process, and the photo-elicitation task. The pre-interview provided an opportunity to ensure clarity and understanding of the research purpose and process. It also created an opportunity for dancers to ask questions that could inform their decision to consent (Isobel, 2021; Nicholson et al., 2013).

6.3.4 **POWER BALANCE**

Some dancers were current students of, or known to, the primary researcher. In this instance a research assistant, trained in the interview process and field notation, conducted the

interview. To ensure confidentiality and maintain a standard of ethical practice the research assistant transcribed the interviews and field notes and de-identified the transcripts for these interviews. A third researcher who was not involved in the interviews participated in the coding process.

6.4 **ANALYSIS**

An iterative reflexive thematic analysis was used (Braun & Clarke, 2019; Nowell et al., 2017). Each interview was de-identified and transcribed verbatim alongside the video recordings and shared back to the dancers for their review, amendment, and acceptance (Lincoln & Guba, 1985; Nowell et al., 2017). Reviewed transcripts were then uploaded to NVivo 12© (Ltd., 2020) software for analysis. NVivo was used to code, contextualize, and interpret the interview data (Braun & Clarke, 2019). A reflexive journal was maintained throughout the coding process and debriefing occurred with the second researcher to consider initial thoughts on the codes, evolving themes, and saturation (Braun & Clarke, 2022; Nowell et al., 2017). The transcripts were created by the interviewer (JL or EB) and included the collected images, field notes and notes on non-verbal communication such as gestures (e.g., pointing, head nods or turns), facial (e.g., smiles or frowns), and vocal expressions (e.g., words or sounds) from the interview video recordings (Lincoln & Guba, 1985; Nowell et al., 2017).

An inductive analysis was used to reveal the codes grounded in the data (Coffey & Atkinson, 1996). Selected text was coded and then grouped by category throughout this phase (Braun & Clarke, 2022; Nowell et al., 2017). To ensure analytic rigor two researchers (JL and JR) independently reviewed the first transcript and conducted initial coding of salient phrases and passages. The researchers then met to discuss, compare, and come to an agreement on the coding process. This process was repeated across the first four interviews. The data collection

and analysis continued in an iterative manner, with new interview data added to the codebook with the analysis of each transcript. Saturation was defined as the point at which the data did not lead to any new codes and adequate depth of understanding was reached (Braun & Clarke, 2021; Morse, 2015). The researchers agreed that saturation occurred at the twelfth interview and was confirmed by the thirteenth and fourteenth interviews indicating the end of recruitment. Diagrams were created to further explore and visualize the relationships between codes, to collapse, revise and generate codes and themes, and to consider existing theory (Attride-Stirling, 2001; Morse, 1999; Nowell et al., 2017). Visualizing the data in this manner transformed the 'chunks' of information gathered into more meaningful data (Attride-Stirling, 2001; Coffey & Atkinson, 1996; Nowell et al., 2017).

6.5 **FINDINGS**

6.5.1 **PARTICIPANTS**

Seventeen dancers and six support persons completed the pre-interview process and consented to the interview. Three individuals did not attend their interview, nor did they respond to requests to reschedule. Fourteen dancers were interviewed (nine male and five females; see Table 3). The mean age of the dancers was thirty years-old and the average experience in dance was twelve years. The dancers identified autistic (autism spectrum; AS), as well as living with Down syndrome (DS), attention deficit hyperactivity disorder (ADHD), and cerebral palsy (CP) (see Table 3). Thirteen individuals participated in dance one to three times a week (in-person or online) and one individual participated in dance five days a week. Eight dancers provided their own images. Four dancers invited their support person/s to take part in the interview. Support persons were welcome to participate in the interview in the manner they felt comfortable. For example, rephrasing questions, translating non-verbal communications (e.g., eye blinks and/or

head movements), expanding on the communications of dancers who were non-verbal, and contributing their own perspective to the interview. The support persons' contributions were clearly identified within the dancers' transcript and any contributions included in the analysis and discussion were clearly identified as the support persons perspectives.

Table 3

Participant profiles

Total participants			**Self-reported Diagnoses**		
Dancers	14	(M =9; F = 5)	Autism (AS)	7	M=5; F=2
Support persons	6	(4 dyads; 1 triad; F=6)	Down syndrome (DS)	5	M=2; F=3
Average age (of dancers)	30		Attention deficit hyperactivity disorder (ADHD)	1	M=1
Average years in dance	12		AS & Cerebral Palsy(CP)	1	M=1
			Other	1	F=1

Note. M=self-identified as male; F= self-identified as female.

The dancers shared their perspectives and personal experiences in dance, in the culture of dance, and with instruction received in dance. We identified three central themes in the data: i) Dance is who I am, ii) Dance provides skills for life, and iii) Inclusive instruction and dance culture. The codes collapsed into each main theme are detailed in Table 4. We acknowledge the intersection of the themes 'dance is who I am' and 'dance provides skills for life' and have chosen to present each theme individually for clarity.

Table 4

Overview of themes

Theme	Codes
Dance is who I am	My identity & purpose
	I feel a sense of belonging & connection
	Makes me happy & gives me joy
Dance provides skills for life	Practice social skills
	I am (cap)able; (self-efficacy & esteem)
	Dance organizes my life
Inclusive instruction and dance culture	Environment of acceptance and safety
	Tailor Instruction
	Strategies used by instructor

6.5.2 **DANCE IS WHO I AM**

This primary theme represented the dancers' identity which arose from the purpose, identity, belonging, connection, and joy, that each dancer derived from dance. The dancers described their experiences in dance as critical to their identity as they expressed how, through dance, they found a sense of purpose as well as belonging and connection with others who identified the same. For example, one participant expressed how dance is central to their daily life and is what brings them joy, and in turn motivates them to explore life more fully: "...dance is like my life now.[...] and it's what, like, brings me joy and happiness. It's kind of an outlet to everything in my life and everything that makes me happy" (#19). This quote expressed how the experience of participating in an activity that is meaningful has given the dancer a sense of purpose and direction. This sense of purpose influenced their experience in the dance class as well as their life outside of dance.

Support persons expressed their observations of the ways the dancer communicated dance as their purpose or passion. One support person characterized purpose or passion as the opportunity to express themselves creatively and how dance transformed the dancer they support "[...]when they chose to go back to contemporary lyrical dance[...] it's like a light came on for them. They found their passion" (#23). This dancer also shared how their passion for dance and the opportunity to creatively express their emotions enhanced their well-being: "I love dancing to the music I listen to. I like to be expressive and creative. Dancing is one of my passions. It keeps me well." (#23)

*6.5.2.1 **BELONGING AND CONNECTION***

Dance experiences were often described as providing a sense of belonging and connection. The dancers defined belonging as feelings of a larger sense of community and connection that extended beyond the studio for some. One participant described this sense as familial, "We call each other family, one big family" (#21). For some, their sense of connection was derived from the ethos of their dance schools/studios, which was both a tangible (love) and an intangible (spirit) feeling. "So, in my school, we really love each other, and there is a connection among us, even when we are dancing -- you see the spirit and feel it" (#10). Another dancer referenced the significance of the relationships they gained through dance and how those relationships extend beyond the studio:

> Because I never really had real friends outside of dancing. I think dance is like my whole life, something that I was made to work my whole life around. So, the people I met there, I kind of cherish the relationships more than my outside relationships. (#19)

While current experiences discussed in the interviews were expressed as a positive sense of belonging, conversely, some recalled past experiences in dance as resulting in a sense of

disconnection and isolation. These experiences were described as struggling to interact with people in their own age range, feeling like an outsider amongst a group of neurotypical dancers (isolated), feeling lonely, being left on the sidelines, or feeling left out. One dancer described their awareness of, and frustration with, their experiences of being intentionally excluded in dance.

> [...] some of these kids in my own class were able, although they weren't that good at dance, they were still able to do it, like they still got to do it [continue taking dance classes]. So yeah. So that's basically saying OK, everybody can do it except for me, who has Autism. (#29)

Dancers also described their experiences of feeling excluded as being rooted in their relationship to the instructor or in social culture of a studio or organization. They expressed their awareness of being excluded when well-intended instructors highlighted a dancer's challenges while trying to be helpful and their resultant feelings of isolation and loneliness. "The teacher says (in front of their peers) like 'okay you should take a rest and let the other students go on with the dance'[...] I just feel maybe I wasn't good enough or maybe I wasn't focused enough – or balanced enough" (#14). Another dancer described how knowingly being socially excluded by their peers in dance made them feel.

> I don't like when I'm excluded [...]when all the other dancers sit together and laugh together. [...] I don't like it when other dancers don't say hi back to me, or don't really respond when I try and talk to them [...] I felt quite lonely. (#23)

*6.5.2.2 **DANCE MAKES ME HAPPY AND GIVES ME JOY***

The dancers shared that being able to express themselves through dance was a joyful act that made them happy. One dancer stated, "[...] I mean, I'm dancing, I'm expressing myself.

Yeah, so... I just like, I just have this happiness when I am dancing, this joy...” (#3). One dancer linked how dance made their body feel and their desire for expressing themselves through dance together.

> Dancing makes my body feel good, I would say. Because I love dancing and, you know, am so enthusiastic about dancing, like I have so much desire for dancing. So, I feel good whenever I am dancing and feel like ‘yeah, I’m really doing this, am loving this’. (#14)

6.5.3 **THROUGH DANCE I LEARN SKILLS FOR LIFE**

This second theme revealed dance as being transformative as the dancers’ discussed how their experience in dance influenced their personal growth in dance spaces, and daily life. The skills learned through dance translated into the dancers’ lives outside of dance and included skills such as active listening and social skills, body awareness and persistence, learning and practicing skills to regulate anxiety. The dancers expressed that because these skills impacted their personal growth within dance and into daily life, they gained a sense of autonomy, safety, and control. For instance, one dancer explained that before (dance) they didn’t like to communicate with larger groups of people and that communication was frustrating. Through dance they learned how to calm their body and mind through the practice of breathing. Importantly, this dancer also described how learning to calm their mind through the practice of breathing strengthened their belief in their ability to communicate, to interact in social settings, and to both communicate and listen with more clarity in social situations.

> [Dancer] before you start the dance you do, like 5 minutes. You breathe slow. So, you’re calm. Then you start to dance. When your mind is calm. You think better. (I am) more powerful.... I don’t think about the scenes around me. I am calm (gestures with hands – pressing downward). No rushing (wagging finger and shaking head no). Step – by – step.

> You will not make a mistake. Step – by – step. No mistake. No panic. Calm (pressing hands downward). (#07)
>
> [Interviewer]: Do you find that it (dance) has changed how you interact with your friends at all? Or family?
>
> Dancer: yeah. (gestures a thumbs up) [...] No anger. Gentle talk. Understand more (points to head). (#07)

Another dancer expressed how dance (class) became a safe outlet to manage any stressors and frustrations they were struggling with in their daily life. "...it gives you the chance to get stress or whatever else out in a safer way than taking it out on somebody. So, you know, in that perspective that becomes a safety thing as well" (#01).

6.5.3.1 ***PRACTICING SOCIAL SKILLS***

Several dancers expressed a general sense of isolation, and some shared that their friend groups were extremely small, or nonexistent, and therefore had few opportunities to practice social skills. The dancers expressed how dance taught them the skills to communicate more effectively, which in turn has improved their social interactions. For one individual, dance became a safe place to discuss issues (with other dancers).

> We are always talking, no matter what topic comes up. Whether we are talking eating disorders, nutrition, sports injuries[...]does not matter what. But if somebody else deals with something like that, that's what we end up talking about while stretching [in class]. We're never quiet. (#01)

6.5.3.2 ***I AM (CAP)ABLE***

The juxtaposition of the words capable and able in this code is intentional and reflects the dancers' expressions of self-confidence, self-belief, competence, and skills gained through

dance. They expressed how dance had improved their ability to dance, their self-confidence, and their ability to interact with others in dance and in life outside of dance. One dancer expressed how the process of learning a difficult dance taught them that they can do anything, “it was hard at first, but I learned it. And whenever I remember that, yeah, I remember that I can do anything”(#14). This was reflected in another dancers’ description of how the confidence they gained through dance has permeated all aspects of their life.

> I have more confidence in myself to do things now, compared to what I did before (dance).[...] It kind of resonates in everything I do. I just have more confidence in everything I do. And I have the mindset now that everything I do, I am going to achieve it. (#19)

Another dancer expressed how dance has improved their confidence in themselves and in their capabilities both in and outside of dance because they are less fearful and more willing to take risks.

> Because I think it's, you know kind of, changed my mind set about myself. About maintaining my mind set and my outlook towards life. So, it made me defeat the fear within myself. And once I defeated the fear within myself, now everyone can see the confidence and the difference in me. (#12)

For some dancers, their dance experiences reinforced that they are capable in a world that typically does not readily recognize their capabilities or potential. One dancer shared their childhood experience of being excluded from dance classes. They expressed that being able to participate in dance as an adult has renewed their belief in their capabilities.

> I feel like I can like do this, like... believing I can, and I spent all these years watching my sister and (wondering) why can't I be like her at this activity (dance)... like, I want to be

like my sister, who's just a dancer [...]. Dancing makes me feel like I have more strength and dance ability than I thought I had before. I also realized that my body is healthy and that dance is a good exercise. (#29)

*6.5.3.3 **DANCE ORGANIZES MY LIFE***

The dancers expressed how participating in an activity that is meaningful brought them joy and fostered the motivation to structure their daily life around dance. This was reflected by one dancer as follows; "Dance is what my life revolves around" (#19). Similarly, another dancer stated "[...]what I like about the dancing is, it gives me kind of like a pivot point where I can structure my week around that [...] I can build my workouts and stuff (nutrition) around dance" (#01). When asked how important this structure is in their life, another dancer expressed how the structure gained through dance was a needed impetus for personal growth. "It's been really....because it's kind of like shifts me into the next phase of my life. I just feel everybody needs like a push sometimes...I feel that was like the push I needed to get in the next phase of my life" (#12).

6.5.4 **INCLUSIVE INSTRUCTION AND DANCE CULTURE**

This theme addresses the interaction between the dancer, the dance culture, and the ways that instruction was adapted to accommodate dancers' needs. Dancers and support persons expressed that they had more positive experiences when schools and instructors were willing to adapt the traditional, rigid structure of the dance school. One pair explained that the rigidity of the traditional requirements of dance, such as a specific dress code and long hair to be tied back in a tight bun, made the dance experience about conformity, rather than having fun. The result was that the dancer was uncomfortable and unable to enjoy dance because of the sensory

implications of the dress code and hair requirement. In contrast, they discussed their experience in a more inclusive dance program:

> ...there was more emphasis on moving your body as opposed to having full makeup, as opposed to having the tight bun[...] there were accommodations made for clothing, so that they could, you know...be comfortable. And that, I think, that made a difference. I (also) saw a difference in the message of the instructor. They had them imagine things, 'pretend you're this, pretend you're that', and it was more of a focus on moving your body to how you felt, to identify with the music or the song. (#16 and 20)

*6.5.4.1 **CREATING AN ENVIRONMENT OF ACCEPTANCE AND SAFETY***

The dance culture included creating an accepting and safe environment for the dancers to authentically express themselves and participate in dance. For example, one dancer described the way instruction was provided:

> It's very respectable, everybody can't learn the same way [...] they allow people to express themselves. So, everybody does the same thing [...] and everybody does it in their own space and circle. They [instructors] come to where we are and you know, ease the message across. I think that method really helps everyone. (#12)

In contrast, one dancer described how the experience of being bullied by another dancer in a dance class led to the instructor creating a more accepting environment. They described how the experience of ongoing bullying in a dance class led them to become sensorily dysregulated and experience a 'sensory meltdown' to the point of losing consciousness. They also described how the instructor subsequently established clear expectations for how dancers interact with one another in the dance space such that, in the end, the dance space felt safer.

*6.5.4.2 **TAILORING INSTRUCTION***

Many dancers were not aware of any specific adaptations made to dance movements or steps, however the structure of the class, the flexibility of the instructor to allow dancers to learn at their own pace and in their own way, their ability to understand the strengths and weaknesses of a dancer or the group, and using this information to fine-tune the class, were explicitly expressed as helpful strategies and supported an inclusive dance culture. Importantly, one dancer who is quadriplegic, described (through their support person) that the ability of the instructor to respond to the somatic cues of the dancer was important, and necessary. "[...]the instructor knows that they (the dancer) will not be able to achieve a particular movement so the instructor will adapt the movement (to their physical capabilities) to allow them to still participate, maybe a little bit of a different level" (dancer nods in agreement). (#27, #31)

*6.5.4.3 **STRATEGIES ENGAGED BY THE INSTRUCTOR***

Critical to the theme of 'inclusive instruction' are the skills of the instructor and strategies they engage when tailoring instruction. Characteristics of the strategies included were respect, reduction of assumptions, and guidance. The dancers' explained that when the teacher respected the dancers and their needs, the experience of dance was enhanced. For example, one described how their instructor "really just encourages us to always work to do better" (#12). Another dancer described that how their instructor communicated with them had been important for their experience, "I think they personally attend to us and our grievances and um, our fears and everything. They listen to us and teach us both individually and group" (#19). For the dancers, several perceived that the choreography and steps were not always modified specifically for them or was modified in subtle ways. One support person also noted that (speaking to the dancer they support), "So you said that she teaches you or she changes things up for your group. I can

say that there are variations (of the choreography) I've seen in a recital, but it's so beautifully choreographed and it's done in a way that is not too obvious". (#24)

6.6 **DISCUSSION**

The present study explicitly engaged the perspectives of adult dancers who identify as having an NDD. The dancers' perspectives have shed light on the benefits of, and need for, engaging a strengths-based and person-centred approach to dance instruction and adaptive and/or inclusive dance environments. These findings further highlight the importance of shifting the focus of physical activity opportunities and instruction to the shared characteristics across NDD including difficulties with social interactions and communication (Carmeli et al., 2012; Linehan, 2019; Lyall et al., 2017; Verschuren et al., 2016), motor skills/function (Bhat, 2020; Carmeli et al., 2012), mental health (Sullivan et al., 2019; Wise, 2020), and a higher risk for comorbidities related to increased sedentary time (Healy et al., 2018; Verschuren et al., 2016). Collectively the dancers' gained a sense of belonging and connection through dance that served as the impetus to explore social interaction and communication, practice mental flexibility and persistence, build motivation and self-efficacy. When an environment of acceptance and safety was cultivated in dance classes and environments, and a strengths-based and person-centred approach to dance instruction was engaged, the dancers' felt a greater sense of purpose and direction and were able to connect the skills they learned and practiced through dance into their lives outside of dance.

6.6.1 **MEANING AND BELONGING**

Each of the dancers' shared that through dance they found meaning and belonging in an activity that gave them a sense of identity and purpose, as well as joy and motivation. These ideas were shared when dancers expressed that they could not imagine what their life would be like without having discovered dance. These sentiments reflect the concept of flourishing which

has been defined as the embodiment of positive emotion and relationships, of engaging in purposeful and interesting activities, and a sense of accomplishment (Agenor et al., 2017; Seligman, 2011). When belonging, meaning, and purpose are present individuals are likely to experience an internal drive toward self-actualization, or the drive to be a part of something larger than oneself and a sense of flourishing (Agenor et al., 2017; Maslow, 1943). Here, the dancers' perspectives on the meaning, structure, and identity gained through their dance experiences are consistent with the concept of dance contributing to a sense of flourishing and self-actualization.

Across the interviews the dancers' experiences highlighted the significance of belonging and included familial connections in dance, interpersonal connections arising from the ethos of the dance culture, and strength of those connections. Belonging is defined as the universal human need for feeling valued and accepted 'as I am' and is a critical factor in the physical and mental health of all persons (Maslow, 1943; Simplican et al., 2015). Belonging is also thought to reflect our sense of connection to others and community, and to the development of interpersonal relationships (Baumeister & Leary, 1995; Brown, 2021; Jones & Gallus, 2021; Massey et al., 2021). The model of constraints further suggests that belonging and participation are inexplicably linked to when and how the dance environment and instruction are adapted to the characteristics of the individual. Importantly, how instruction and the environment are adapted may have a positive (encouraging) or negative (discouraging) impact on the dancers' experience (Newell, 1986).

Not all experiences in dance were described as promoting a sense of belonging. The dancers and support persons shared experiences of exclusion when receiving microinvalidations in the dance setting made them feel 'othered', and shared feelings of disappointment, frustration,

and disconnection from the group (Lee, 2019). Microinvalidations, a form of microaggression, may be intentional or unintentional and are defined as actions that "exclude or negate the thoughts, feelings or lived experience of an individual" (Lee, 2019). One dancer described this as feeling left out and not good enough during a dance class when their dance teacher would 'call them out' in front of the whole class because they were having a difficult time keeping up with the class or choreography and would have them sit down and watch instead of assisting or guiding. It is of interest that those dancers who described experiences with microinvalidations were not deterred from continuing their participation in dance. Several dancers were self-reported strong self-advocates, and others had support persons who advocated with and for them. The resilience and ability to persevere and grow despite negative experiences suggests a psychological flexibility that is indicative of flourishing and well-being and may contribute to self-actualization (Agenor et al., 2017; Maslow, 1943). Based on these findings, when efforts to engage a person-centred and strengths-based approach to dance instruction was present an inclusive dance culture was fostered, and dancers experienced a deep sense of belonging.

6.6.2 **DANCE AS TRANSFORMATIVE**

Social isolation and loneliness are proposed barriers to social participation for persons with disabilities (Macdonald et al., 2018). In the current study, several dancers described their life before discovering dance as isolated and lacking social interaction and connection with persons outside of their immediate family. In alignment with current literature, when the dancers described instruction as consistently engaging a strengths-based approach to dance the focus of instruction shifted to enhancing skills for learning, social connection, and overall wellbeing (Leadbitter et al., 2021). The dancers described this critical shift of focus as being transformative as dance became a place to explore social participation within a familiar, accepting, and safe

space. Importantly, through dance individuals had the opportunity to develop and practice social skills and strategies that enhanced their experiences within dance spaces and carried over into daily life. Some of the skills developed through dance also helped with the regulation of anxiety and focusing attention in social settings.

The dancers also expressed how finding a meaningful and purposeful activity facilitated their drive to structure their life in a variety of ways, including how they organized their workouts, nutrition, and rest, around dance and to support their dancing. Further, the practice of organizing seemed to bolster the dancers' self-efficacy for managing their own schedules during the dance season, as well as in the off-season. This finding further supports the importance of engaging a person-centred, and strengths-based approach to dance instruction. Engaging an ecological lens to instruction acknowledges the necessity of taking the time to understand both the physical and emotional aspects of the individual (Newell, 1984). When flexible approaches to instruction were used the opportunity to explore a variety of ways of moving and to find an activity that is meaningful and transformational increased.

6.6.3 **FLEXIBILITY OF INSTRUCTION**

From a constraints-based perspective, the environment is defined as the physical structure of the dance space, as well as the culture and social climate of a dance school/studio/program. Task constraints include strategies used by the teacher and how instruction is given in relation to the capabilities of the dancer (Newell, 1986). In the context of this study the flexibility, or willingness, of a teacher and/or school to provide adaptive task instruction is also thought to inform the culture of the dance environment. The strategies described by the dancers as essential to their experience included taking the time to get to know individual communication and learning styles, proactively adapting movement, or instruction if/when needed, and creating

opportunities for dancers to learn and explore movement concepts in a manner that is most comfortable for them. The dancers shared that when their differences and needs were recognized, respected, and supported by the instructor, school, and fellow dancers they experienced a sense of acceptance and safety in the dance space. Likewise, the dancers described purpose, belonging, acceptance, confidence, and self-esteem as arising from experiences in dance spaces that were accepting and supporting. In addition, schools and/or instructors willing to modify the rigid expectations of dance such as enforcing a strict dress code, how to wear one's hair, conforming to normative standards of technique, what bodies are considered 'dancer bodies', and following a strict top-down approach, led to the dancers' feelings of acceptance in the dance space (feeling 'seen') and they had more enjoyable dance experiences. This finding agrees with current literature that proposes acceptance as a building block for self-esteem that also contributes to self-worth, confidence, flourishing, and self- actualization (Agenor et al., 2017; Jones & Gallus, 2021; Maslow, 1943).

6.7 LIMITATIONS AND FUTURE DIRECTIONS

It is important to acknowledge the heterogeneity across diagnoses and definitions, as well as the shared characteristics across diagnoses and instances of overlapping diagnoses (Kangarani-Farahani et al., 2023). Of the 14 dancers interviewed 50% identified as autistic, 35% as having DS, whereas only 14% as having a diagnosis of CP. Capturing the perspectives of the dancers lends critical insights into their experience in dance and demonstrates that dance can be a positive and meaningful activity for persons with NDD. We also acknowledge that there are nuances of each diagnosis that may not have been captured in this study. To facilitate the participation of dancers across North America most interviews were conducted virtually using the Zoom platform®. Care was taken to familiarize dancers with the virtual platform, the

interviewer, and the study itself before attaining consent (Isobel, 2021). We acknowledge that some participants may have experienced, but may not have identified, experiencing 'Zoom fatigue' during the interview. This may have limited the extent of the dancers' responses.

To preserve the dancers' power over their words and experiences, we took a trauma-informed approach to the interviews that included allowing dancers to skip questions, choosing to have a support person with them during the interview, and offering regular breaks (Isobel, 2021). While all dancers did respond to all interview questions, some dancers indicated explicitly their preference to discuss only positive experiences. This may limit our understanding of the breadth of the dancers' experiences.

It is recommended that future research in this field work to regularly engage and include the perspectives of dancers with disabilities and the persons who support them using participatory research methodologies. Reflecting on our research process we recommend that future research engaging persons with NDD ensure that participants from the disability community are familiarized with the chosen platform beforehand and take additional steps to build trust with the interviewees. Future research may include: i) developing recommendations for adaptive/inclusive dance practices with NDD community members and ii) engaging with dancers who have NDD in the co-design of opportunities to share the study findings with the dance community and reporting on the plan, process, and execution of the dissemination of the findings.

6.8 **CONCLUSION**

Themes of meaning and belonging, the transformative skills learned through dance, and the flexibility of how instruction is given were revealed through this study. The dancers' narratives demonstrate that a person-centred and strengths-based approach to instruction fosters

the development of a variety of skills that carry over into daily life. Deepening our understanding of the dancers' experiences lends important insights to the formation of adaptive and/or inclusive pedagogical practices and instructional strategies in the dance setting for persons with NDD. Importantly, these findings enhance our collective understanding of the importance of actions of inclusion in the dance community. This study lends critical insights into the need for the dance community and dance researchers to interrogate why and how to change both the normative assumptions within dance environments and methods of dance instruction in relationship to the inclusion of dancers with neurodevelopmental disability.

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7.0 PREAMBLE TO CHAPTER 5

The findings in studies one and two support the need for informed, knowledgeable instruction that centres the perspectives of the dancers. In response to these findings Chapter 5 (study three) examined the instructional priorities of: i) dancers who live with NDD and those who support them, ii) dance teachers who provide adaptive and/or inclusive programming, and iii) rehabilitation professionals who work with persons who identify as having an NDD. In study three, the language used around the participants with NDD shifts to reflect their role as experts in this study (community experts).

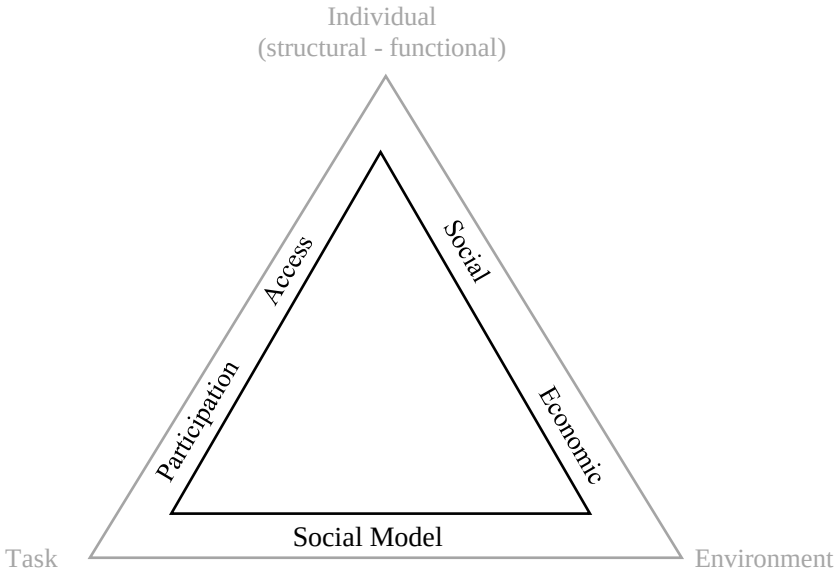

Figure 4. *A visual depicting how the social model of disability was incorporated into the constraints model of motor development (Getchell & Gagen, 2006; Newell, 1986; Oliver & Barnes, 2012)*

As described in Chapter Two, the constraints model of motor development was the guiding framework for this thesis. In study three the focus shifted from understanding the experience of individuals with NDD in dance to gathering the perspectives of experts. The constraints model of motor development is thought to be focused on the individual, rather than a group. To situate the model in a broader social and political context the social model of disability was incorporated into the constraints model to emphasize the role of the dance community in driving change

towards inclusion (see Figure 4; Oliver & Barnes, 2012). A brief description of the social model of disability is provided next.

7.1 SOCIAL MODEL OF DISABILITY

In the 1980s the World Health Organization published the International Classification of Impairments, Disability and Handicap. This biomedical model categorized disability into three static categories including: i) impairment, ii) disability, and iii) handicap (Marks, 1997; Oliver & Barnes, 2012). The focus of this model was to link the impact of the disease or disability to the three categories, however social and environmental constructs were ignored (Oliver & Barnes, 2012; Rosenbaum & Stewart, 2004). Through this lens the person is viewed as impaired/disabled, (the diagnosis) as something to be fixed or corrected and placed the onus on the individual to adapt to both their diagnosis and surroundings (Oliver & Barnes, 1983).

In the mid-1980s a social model of disability emerged and proposed a shift of focus away from the individual to the economic, environmental, and cultural barriers that face persons who live with disability (Oliver, 1983; Oliver & Barnes, 2012). The diagnosis itself is not denied, but it is not considered to be the sole cause of the disadvantages that individuals face under the tenet that all individuals have the right to be treated with respect and to maintain a basic socioeconomic status (Oliver & Barnes, 2012). Further, the social model of disability engages a civil rights perspective highlighting that only persons who live with disability hold the experience of disability and therefore their insights into the political, social, economic, and policy issues around access, inclusion, and disability are of prime importance (Franits, 2005; Roush & Sharby, 2011).

Incorporating the social model of disability into the constraints model recognizes the perspective and experience of the individual rather than as a patient to be rehabilitated, where it

is incumbent upon dance instructors to consider the individual's physical and affective characteristics. The integration of the social model of disability with the constraints model of motor development, study three aimed to empower the dance community to drive change towards inclusive practices that are centred in an understanding of the experience of persons with disability. From this perspective study three works to dismantle normative ableist approaches to adapting instruction in dance and physical activity contexts.

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CHAPTER 5

STUDY 3: Disability, dance, and rehabilitation expert recommendations for developing inclusive dance opportunities for persons with live with neurodevelopmental disability: A Hybrid-Delphi technique

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CONTRIBUTIONS OF AUTHORS TO THE MANUSCRIPT:

J.L. designed the protocol for this study and led the focus groups, ranking procedure, analysis, and interpretation of the data. All authors will critically revise the draft of the manuscript for intellectual content and review the final draft for submission to the *Journal of Autism and Developmental Disorders*.

ABSTRACT

Dance is a form of expression that spans cultural and socioeconomic contexts. In Canada dance curricula exist in both dance and education contexts, yet expert informed guidelines for adaptive and/or inclusive dance environments are scarce. The purpose of the present study was to develop a list of recommendations for adaptive and/or inclusive dance opportunities through the lens of critical experts who have experience with, or identify as having, neurodevelopmental disability (NDD). A Hybrid-Delphi technique was used: i) to collect and articulate expert perspectives on methods of adapting dance environments and instruction; and ii) to formulate their contributions into a set of prioritized recommendations to be shared with the dance community. Over five months three expert groups (rehabilitation professionals (n=6), dance educators (n=7), dancers and support persons or carers (n=5)) engaged in virtual focus groups to generate statements, followed by an e-survey process to rank and consolidate statements. The constraints model of motor development and the social model of disability were used to frame questions around: i) physical environment and culture, ii) instruction and strategies, and iii) assistants/carers; and informed the reduction and ranking of responses. Three key themes were identified: i) adapting the environment (physical, culture, and instruction), ii) how to adapt instruction and strategies, and iii) ongoing communication and education. Expert discussions emphasized the importance of centering the perspectives of the dancers and their support persons/carers (community group) in the final list of recommendations, as well as in ongoing education, dance spaces and culture, and communication of instructions.

8.0 INTRODUCTION

Dance is a form of expression that spans cultural and socioeconomic contexts (Fancourt & Finn, 2019). The ableist history of dance has influenced societal perspectives on who is a dancer, what dance looks like, and how it is performed, across generations (Albright, 2011; Aujla & Redding, 2013; McCarthy-Brown, 2017). Ableism is pervasive, powerful, and elusive and therefore continues to restrict how persons with disability participate in society broadly (Kattai, 2023; Taussig, 2020). This history continues to inform how dance is taught and the structure of the dance environment (Anderson, 2020; McCarthy-Brown, 2017). Today, formal training or licensing requirements are not required to teach dance in North America. Accredited teacher training programs within dance institutions, organizations, and dance societies commonly include anatomy and health education; however, the fundamentals of disability and adaptive/inclusive teaching strategies are often absent from required coursework and certification processes. Currently in Canada dance curricula exist in both dance and education contexts (ADAPT, 2023; CSC, 2019; PHEC, 2023; RAD, 2023), however expert-informed guidelines for adaptive dance instruction and dance environments are scarce. In the absence of evidence-informed guidance, expert recommendations can help dance educators, schools, and organizations to grow their collective understanding around neurodevelopmental disability (NDD) specific to adaptive instruction and inclusion broadly. The present study aimed to systematically develop a list of recommendations to foster adaptive and inclusive dance environments through the lens of experts who have experience with, or identify as having, an NDD.

Over the past 20 years research interest in the field of dance and disability has grown, however, literature specific to adult populations who have a diagnosis of NDD is limited

(Ladwig et al., 2023). Though the literature does enhance our understanding of the physiological (DiPasquale & Kelberman, 2018; Teixeira-Machado & DeSantana, 2019; Terada et al., 2017) and psychosocial benefits (Aujla & Needham-Beck, 2020; Mastrominico et al., 2018) of dance for adults with NDD, researchers have primarily engaged a biomedical lens to disability. The biomedical approach focuses on the diagnoses first and therefore engages dance as a therapeutic mode of changing or modifying behaviours and/or symptoms related to a diagnosis to be more 'socially acceptable' (Ladwig et al., 2023; Leadbitter et al., 2021). Working to eliminate such behaviours enforces a normative perspective on persons with NDD and may remove preferred coping mechanisms or strategies that can aid self-regulation or, when communication is impaired, may be a mode of communication or an expression of emotion (Jacobson et al., 2007; Leadbitter et al., 2021). Importantly, in what ways dance has been adapted for persons with NDD and how their perspectives may or may not have been included in the literature remains unclear (Ladwig et al., 2023). Both the underlying ableist assumptions of who is a dancer, and the absence of disabled bodies in dance broadly, may contribute to a lack of confidence and/or fear around what and how to adapt dance instruction and spaces for persons who live with NDD (Aujla & Redding, 2013; Hansen & Philo, 2007; McCarthy-Brown, 2017). The ability to adapt the content of a dance class and environment requires discipline specific knowledge (e.g., dance form) balanced with an understanding of the issues that dancers with disabilities experience and the ways in which the dancers may require assistance (Whatley, 2008). In the current context of dance education, expert-informed recommendations on how to develop and foster inclusive or adaptive instruction and dance environments are lacking; especially recommendations that are based on the voices of dancers with NDD and those who support them.

When considering what strategies and methods are best to include in recommendations, we recognize that the experiences of dancers with NDDs can only be communicated by the dancers themselves, i.e., the knowers (Oliver & Barnes, 2010; Stone & Priestley, 1996). In addition, the development of the recommendations should recognize and respect both the viewpoint and autonomy of persons with NDDs, as well as recognize the voice of support persons and carers as separate (Leadbitter et al., 2021). Recently we reported that despite engaging persons with varied communication abilities and functional levels, descriptions of how dance interventions were adapted for those with more complex communication and functional abilities in published research were lacking (Ladwig et al., 2023). Further, the viewpoints and perspectives of those who support the dancers in the dance setting were often not recognized (Ladwig et al., 2023). Support persons who participate in dance alongside the dancers would provide insight into the level of training that may be required for support persons, in what ways physical assistance might be most effective (e.g., ways to approach engaging dancers who are quadriplegic, how best to encourage independent movement), and flexible options for communication strategies. In this study, the perspectives of both parties (dancers and support persons/carers) were included as their combined perspectives may provide important insights that could drive how verbal and physical instructions are provided.

The potential benefits of dance for adults who live with NDD are supported by current literature (Aujla & Needham-Beck, 2020; DiPasquale & Kelberman, 2018; Teixeira-Machado & DeSantana, 2019; Terada et al., 2017). The aim of the present study was to develop explicit, expert-informed recommendations for dance instruction and environments that are centred on the perspectives of the dancers with NDD and support persons/carers. Experts were engaged from the disability, dance, and rehabilitation communities in a systematic process that asked them to

consider ways to holistically facilitate and promote more inclusive dance instruction and environments. The specific objectives of the study were to: i) collect and articulate expert (community, dance, and rehabilitation) perspectives on methods of instruction and strategies for adapting dance and dance environments, and ii) formulate the methods and strategies into a set of prioritized recommendations to be shared with the dance community broadly. The recommendations will be offered as a guide for the development of inclusive and adaptive pedagogical approaches to dance and movement education environments and interventions.

8.1 **METHOD**

To achieve the above objectives, we used a Hybrid-Delphi technique to gather and prioritize expert perspectives (Landeta et al., 2011). The Hybrid-Delphi technique is a systematic and iterative method of assembling viewpoints of experts on a specific subject using a combination of focus groups and classical Delphi techniques to rank the statements (see Appendix F, Table 14 for overview). Rather than developing responses solely during the focus group, a modified nominal group technique was used and included: i) sharing the questions with the participants in advance and asking participants to review and consider the questions, and prepare their initial responses offline, ii) during the focus group asking participants to share their initial or prepared responses, and iii) facilitating discussion around presented responses and allowing for any revision of responses to occur during the focus group. In this way the Hybrid-Delphi technique addressed the lack of opportunity for interaction in the classical Delphi procedure as the classical Delphi procedure typically occurs solely by email and involves the completion of e-surveys. Thus, another advantage of using the Hybrid-Delphi technique was that it allowed for group interaction and participant engagement (Hasson et al., 2000; Mead & Moseley, 2000).

All focus groups were held virtually on the Zoom™ platform and were recorded by audio and/or video with participants' consent. A research assistant attended all focus groups and was tasked with taking notes, monitoring questions, and ensuring that each participant had the opportunity to share their responses and perspectives. Following each focus group, the researcher and assistant met to debrief any concerns or ideas that emerged during the session. All e-surveys were created using Microsoft Forms®. All procedures were approved by the Research Ethics Board 1 of the University of Manitoba, in accordance with the Declaration of Helsinki (2002).

8.1.1 **PARTICIPANTS**

Study information was shared with fifteen Canadian professional, disability, rehabilitation, and arts organizations as well as directly to thirteen known experts. Experts were defined as individuals ≥18 years of age and older and i) identify as having a NDD and currently participates in dance, ii) persons who currently assist or support an individual with NDD in dance, or iii) a dance or rehabilitation professional who has experience working with individuals with NDD (see Table 5). In the context of this study the term 'assistant' refers to any individual who assists a dancer in the class including support persons hired by the dancer or their family, employed by the dance school, or is a volunteer who provides support in the class.

8.2 **THE FRAMEWORK**

The social model of disability was incorporated into the constraints model of motor development to frame the questions and contextualize expert recommendations (Newell, 1986; Oliver, 2013). In combination, these models respond to and acknowledges the ways in which society, and the dance community broadly, places economic, environmental, and cultural

Table 5

Detailed Inclusion Criteria

Group	CRITERIA
Community Experts	• Adult dancers who have a NDD and in the past six years have participated in an adapted/inclusive dance program. • Carers and support persons who had been an active participant alongside the individual they support in dance or have supported an individual through presence and observation alone.
Dance Experts	• Dance educators who, in the previous six years, have taught adults with NDD in either inclusive or traditional dance settings, such as academic (high school or post-secondary), dance studios, adult day programs, or in the community. • No specific education or training experience was required.
Rehabilitation Experts	▪ Rehabilitation professionals, including physiotherapists and occupational therapists, who have currently work with or in the past six years have worked with neurodiverse clientele.

restrictions on persons with disabilities, thus regulating when and how they participate (Oliver & Barnes, 2010, 2012). Taken together, these models consider the relationship between the physical and emotional aspects of the individual, the physical task and instructions, and the environment's social, cultural, and physical elements (Newell, 1986; Oliver, 2013). Specifically, we considered the physical, perceptual, social, and affective constructs within the dance culture that may limit the participation of the dancers in developing the questions and contextualizing the recommendations. With the goal of sharing informed and actionable recommendations, these combined models centre the characteristics, capabilities, and experiences of the dancers and addresses in what ways and how the instructions and environment (culture and physical) may be adapted to accept and embrace the physical, psychological, and social needs of the dancers (Getchell & Gagen, 2006; Leadbitter et al., 2021; Oliver & Barnes, 2012).

8.3 DATA COLLECTION AND ANALYSIS

8.3.1 STAGE 1

Virtual face-to-face meetings were held with each of the three expert groups (see Table 6). We chose to separate the experts according to their training to address potential power differentials, foster group cohesion, limit potential 'Zoom fatigue', and to facilitate scheduling. During the first meeting with each group the first author provided context for the research and summarized both the process and theoretical approach. These first steps were done with the goal of preparing panelists and enhancing response rates (Humphrey-Murto & de Wit, 2019; Mead & Moseley, 2000). To encourage group connection and foster the commitment of the group, the participants were asked during this first meeting to share their thoughts, doubts, and ideas, and to reflect on the study purpose and procedure (Landeta et al., 2011). To prepare for the next stage and encourage reflection all participants received the questions following this meeting (within 24 hours) and were encouraged to write out their responses before Stage 2 (see Table 6).

Table 6

Planned stages of the data collection process

	Action	***Purpose***	***Who?***
Stage 1	Virtual meeting	Orient to study purpose and process; share the questions.	Individual groups
Stage 2	Virtual focus group	Share participants initial response to questions to the group.	Individual groups
Stage 3	Virtual focus group	Review lists of responses generated in Stage 2; discuss questions and which statements could be collapsed.	Individual groups
Stage 4	Ranking by e-survey (by email)	Participants were presented with the three separate lists of collapsed statements and asked to rank each.	Individual participants
Stage 5	Review of Rankings	Rankings were shared with the community experts for review*.	Community experts
Stage 6	Final Lists	Lists were compiled by ranking and shared back to all expert groups.	Lead author

Note. (*) If community experts disagree with any rankings the statement would be revised, and the ranking process repeated.

*8.3.1.1 **THE QUESTIONS***

We developed a set of three open-ended questions, informed by the combined constraints model of motor development and social model of disability, and our previous scoping review (Hasson et al., 2000; Ladwig et al., 2023; Mead & Moseley, 2000). The questions were specific to the class environment and structure, instructional strategies, as well as the inclusion and training of core support persons who work with persons who have NDD. The questions included: i) What considerations do you believe should be prioritized regarding the class structure and the environment of the adapted/inclusive dance class (e.g., methods of communication, setup of the space, use of assistants, use of music, flow and/or pace of the class, etc.)?, ii) What teaching strategies (e.g., verbal and/or physical cues, how steps are modified, how modifications are presented, groupings and groups performing for one another, etc.) do you believe should be included?, and iii) What forms of information, assistive strategies, and/or training do you feel should be provided to prepare and support the caregiver or support person for their role?

8.3.2 **STAGE 2**

A virtual focus group was conducted with each expert group (see Table 6). At the start of the focus group the researcher reviewed the task and presented each question to the group (Landeta et al., 2011). A round table technique was used to ensure that each participant had the opportunity to contribute. Specifically, each participant was asked to share what they felt were their most important responses to each question. All participants were encouraged to share their insights on the responses presented. Participants were also directed that they would have the opportunity and time to revise their responses during the focus group. Each focus group was approximately seventy-five minutes in length. During the focus group, all group participants were asked to share their complete list of responses to the research assistant by email.

*8.3.2.1 **LIST PREPARATION AND ANALYSIS***

To prepare for Stage 3 each list of responses for each question and from each group was aggregated, de-identified, and input to separate master Excel® spreadsheets; each spreadsheet was then uploaded into NVivo™. Using the model of constraints and the social model of disability as a guide, an inductive approach was used to determine the code (category) of each response. All codes were added to the original lists in Excel® and the spreadsheet for each question was then sorted by code. To enhance credibility, accuracy and panelist engagement, each list of responses for each group was shared back to each group participant via individual Excel® shared file links for their review, revision, and feedback. Participants were given two weeks to complete this task.

8.3.3 **STAGE 3**

The list of statements generated to this point were reviewed in virtual face-to-face focus groups. The researcher presented questions that arose through the feedback and review process (in Stage 2) for discussion. Participants also discussed responses they felt could be collapsed. From this feedback, the responses were then further collapsed by the researcher. This process was completed using Excel ™ spreadsheets to track the original statements and facilitate sorting by codes/categories.

8.3.4 **STAGE 4**

The reduced statements were then shared back to the corresponding group participants for ranking by e-survey. Participants were asked to prioritize each statement using a seven-point Likert scale where seven was the highest priority and one was the lowest. Upon completion of the ranking procedure all mean scores were calculated in an Excel ™ spreadsheet and all lists for each group were ordered accordingly. The ranked results and mean scores for each statement

were shared back to the participants using individual Excel™ shared file links. Participants were asked to indicate their agreement or disagreement with each ranking and, should they disagree with a ranking, asked to provide additional feedback. Participants were given a period of two weeks to respond to each e-survey. To encourage a response rate of ≥ 70%, panelists received two email or text message reminders before the deadline (Hasson et al., 2000).

8.3.5 **STAGE 5**

The researcher reviewed the rankings with each community group participant individually, either in-person or virtually. Each participant was asked to indicate their agreement or disagreement with the rankings and were asked for their feedback on the statements. The ranking process would be repeated if agreement was not reached at this stage. If agreement was reached, then the mean scores for each statement guided the compilation of the final list of recommendations.

*8.3.5.1 **CONSENSUS***

For the present study consensus was defined as a median score of 71% or higher (≥ a rank of 5), 80% agreement of the rankings from the community expert group, or the completion of no more than the described two rounds of statement rankings, whichever was attained first. Consensus was required for inclusion in the final list of recommendations.

8.3.6 **STAGE 6**

The final lists of statements from each group were integrated into one list per question forming three final lists. Statements with an overall ranking of 5.0 (71%) or higher were included in the final lists. Statements with mean scores of less than five were removed and saved to a

separate list in case the panelists wished to return to a statement (Mead & Moseley, 2000). The final lists were shared back to all participants with an invitation to provide feedback.

8.4 RESULTS

8.4.1 PARTICIPANTS AND ATTRITION

Twenty-one experts consented to participate in the study: rehabilitation experts (n=7), dance experts (n=9), community experts (n=5). Participation and response rates were > 80% across all stages. Attrition primarily occurred due to personal schedules (n=3) and if an expert missed a deadline and did not respond to additional reminders, nor request additional time to complete the task, (n=1). Of the experts remaining upon study completion (n=17) 80% self-identified as female, 61% resided in Manitoba while the remainder resided in Ontario, Alberta, and British Columbia, 18% self-identified as autistic, 82% had completed an undergraduate, masters, or doctoral degree. Participant characteristics are outlined in Table 7.

8.4.2 STATEMENT GENERATION

In Stage 1, all experts participated in the initial virtual meeting for their group. Questions that arose included: i) How much input will we (experts) have on the language used around disability?, ii) Is there an opportunity to provide or include definitions of terms such as ‘support person’ and ‘inclusive’ within the recommendations?, and iii) How much time do we have to complete each task? And, if we can’t meet the deadline are we removed from the study? Reflecting on this first meeting each group was supportive of the study purpose, the inclusion of the perspectives of the three expert groups and were particularly supportive of apriori plan to centre the Community expert voices.

In stage 2, participants identified and shared what they felt were their most important responses and provided related contextual information. Participants suggested using some of the

statements as a preamble to the lists. One dance educator expressed a concern that the 'fun' factor had not been addressed and suggested the inclusion of a related a statement on the list for question two (instruction) or in a preamble to the lists. Following stage two each participant reviewed a spreadsheet of the statements generated for each question within their group and provided feedback regarding language (90% response rate). As each group had reviewed their own statements no changes in wording or language were required.

Table 7

Participant characteristics and attrition across the data collection phase

		At start of Delphi	**At completion of Delphi**
Gender	Female Male	n=21 (95%) n=1	n=17 (94%) n=1
Age	26-65	22	17
NDD representation (Across all expert groups)	AS, ADHD, ID or learning disability	8 (36%)	6 (33%)
Years of experience (by group) *Rehabilitation Professionals*	1-5 years 10 or more years N/A	3 3 1	3 2 1
Dance Educators	1-5 years 6-10 years 11 or more years	2 3 3	2 3 2
Support persons/carer	1-5 years 10 or more years	2 2	1 1
Dance Experience (by group; estimated) *Rehabilitation Professionals*	None 10-15 years 15-20 years 31 or more years	1 1 3 2	0 1 3 1
Dance Educators	10-15 years 15-20 years 20-30 years 31 or more years	2 1 0 3	1 0 2 3
Persons with NDD	None 1-5 years 20-30 years	1 2 2	1 3 2

Note. Dance experience refers to participation in dance as a dancer, dance teacher, or assisting the dancers in a dance class setting.

Table 8

Number of responses per question (at each stage)

		Number of responses per question (by expert group)		
		Rehabilitation	Dance	Community
Stage 2 - statement generation	Question 1	97	50	38
	Question 2	60	68	36
	Question 3	45	38	25
Stage 3 – statement reduction	Question 1	28	20	17
	Question 2	25	25	24
	Question 3	17	12	9
Stage 4 – final ranked list	Question 1	25 (26%)*	15 (30%)*	8 (21%)*
(Mean ≥ 5.0; 71%)	Question 2	18 (30%)*	18 (26%)*	21(58%)*
	Question 3	16 (36%)*	8 (21%)*	8 (32%)*

Note. *(*)* indicates the percentage of statements that were reduced through the collapsing of statements.

At stage 3 all three expert groups met to review the three lists for wording and redundancy for each of the three questions. As indicated in Table 8 the lists for each question were reduced by as much as 58%.

Due to the number of responses the rehabilitation group was unable to complete the task for all three lists in one meeting. At the groups' suggestion, the researcher reviewed the remaining lists and tracked any changes in wording or redundancy. The lists were then shared back to the rehabilitation group for review. To ensure transparency and clarity of the participants' intended messages, the collapsed statements were shared back to the participants alongside the original statements to ensure that they could clearly see which statements were collapsed into one another (see Appendix G, Table 15 for example). The feedback received from all groups included suggestions around language and specific statements to be collapsed. Once the revisions were completed by the researcher the revised statements were shared back to the participants who suggested the revisions to ensure that their input was captured and that the intended message of the original statements was maintained.

At stage 4, each ranking e-survey took from three to eight minutes to complete (85% response rate). There were no disagreements across the three groups with the final rankings, therefore an additional round of ranking was not required.

It was clear upon completion of the ranking procedure that there were common categories across the groups that resulted in overlapping statements between groups. However, the language differed between the lists as the rehabilitation and dance experts used more technical language specific to their professions and included explicit detail. Additionally, a review of the lists of recommendations from each group side by side highlighted the shared focus for each question across the groups. For example, comparing the responses for question one (environment and class structure) the shared focus across the groups included the space, class size, accessibility, flexibility of instruction, sensory needs, fostering participation, observation, and communication. The level of detail provided by the dance and rehabilitation experts highlighted and supported the community expert responses by providing explicit details and examples. With the goal of ensuring that the community expert perspectives were not overshadowed by the level of detail in the recommendations from the rehabilitation and dance experts, it was proposed to all expert groups that the community expert list serve as the primary recommendations. The primary list of recommendations would then be supported by the rehabilitation and dance expert recommendations in a separate supporting list. As this proposition deviated from what was described to the participants at the outset of the study, it was agreed that the community experts would be consulted first and, if they agreed, the remaining expert groups would then be consulted.

At stage 5 all community experts agreed with the proposition to maintain their recommendations as the primary list. The community experts also suggested that the final lists of

recommendations be prioritized in the following order: 1) community expert (primary list), followed by 2) dance experts, and 3) rehabilitation professionals in a supporting list. See Tables 9-11 for more detail. Considering the duration of the experts' engagement at this point (four months), available participants from each group (rehabilitation, n=2; dance, n=2) were contacted by phone to discuss the final list development. It was explicitly noted that shifting their recommendations to a supporting list of recommendations meant that their responses would not be listed in ranked order. The participants agreed to the supporting list and had no concerns regarding the ranked order of their statements. One participant did express a concern that developing these lists might make it seem 'simple' to create and teach inclusive programming. It was discussed that shifting the dance and rehabilitation experts' recommendations to a supporting list would supplement the primary list by providing specific detail and highlight the importance of ongoing education.

The final lists were shared with the participants five months after the start of the study (stage 6). Participants could choose to provide additional feedback. Three participants responded to the final list and one participant provided minor feedback. A summary of the primary recommendations is provided in Tables 9-11. The detailed supporting lists of recommendations are found in Appendices H-J, Tables 15-18.

Table 9

Primary Recommendations by Rank (Question 1)

(Q1) Primary Recommendations for adapting the class structure and environment	
1.	Understand and anticipate that changing the location of the class and sounds within and surrounding the class can be a source of anxiety and distraction. • *See section 7.10: (1) The space**
2.	Smaller class sizes (< 10 persons) and organized by age (children and adults separate) are immediately most inclusive. • *See section 7.10: (2) Class sizes**
3.	Ensure that both the building, dance space (studio), bathrooms, and changing areas are accessible. • *See section 7.10: (3) Accessibility**
4.	To reduce uncertainty and anxiety for the dancers follow a consistent class structure, remain flexible, and respond to the needs of the group. • *See section 7.10: (4) Consistency and flexibility of instruction**
5.	Design instruction to deliberately incorporate adaptive sensory transitions such as adjusting the volume of music or dimming the lighting to help direct and maintain dancers' attention. • *See section 7.10: (5) Consider sensory needs and transitions**
6.	Encourage all dancers to actively participate in their own way. • *See section 7.10: (6) Facilitate participation**
7.	To reduce anxiety around being observed provide options to cover viewing windows and mirrors and provide a waiting area outside of the studio. • *See section 7.10: (7) Observation**
8.	Clearly communicate class structure, expectations, and changes before the class to both dancers and families/support persons. • *See section 7.10: (8) Communication**

Note. (*) The details of the related supporting recommendations can be found in section 7.10.

Table 10

Primary Recommendations by Rank (Question 2)

(Q2) Primary Recommendations for Inclusive Instruction
1. Provide and demonstrate adaptations for the different abilities and capabilities of all the dancers, or if a dancer is struggling. • *See section 7.11: (1) Adaptation for different abilities of dancers**
2. Acknowledge progress and effort through honest feedback and direction. • *See section 7.11: (2) Feedback and direction**
3. Instructors should have a background in dance and are able/willing to move with the dancers during the class (active), rather than just sit and observe (passive). • *See section 7.11: (3) Active vs. Passive instruction**
4. Lead with empathy and understanding. Be open to adjusting the class plan and/or structure when needed. • *See section 7.11: (4) Flexible instruction**
5. It is critical for instructors and assistants to gain an understanding of the general characteristics of the dancers' diagnoses *and* the experience of disability. • *See section 7.11: (5) Understanding disability**
6. Allow dancers to choose to rest when needed. • *See section 7.11: (6) Attend to dancers physical & social cues**
7. The incorporation of breathing exercises on a regular basis can help to regulate both anxiety and heart rate. • *See section 7.11: (7) Incorporate regulation skills**
8. When offering help do so in an unobtrusive way to ensure that no dancer feels left out or singled out. • *See section 7.11: (8) How to assist dancers in class**
9. Ensure that the pace of the class progresses in a timely manner (i.e., don't be swayed by students talking during instruction). • *See section 7.11: (9) Pace of the class**
10. It is important to understand that the dancers experience good and bad days; sometimes there are no solutions, just let all feelings be valid. • *See section 7.11: (10) Understanding & self-regulation**
11. It is helpful when instructors and assistants are positive and energetic. Make the class fun, yet balanced with purposeful activities and provide respectful, direct guidance. • *See section 7.11: (11) Positive and energetic**
12. Engage strategies that encourage participation and support learning. • *See section 7.11: (12) Support participation & learning**
13. For *some individuals* it can be helpful to talk them through what is happening to their body if injured or experiencing dysregulation, etc. • *See section 7.11: (13) Be prepared**
14. The instructor needs to be aware that their tone of voice or how they look at a dancer can be encouraging or discouraging. • *See section 7.11: (14) Be self-aware**
15. Cultivate a culture of acceptance that allows and welcomes the dancers' voices, opinions, and perspectives on issues they feel are important in class. • *See section 7.11: (15) Cultivate a culture of acceptance**
16. Integrate the principle of inclusivity into class instruction so that dancers understand that they are also building life skills such as self-advocacy, resilience, and adaptability. • N/A
17. To foster communication and flow of the class incorporate visual cues (signs & schedules) and hand signals (e.g., follow along, please be quiet, listen). • *See section 7.11: (17) Visibility & visual communication**
18. Some behaviours related to NDD may cause anxiety or intimidate other dancers. To foster familiarity and connection incorporate ways for students to get to know one another during the class. • *See section 7.11: (18) Foster familiarity and understanding**

Note. (*) The details of the related supporting recommendations can be found in section 7.11. N/A indicates that there are no supporting recommendations for this recommendation.

Table 11

Primary recommendations by rank (Question 3)

(**Q3) Primary Recommended Information for Assistants****	
1.	It is important that assistants are an active participant in the class, rather than being a passive observer. • *See section 7.12: (1) Be an active assistant**
2.	It is critical that support persons and assistants allow dancers to initiate movement before jumping in to assist with movements. • *See section 7.12: (2) Dance with, not for**
3.	Provide and encourage opportunities for assistants and support persons to share strategies and ways to support dancers. • *See section 7.12: (3) Provide support and ongoing learning**
4.	It is most helpful when assistants model the teacher, the dance/activities, a sense of humour and positive attitude. • *See section 7.12: (4) Model behaviour**
5.	Assistants must understand that every other participant in a classroom deserves to have their time and effort considered and respected; it is not acceptable to presume that disrupting an entire class is "no big deal" because "it's just one question". • *See section 7.12: (5) Be respectful**
6.	Provide regular learning opportunities for all leaders within the dance community (teachers, assistants, directors, dancers, parents, etc.). • *See section 7.12: (6) Ongoing learning**
7.	Ask in advance how each dancer prefers to communicate best (any specific cues that should be used, ASL, etc.). • *See section 7.12: (7) Communication**
8.	An agreement to abide by protocols and expectations (such as anti-bullying policies) ought to be a prerequisite for participation. It is the responsibility of instructors to communicate and uphold this structure. • N/A

Note. (*) The details of the related supporting recommendations can be found in section 7.12. (**) The term assistant is defined as persons who are hired as teaching assistants or volunteer as a class assistant. Support persons are defined as carers (employed by a day program, individual, or family) or family participants attending with the dancer. N/A indicates that there are no supporting recommendations for this recommendation.

8.5 **DISCUSSION**

The findings of this study have led to the development of an expert-informed list of recommendations for inclusive and adaptive dance that was built from the perspectives of the dancers and those who support them, dance educators, and rehabilitation professionals. We intentionally centred the experiences and perspectives of the dancers using the constraints model of motor development and social model of disability to consider how and what aspects of dance instruction, environment and culture can be adapted or modified to proactively anticipate the needs of the dancer (Newell, 1986; Oliver, 2013). Through the insights of the eighteen experts,

we systematically developed thirty-four primary recommendations (see Tables 9-11) and one hundred and eleven supporting action-oriented recommendations (see Appendices H-J, Tables 15-18) to guide adaptive and/or inclusive instruction and dance environments. The ranked responses of each group were synthesized into two lists: i) community expert recommendations (see Tables 9-11), and ii) supporting recommendations as proposed by the dance and rehabilitation professionals (see Appendices H-J, Tables 15-18).

8.5.1 **THE CLASS STRUCTURE AND ENVIRONMENT**

Each expert group was asked to consider what aspects of the dance class structure and environment may need to be adapted to create a more inclusive environment for persons with NDD. Usually, how the dance class and environment are structured stems from its ableist origins and follow a standard structure including what will be taught and how, the 'rules' of the dance class, where dance can be performed, and who can access dance spaces as determined by persons without disability (Aujla & Redding, 2013; McCarthy-Brown, 2017). The community experts' recommendations highlight the elements critical to their experience including access, flexibility, consistency, participation, communication, and being proactive regarding sensory considerations (see Table 9). Likewise, the dance and rehabilitation experts' recommendations included explicit actions to address sensory processing (light, sound, proprioceptive) in relationship to the space and instruction, the functional accessibility of the space and building, ways to promote participation through instruction, and engaging a structured yet flexible class structure, and communication. The applied nature of these recommendations lies in the supporting list of recommendations derived from the practical experiences of the dance and rehabilitation professionals (see Appendix H, Table 16). Previous literature has proposed barriers to participation as including lack of building access as well as spaces and instruction that account

for students' sensory needs (Aujla & Redding, 2013; Suppo & Swank, 2019). The supporting list builds on the previous literature and directly responds to issues around accessibility of buildings and dance spaces, incorporating concrete actions and contextual information around instruction and the studio environment (Whatley, 2007). Principal to the design of adaptive and/or inclusive dance opportunities is a foundational understanding of disability, the ways in which instruction is designed, and if and how expectations of movement performance can be adjusted.

8.5.2 **INCLUSIVE INSTRUCTION**

The combined constraints-based and social model of disability position instruction as relative to the dancer, therefore the characteristics of the individual are taken into consideration by the instructor when adapting movement and forming instruction (Newell, 1986; Oliver, 2013). Each expert group was asked to consider instruction and what strategies might need to be included/adapted and how to include those strategies in the dance experience. Congruent with existing literature (Aujla & Redding, 2013; Suppo & Swank, 2019; Whatley, 2007), an underlying theme across the recommendations is the need for the provision of, and a base competence with, foundational knowledge of disability including diagnoses and behaviours, barriers and facilitators to participation, methods of communication, and the importance of the instructors' role in creating an inclusive dance experience more broadly (see Table 10). The experts also prioritized recommendations around qualities of the instructors and assistants, such as being encouraging, clear and direct in their instruction, honest in their feedback, positive and energetic, actively dancing with the dancers rather than passively observing, and communicating clearly with the dancers. These findings support the suggestions of Morris et al. (2015) and Suppo and Swank (2019) regarding instruction and assistants. The authors suggest providing training opportunities for assistants to familiarize them with common characteristics of the

dancers, and the importance of being enthusiastic. For both instructors and assistants, the authors propose they embrace a discovery-oriented, collaborative shared-learning approach (Morris et al., 2015; Suppo & Swank, 2019). Taken together the suggestions around instruction and assistants further highlights the importance of the instructor and assistants' positive energy and open communication with dancers and assistants.

The supporting list of recommendations related to instruction provides the groundwork for developing more inclusive dance instruction and reinforces the importance of teachers and assistants engaging in ongoing skill development specific to disability and accommodations (see Appendix I, Table 17). One focus of the strategies around instruction is the flexibility of the class structure and the instructor. This highlights the importance of balancing instructions around technical dance elements with an exploration of dance concepts. This approach ensures that dancers gain a foundational technique within their own physical capabilities and can explore the concepts of dance and movement more broadly. Similar approaches, though derived from the training requirements of performing companies, have been used by Tomasic (2014) and Morris et al. (2015), and for children's programs by Suppo and Swank (2019).

Another focus of the strategies for class instruction is recognizing that progress may look different for dancers with NDD. For example, it may take more time for a dancer to master a step or movement or may not be able to perform a movement in an expected manner, or they may express their feelings or needs differently, as compared to a dancer who does not have a disability (Aujla & Redding, 2013). Understanding, questioning, and reflecting on how a dancer might participate in the dance class is critical to the process of creating adaptive and inclusive dance spaces. Taking these steps may foster the instructor's ability to proactively guide dancers through their class. For example, in a recent study we asked dancers with NDD about their

experiences with and perspectives on dance instruction (see Chapter 4). The dancers expressed that when instruction prioritized dancers' needs, their experiences in dance led to a sense of belonging and purpose. In contrast, the dancers also expressed that when their differences were pointed out by the instructor in front of others they experienced feelings of isolation, feeling 'not good enough', and lonely. This finding demonstrates how an instructor's communication with dancers can directly impact their sense of belonging and inclusion. Thus, highlighting the importance of the instructor's role in the process of inclusion as the approach they choose can create a culture of acceptance, where instruction begins with the presumption that all individuals/dancers are competent, or conversely can create a culture that excludes and isolates persons with NDD through their words and actions. Here, the actionable recommendations provided in the secondary list around instruction demonstrate how instruction can be designed to consider the capabilities of dancers with NDD. Persons who assist the dancers and/or the teacher directly also play an important role in the dance class. How instructors acknowledge and communicate with the assistants, support staff and/or carers may also influence dancers' experience in, and the culture of, the dance class.

8.5.3 **INFORMATION FOR ASSISTANTS**

Lastly, each expert group was asked to consider what information assistants might need when assisting a dancer with a NDD (see Table 11). Assisting can involve dancing alongside and/or with a dancer or may involve physically assisting a dancer to move their limbs, or both. Here, the primary themes included understanding ones role as an assistant, being an interactive assistant, getting to know the dancers you assist and how they communicate, ongoing learning, and maintaining open communication between the dancer and instructor. As other authors have suggested, it is ideal if the instructor, dance school or organization can provide regular volunteer

or employed assistants in the class (Morris et al., 2015; Suppo & Swank, 2019), however for some individuals it may be helpful to have a known assistant/support person assist them during the class. The supporting recommendations (see Appendices H-J, Tables 16-18) highlight the need for assistant training in advance of, or during, their participation in a program (Suppo & Swank, 2019). These findings outline specific strategies that highlight the importance of the role of assistants and their impact on the dancers' experience, the importance of communication between the instructor, assistant, and dancer, and support ongoing education for all assistants and instructors. These insights may also inform how to best incorporate, direct, and train support persons for adapted and/or inclusive dance experiences.

To the best of our knowledge this is the first study to use a Hybrid-Delphi approach to establish and prioritize expert recommendations on what, and how, aspects of the dance culture, environment, instruction, and assistance should be considered and adapted when designing adaptive and/or inclusive dance programming. A strength of this study is the shared recommendations across the three expert groups with the prioritization of the community experts' perspectives. We explicitly engaged and centred the recommendations on the perspectives of the dancers and those who support them through; i) an apriori plan for rankings to be reviewed and agreed upon by the community experts, and ii) a post hoc revision to present the community expert recommendations as the primary recommendations.

The findings of this study align with existing literature and reflect the need to include the perspectives of the dancers with NDD, as well as known barriers and facilitators to participation in PA for persons with NDD broadly (Aujla & Redding, 2013; Ladwig et al., 2023; Suppo & Swank, 2019; Wright et al., 2019). Another strength of this study lies in the applicability of both lists of recommendations to a variety of dance and physical activity settings. Notably, these lists

are not intended to be prescriptive in nature; instead, these recommendations are tools to guide educators in a range of movement based settings including, but not limited to, dance schools and studios, community programs, and physical education.

Finally, this study adds to previous reports around a lack of instructor training in relationship to disability and movement, specifically the integration of dancers with disabilities into physical activity and dance environments (Aujla & Redding, 2013; Whatley, 2007; Wright et al., 2019). Importantly, this study provides actions to shift the narrative in dance and physical activity towards normalizing difference and adaptive approaches to (dance) instruction (Hansen & Philo, 2007). These comprehensive findings may also be used to promote discourse around common practices engaged in the dance studio and the assumptions made about persons who live with disability, in the context of instruction and the culture of the dance community (Aujla & Redding, 2013; Leadbitter et al., 2021).

8.6 LIMITATIONS AND FUTURE DIRECTIONS

The response rate throughout the Hybrid-Delphi procedure was 81% with eighteen of the twenty-two experts remaining engaged through the final stage. With respect to representation, autism was the prominent diagnoses across the groups. Further, the community expert group communicated independently and was also smaller in number than the other two groups. This limitation reflects the tendency for literature in dance and disability to engage individuals who function and communicate independently (Ladwig et al., 2023; Leadbitter et al., 2021). Future research in the dance and disability paradigm should work to equally engage dancers with physical disabilities as they hold a unique perspective and life experience that may contrast those who are primarily neurodivergent. Another possible limitation is in the design of the groups. Rather than combining all experts into one group we chose to engage each cohort of experts

separately. This format was more conducive to the virtual focus group setting as smaller group sizes are better facilitated in an online format. Scheduling the focus groups for each cohort took more time than anticipated due to the participants personal and professional schedules. This limitation may have contributed to some of the participant attrition. Finally, future studies will include the development of a dissemination plan to share these recommendations with the dance community using a process that is co-designed and delivered alongside dancers who have NDD, dance, and rehabilitation professionals.

8.7 **CONCLUSION**

This study examined common practices in dance instruction through the combined constraints model of motor development and social model of disability that highlights the interactive relationship of the characteristics of the dancer (physical and affective), the task and instruction, and the environment and culture of the dance setting, including the ways in which these characteristics might restrict participation for dancers with NDD. The result of this Hybrid-Delphi process is a comprehensive list of actionable recommendations that are based on the priorities and experiences of persons with disabilities. The recommendations are applicable to a variety of education and dance settings and can be selected and explored by dance educators, schools, and organizations to guide both the development of adaptive and inclusive dance and education pedagogies and spaces. Finally, each recommendation is presented as an invitation to further examine and reflect on the location of ableism in the broader culture of the dance community, and specifically in dance instruction, and dance environments.

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CHAPTER 6

GENERAL DISCUSSION

9.0 GENERAL DISCUSSION

This thesis responds to the question; ‘How can I help the (my) dance community to create dance environments and instruction that are more accessible and inclusive for persons who live with invisible and visible disability?’. The choice to focus on NDD was informed by my experience teaching dance to and with this specific population. I chose to employ qualitative methods to systematically gain insight into this underlying question using processes that deepen our collective understanding of the experience and embodiment of disability in dance settings. Reflecting on my experience and process of conducting this research and my teaching experiences and interactions with this population, I have come to better understand the importance of intentionally challenging ableist assumptions through my teaching and this thesis.

9.1 AIMS OF THESIS

The fundamental goals of this thesis were to establish a foundation of understanding of the current dance and disability literature, understand the experience of dancers who live with NDD, and to gather expert recommendations for the creation of adaptive dance instruction and dance environments with the disability, dance, and rehabilitation communities. Specifically, the aims of this thesis were to examine the existing relationship between dance and NDD by conducting a synthesis of the literature, gaining an understanding of how and what is important in the experience of dance for persons who live with NDD, and gathering expert perspectives to describe what and how instructors can make dance classes and environments inclusive.

A multiple methods design was chosen for this thesis, starting with a scoping review of the literature for the first study. This review examined the present state of literature specific to dance and adults with NDD. It also included a synthesis of instruction and intervention characteristics, and outcomes. In the second study, I used narrative inquiry to gain a deeper

understanding of the lived experiences of dancers who live with NDD through semi-structured interviews with the dancers. Finally, in the third study, a Hybrid-Delphi technique was used to understand the priorities of key stakeholders, including dancers who live with NDD, and those who support them, dance teachers who provide adapted and/or inclusive programming, and rehabilitation professionals who have experience working with this population.

9.2 SUMMARY OF KEY FINDINGS

The objectives of the first study, included in Chapter Three, were to: i) determine the characteristics of, and common instructional strategies used in dance interventions for adults with NDDs, ii) synthesize the outcome measures used to assess the efficacy of dance as an intervention, and iii) consider the relationship between the reported outcomes and the characteristics of the dance interventions. To reflect the interactive nature of motor and perceptual development specific to the person, task, and environment, the constraints model of motor development was used to frame the study findings (Getchell & Gagen, 2006; Newell, 1986). The fourteen studies reviewed in study one lacked sufficient detail and transparency in the description of the intervention characteristics, thus limiting the replicability of the studies. Additionally, the studies often included outcome measures that were not validated for a particular population, used comparisons to normative scales or were self-report measures, and lacked assessments of movement quality.

The key findings derived from the scoping review include the need to engage a person-centric approach to: i) the development of interventions, ii) how dance environments and instruction are adapted, iii) the specific aspects of dance and dance instruction that might influence changes in fitness, mobility, movement quality, or psychosocial constructs, and iv) a need to examine the relationship between study outcomes and specific intervention

characteristics. The analysis revealed a need to shift our collective view of dance and movement-based opportunities (and instruction) for persons with disability from a behavioural and symptom (deficit) based to a strengths-based approach. Specifically, one that focuses on individual motor and psychosocial skill development through enjoyable recreation. This shift is important for developing skills through dance that directly impact individuals' daily lives at home and in the community (i.e., strength, balance, social skills, confidence).

Study two, presented in Chapter Four, builds upon the recommendations noted in study one. Using a narrative inquiry approach, I used a constructivist lens to examine dance instruction and environments through the perspectives of the dancers as only they can truly understand and express the experience and embodiment of disability. In response to the need to centre the voices and experiences of the dancer (Leadbitter et al., 2021), both the constraints model of motor development and embodied knowledge theory were used to develop the methods, including to frame the interview questions and data analysis (Getchell & Gagen, 2006; Newell, 1986; Lakoff & Johnson, 1999). Thus, the aims of study two were to understand: i) the dancers' experiences in inclusive and/or adaptive dance settings, ii) the dancers' perspectives on instruction, and iii) the dancers' broader narrative as related to their dance experiences. To do this I conducted semi-structured interviews virtually or in-person with fourteen dancers who identified as having an NDD from across North America.

Three main themes were revealed through the thematic analysis: i) Dance is who I am, ii) Dance teaches me skills for life, and iii) Inclusive instruction and dance culture. The dancers shared that their experiences of belonging, and the connections gained through dance facilitated their individual exploration of social skills, encouraged persistence and mental flexibility, and bolstered their motivation and self-efficacy within the dance space. The dancers expressed that

when dance instructors and schools cultivated an environment of acceptance and safety, they experienced a greater sense of purpose and direction, and were able to weave the skills learned through dance into their daily lives. These themes echoed the findings in study one and provided insights into the importance of interrogating the normative assumptions often made about disability by the dance community in relation to instruction, spaces, and the dance culture (see Chapter 4, Table 4).

Study three builds on the findings of belonging, learning transformational skills, and flexibility of instruction uncovered in study two. In study three I systematically engaged Canadian experts from the disability, dance, and rehabilitation communities to build expert informed recommendations on what strategies are needed to cultivate a dance culture, environment, instruction, and assistance that is adaptive and/or inclusive. To do this I used a Hybrid-Delphi technique that included virtual focus groups and an email ranking procedure to prioritize expert responses. The constraints model of motor development and the social model of disability were used to frame the questions posed to the experts and to inform the final lists of recommendations and strategies (Getchell & Gagen, 2006; Newell, 1986; Oliver, 1983). To ensure that the final lists were centred on the views of the community expert group (the dancers and those who support them), the experts agreed to the formation of two interconnected lists. The primary list consists of the community groups ranked recommendations, while the ranked recommendations of the dance and rehabilitation groups formed a supporting list of actionable recommendations linked to each item in the primary list of recommendations. The final lists echo the findings from study two and reflect practices proposed in earlier literature (Morris et al., 2015; Suppo & Swank, 2019; Tomasic, 2014), yet prioritizes the perspective of the dancers and

provides explicit implementation strategies from the dance and rehabilitation community perspectives.

9.3 CONTRIBUTIONS TO THE LITERATURE

Broadly, this thesis responds to the call to dismantle ableism in the dance community by intentionally centring and including the perspectives of dancers who identify as disabled or living with a NDD (Goodwin & Connolly, 2022). Actions to disrupt ableism (in dance) are implicitly woven throughout each study and add to the novel contributions of this thesis (Hansen & Philo, 2007). Specifically, the novel contributions to the literature include: i) study designs that address ableism in dance by centring dancers' preferences and perspectives, ii) balancing existing perspectives of disability, and iii) adding to the literature supporting dance as a feasible and meaningful form of recreation for persons with NDD. In the following sections each contribution is expanded and discussed in more detail.

9.3.1 ADRESSING ABLEISM THROUGH STUDY DESIGN

Reflecting on the design of this thesis, as a doctoral candidate who identifies as non-disabled, I made intentional choices to address ableism throughout the research methods and process. As Stone and Priestly state: "If research is to be relevant, and if the researcher is to demonstrate commitment in actions as well as words, then anti-oppressive practices must begin with the research production process itself" (Stone & Priestley, 1996, p. 703). In other words, it is necessary to 'normalize doing research differently' by mindfully selecting and questioning our methods when researching disability (Hansen & Philo, 2007). I approached the design of this thesis with an understanding of the inherent power that the (non-disabled) researcher holds and the knowledge that only those who embody the experience of disability can speak to their experience (Lakoff & Johnson, 1999; Stone & Priestley, 1996). The scoping review revealed the

need for research in dance and disability to examine how research is designed, what is being measured and why, and consider the ways the results can create change in our disciplines (e.g., dance, human movement, and physical education) and communities. Studies two and three engaged specific anti-oppressive strategies, including using a trauma-informed approach to the study design.

Disability and trauma often intersect (Eales, 2023). Ableism is a form of harm that may be overtly or covertly perpetuated in both research and practice (Eales, 2023). I chose to take a trauma-informed approach in the design and process of studies two and three (Isobel, 2021; Stone & Priestley, 1996). For example, to reduce uncertainty and anxiety, the dancers in studies two and three could choose to have a carer or support person attend the interview alongside them. To demonstrate transparency all interview and focus group questions were provided in advance and all participants were encouraged to review and respond to the questions in advance of their interview or focus group. During the interviews and focus groups all participants could choose to read prepared responses or respond in the moment. To ensure our (myself and the research assistant) ability to focus on the participants, each session was held in a quiet space, and we prepared by reviewing the study notes in advance. We also explained to the participants that we might take notes during the interviews or focus groups and regularly checked in with each person during the sessions to see if they wanted to take a break (Isobel, 2021). It is of interest that each of the strategies used in this thesis were beneficial for all participants.

9.3.2 **BALANCING PERSPECTIVES**

Current adaptive physical activity (PA) and autism literature suggest a shift in the focus of PA and recreation opportunities from a deficit focus to a recreational and strengths-based focus where PA is enjoyable and builds on individual strengths, and provides opportunities to

develop motor, perceptual, and social skills (Goodwin & Connolly, 2022; Leadbitter et al., 2021). At first glance this proposed refocusing may be perceived as an 'all or nothing' approach that suggests replacing the biomedical (deficit-based) perspective with the social (strengths-based) approach. In the context of adapting movement or dance instruction and environments, a novel contribution of this thesis is the proposition that there is a need to allow practice to be informed by relevant information from the biomedical perspective. This proposition is supported by the findings of study three.

The design of study three engaged three specific groups of experts including: i) dancers who live with NDD and those who support them in dance, ii) dance educators and iii) rehabilitation professionals who had experience working with persons who live with NDD. Throughout the study the three groups worked in isolation from one another but had knowledge that the other groups were also participating in the study. Importantly the final development of the lists of recommendations was guided by the combined constraints-based model and the social model of disability, as well as informed directly by the dancers' preference (Getchell & Gagen, 2006; Newell, 1986; Oliver, 1983). Whether stated explicitly or implied implicitly a common thread across the recommendations of all three groups (community, dance, and rehabilitation professionals) was a need to prioritize ongoing education around disability broadly, the general characteristics of diagnoses, and the shared characteristics across diagnoses for instructors and in-class assistants. This finding highlights a tension in both academic and practical approaches to physical recreational programming with the disability community.

Contrary to current adapted physical activity perspectives that lean into disregarding the biomedical model (De Pauw, 2023), disability scholars Hansen and Philo (2007) suggest that although the onset of the social model of disability shifted our collective focus to consider how

society restricts, limits, and disables, the model has simultaneously created a gap where the attributes of disability are absent from our understanding. The findings of study three echo this proposition and suggest that when adapting any form of recreational physical activity that it is important for instructors to understand the general characteristics of, and the variability within, a given diagnoses. Considering the findings of the present thesis, I submit that the dance community and higher education (e.g., fundamental movement and adaptive physical education courses) may benefit from a dual model approach to adapting movement that includes knowledge of adaptive strategies as well as specific characteristics of disability that are juxtaposed with discussions around the embodied experience of disability from disability scholars, para-athletes and, in the context of this study, dancers who live with disability.

9.3.3 **MEANINGFUL RECREATION and PHYSICAL ACTIVITY**

Ableism and dance, including the influence of ableism on who is a dancer and what dance should be performed, are intertwined throughout history (McCarthy-Brown, 2017). As the biomedical model has influenced education, policy and practice, the perception that dance is not feasible, nor meaningful, for persons with disabilities carries over into broader societal perceptions (Janz, 2019). Thus, it is unsurprising that health practitioners rarely suggest dance as a physical activity (PA) option for persons with NDD (Sung et al., 2022).

As demonstrated in study two, meaningful PA is key to flourishing and promotes positive affect and relationships, engagement in purposeful activities, and a sense of accomplishment for individuals of all abilities and capabilities (Agenor et al., 2017; Seligman, 2011). Others have suggested that dance is an activity that encourages ongoing engagement as it is not only a PA, but one that also engages creativity, promotes social interaction, and may lead to self-actualization and a sense of flourishing (Agenor et al., 2017; Fontanesi & DeSouza, 2021;

Maslow, 1943). A novel contribution of this thesis is adding to the evidence that dance is not only a feasible activity, but an activity that can be quite meaningful for persons who live with disability. Importantly, this contribution arises directly from the experiences shared by dancers who live with NDD in study two.

The findings of this thesis, particularly in studies one and two, are evidence that dance is feasible and can be a meaningful activity for persons who live with disability. Specifically, study one demonstrates that dance, in its varying forms, is a feasible PA for persons who live with NDD who can participate independently, as well as those who rely on the assistance of others (i.e., GMFCS IV or V) (Ladwig et al., 2023; Teixeira-Machado & DeSantana, 2019; Terada et al., 2017). Study two adds to the evidence supporting dance as a meaningful activity for persons who live with NDD when instruction is person-centred, flexible, considers individual needs and capabilities, and encourages an accepting and safe environment for learning and participation. The dancers expressed that these qualities created an environment where they were able to forge new connections, experience a deeper sense of purpose and identity, explore social interactions, and develop skills that carried over into their daily lives.

9.4 LIMITATIONS AND FUTURE DIRECTIONS

As this series of studies is intended for the fulfillment of the requirements for doctoral studies there were limits on how each study was designed. Each of the three studies were led by the PhD candidate who does not identify as having a disability. Thus, my perspective of disability is derived from my experiences working with dancers who live with NDD. This could be perceived as an ableist lens, and thus a limitation across the three studies. Reflecting on this limitation it is my intention to seek out future research opportunities that engage persons who live with disability in collaborative or co-design research and implementation projects.

The heterogeneity of NDD could also be perceived as a limitation of this thesis. I acknowledge that individual variability exists within each person whose diagnosis falls under the umbrella of NDD. To this end, each individual experience and embodiment of NDD is unique, therefore some may feel that they do not see their experience or perspective represented in this thesis. Studies two and three aimed to engage participants with a range of functional and communication capabilities, however most participants were able to dance and communicate independently. Therefore, the experiences and insights of those who require assistance with movement and/or alternative communication methods were not balanced with the perspectives of those who did not require assistance with communication. While the findings in studies two and three include perspectives from dancers with varied levels of physical function, and therefore demonstrate that actions of inclusion can apply broadly to NDD (rather than always be specific to a diagnosis or functional capability). An alternative perspective is that the recommendations may be too broad, or not specific enough to the individual diagnoses under the umbrella of NDD.

9.4.1 **FUTURE DIRECTIONS**

To move the development of dance and adapted physical activity opportunities forward, whether in the arts, sport, or physical activity broadly, it is critical to continue to find ways to engage the disability community directly to ensure that their perspectives are included in the co-design of programming and research in partnership with those who do not have a NDD (Goodwin & Connolly, 2022). To ensure that the perspectives of dancers who require assistance with movement and/or alternative communication methods are represented a future study will add to the findings of study two with this specific population. To disseminate the findings of study three to the broader dance community educational opportunities (e.g., training modules

presented through video and webinar format) will be co-designed with dancers who live with NDD and dance educators and qualitatively evaluated.

Another future direction of this research involves the integration of the two models used to frame this thesis, namely the constraints model of motor development and the social model of disability. In the context of adaptive and/or inclusive dance opportunities, the integration of these two models into a new model or framework may facilitate an intentional shift away from a deficit-based approach to the design of movement instruction (e.g., dance, games, sport) and environments to a strength-based and person-centred approach (Goodwin & Connolly, 2022; Leadbitter et al., 2021). In my experience one of the challenges for students is parsing out how and what aspects of a movement, activity, or environment may require adaptation. This integrated framework could be used to guide the design of activities and environments in arts education settings such as theatre and music, and in higher education settings involving fundamental movement skills and sport, personal training and coaching, and motor learning and development research and practice. For example, in higher education courses such as adapted physical activity the framework could be used to guide thinking around the social model of disability and why providing adaptive options in recreation and movement activities is important for dismantling ableist practices in movement education. The integration of these models has the potential to foster students understanding of why adaptive and/or inclusive instruction and environments are important, what aspects of the person, instruction, and the environment need to be considered to create meaningful activities, and a deeper understanding of the difference between deficit and strengths-based approaches to movement and activity adaptation.

9.5 **REVISITING MY POSITIONALITY**

Positionality is dynamic and context-dependent, and therefore may change over time and through experience (Gary & Holmes, 2020). This thesis has developed over several years; therefore, it is important to revisit my positionality at this juncture. In Chapter one I addressed ableism and its relationship to the biomedical model of disability. Reflecting on my understanding at the start of this thesis, I saw the two models as dichotomous, as having to choose between one or the other. Through studies two and three I have come to understand and appreciate that there is a time and place for the biomedical view. To wholly dissociate the person from their medical condition or diagnoses, as the social model implies, is to ignore part of a person's identity and their embodied experience. I have always believed, and this thesis has supported, that to adapt instruction and/or environment it is best if 'we' (e.g., instructors, coaches, etc.) have a general understanding of the diagnosis encompassed in NDD, as well as an understanding of how an individual embodies disability. This belief is balanced with knowledge that society both implicitly and explicitly restricts how, where, and when the disability community can participate in the larger community. Therefore, when adapting dance instruction or environment I believe it is important to check-in with the dancers who live with NDD and those who support them to ask their perspective, and to consider their perspective in the process of developing adaptations.

I also want to reflect on my language choices used throughout this thesis. As discussed in Chapter 1, there is no one 'correct' answer as the choice ultimately lies with the individual and/or within the disability community. In studies two and three I did not ask the participants their preferences for person-first or identity-first language. While I have reasoning for choosing to use (primarily) person-first language throughout this thesis (see Chapter 1, section 1.1.1),

including an opportunity to ask individual preferences would have been an overt action that demonstrated inclusion at the outset of each study. Likewise, in study two I made the choice to refer to the participants as dancers without asking the participants their preference. This decision is reflective of my teaching experience as I refer to the persons who participate in my dance programming as dancers. Today I question whether this choice might be perceived as ableist as using the term 'dancers' alone may be perceived as ignoring or disregarding part of an individuals' identity as a disabled person.

9.6 **CONCLUSION**

This thesis considered the relationship between dance and disability with the goal to challenge the normative assumptions and practices of the dance community. A multiple methods design facilitated a deeper understanding of the literature, the impact of adaptive dance opportunities and environments for dancers who live with NDD, and the development of both recommendations and strategic actions for adaptive and/or inclusive dance instruction and environments. The foundational understanding gained through this thesis suggests that when educators (e.g., dance, movement, physical educators) are willing to challenge the ableist assumptions of the past and create an environment of acceptance that dance can be an activity that fosters a sense of belonging, joy, and transformation for all those who choose to participate.

9.7 **REFERENCES**

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CHAPTER 7

APPENDICES

APPENDIX A

Table 12

Summary of Included Studies

Authors	Population	Study Design	Age (years)	*n*	Duration	Type of Dance
Tsimaras et al., 2012	MMMR (ID)	Quasi	Intervention (Mean =18.1; SD=20.0). Control (Mean = 18; SD=1.7)	Intervention (10); Control (7)	16 weeks; 45-minute sessions; (48 sessions)	Greek folk dance
Mateos-Moreno & Atencia-Doña, 2013	ASD	Quasi	Experimental group (Mean = 25; SD =4.10). Control group (Mean = 25.6; SD = 8.05)	Experimental (8); Control (8)	18 weeks; 90-minute sessions; (36 sessions)	Dance Movement and Music Therapy
Barnet-López et al., 2015	ID	Quasi	Mean = 47.3; SD = 11.7	(22)	12 weeks; 60-minute sessions; (24 sessions)	Dance Movement Therapy
Koch et al., 2015	ASD	Quasi	Mean = 22; SD = 7.7	Treatment (16); Control (15)	60- minute sessions; (7 sessions)	Dance Movement Therapy
Gutiérrez-Vilahú et al., 2016	DS	RCT	DS (Mean = 20.55; SD =1.37). Control (Mean = 20.27; SD = 2.05).	DS (11); Typically developing (11)	18 weeks; 90-minute sessions; (36 sessions)	Classical, modern, and creative dance principles
Hildebrandt et al., 2016	ASD	RCT	Treatment (Mean =23.07; SD=8.54); Control (Mean= 21.27; SD=5.32)	Treatment (55); Control (23)	10 weeks; 60-minute session per week; (10 sessions)	Dance Movement Therapy
Teixeira-Machado et al., 2017	CP; GMFCS II-V	Quasi	Dance (Mean = 17.07; SD 2.36). Control (Mean =18; SD 3.46);	Dance (13); Control (13)	12 weeks in length, 60-minute sessions; (24 sessions)	Feldenkrais, Horton, Graham Laban/Bartinieff concepts
Terada et al., 2017	CP; GMFCS V	Quasi	Mean=50.7; SD=8.9	(6)	12-months; 6-15 min sessions; (~ 104 sessions)	Ballroom dance: Waltz and Jive
DiPasquale & Kelberman, 2018	DD	Quasi	Mean =36.82; SD=15.38	(17)	12 weeks; 60-minute sessions (24 sessions)	Integrative contemporary dance
Mastrominico et al., 2018	ASD	RCT	Mean = 22.5; SD = 8.52	Treatment (35); Control (22)	10 weeks; 60-minute sessions; (10 sessions).	Dance Movement Therapy
Kim & Hong, 2019	ID or ASD	Quasi	Experimental (20-30) Control (20-30)	Experimental (15); Control (15)	12 weeks; 60-minute sessions; (12 sessions)	Creative Movement
Teixeira-Machado & DeSantana, 2019	CP; GMFCS III-V	RCT	Dance (Mean =14; SD = 3.46); Control (Mean = 15.07; SD =2.36)	Dance (13); Control (14)	3 months; 60-minute sessions; (24 sessions)	Contemporary; (Bartenieff, Feldenkrais, and Laban principles)
Aujla & Needham-Beck, 2020	NDD	Quasi	Mean = 18.14; SD 7.52	(22)	9 months; 90-minute session (~ 36 sessions)	Contemporary; StopGap inclusive (foundational) level
DiPasquale & Roberts, 2020	ID	Quasi	Dance (Mean=49); Control (Mean = 52)	Dance (8); Control (8)	12-weeks; 110-minute sessions; (12 sessions)	Integrative contemporary dance

Note: MMMR, mild-moderate mental retardation; DS, Down syndrome; CP, Cerebral palsy; DD, developmental disability; ID, intellectual disability; ASD, Autism spectrum disorder, RCT, randomized control trial; Quasi, quasi-experimental design.

APPENDIX B

Table 13

Level of Intervention Detail

Level of Intervention Details Provided		
Physical Fitness and Mobility Outcomes		
Study	**Description**	**Level of Detail in Intervention Description**
Teixeira-Machado et al., 2017; AND Teixeira-Machado and DeSantana (2019)	Based on Feldenkrais, Horton, Graham and Laban/Bartenieff methodologies (2 studies)	Low; provided an outline of class structure
Tsimaras et al., 2012	Greek Folk Dance	Low; provided an outline of class structure
Gutiérrez-Vilahú et al., 2016	Based on classical, modern, and creative dance principles	Medium; provided an outline of class structure that included the duration and focus of each section of the class.
Psychosocial Outcomes		
Mateos-Moreno and Atencia-Doña, 2013	DMT and Music therapy combined	Medium-High; provided an outline of the class structure that was well described and included activities and props used in the class, as well when and what types of music were engaged.
Koch et al., 2015	DMT	High; provided a well-described outline of the class structure that included the duration, purpose, general instructions provided, the purpose of volunteer assistants and how they were engaged in each section of the class, and how music was used.
Mastrominico et al., 2018	DMT	Medium-High; provided a well-described outline of the class structure that included the duration, purpose, general instructions, and where music was used.
Hildebrandt et al., 2016	DMT	Medium-High; provided a well-described outline of the class structure that included the duration, purpose, and general instruction.

Note. Each of these eight interventions did provide a description of the intervention with varying levels of detail. These studies have been grouped according to the level of detail provided: low (providing g a general outline), medium (providing an outline along with detail regarding duration and/or purpose of each section/activity), or high of detail (providing comprehensive description).

APPENDIX C

Study One, Sample Search Strategy

Literature searches were conducted using truncated keyword combinations of danc* AND disability*, dance* AND autis*, and the combined queries of both combinations for each database search.

For example, search strategy for the Scopus database:

1. Danc* AND disability*; published from 1959 to 2020 (August); Results were then further refined to include only peer-reviewed articles in the English language.
2. Danc* AND Autis*; published from. 1959 to 2020 (August); Results were then further refined to include only peer-reviewed articles in the English language.
3. These search queries were then combined.
4. Additional searches were also conducted using the search terms danc* and Cerebral Palsy; danc* and Down Syndrome, and danc* and Intellectual disability.

APPENDIX D

Study One PRISMA-Scr Checklist

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.	Pg 1
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.	Pg 2
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.	Pg 1-6
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Pg 5
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	n/a
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	Pg 5
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	5
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Supplemental file
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Pg 5
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Pg 5
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	n/a

APPENDIX E

The Interview Guide

Interviewer: Hello _____ and [caregiver/support worker]!

Interviewer: Can you hear me ok? (yes/no; if no, then troubleshoot the issue)

Interviewer: Thank you so much for making time for our interview today. Have you had a chance to think about the questions that we sent to you?

Interviewee: **Yes;**

Interviewer: great!

Interviewee: **No;**

Interviewer: Have you had a chance to think about the photos you selected?

Interviewee: **Yes;**

Interviewer: great! Let's get started.

Interviewee: **No;**

Interviewer: Would you like a moment to review the questions and the photos you selected before we begin?

Interviewee: Yes/No

Interviewer: First, I want to ensure that everything you say today is confidential/private. We will not share your name when we talk about the results. Does that make sense to you?

Interviewer: This interview will be recorded – when we save this recording and save the transcript of this interview your name will not be used. In addition, the recording files will be deleted from our Zoom account and saved only to the lab computer, external hard drive, and research server at the University of Manitoba.

Does that make sense to you?

Interviewee: Yes; (continue with interview)

No; (then provide further clarification)

Interviewer: This should take about 1-1.5 hours of your time. You will be offered breaks during the interview and please feel free to ask for a break at any point during the interview.

Does that make sense to you?

Interviewee: Yes; (continue with interview)
No; (then provide further clarification)

Interviewer: Great, Let's get started! **I will begin recording our interview now.**

[CLICK RECORD NOW]

Start of interview

1. Confirm name of participant (include spelling of name)
    - If a caregiver or support worker is present include them as participants, ensure that their name is also confirmed.

2. Where do you live?
    - Where the individual lives can be used as a reference for upcoming questions such as why dance is important to you.

3. Establish the relationship between the support person and dancer.
    - How long they have known each other.
    - How often do that attend dance with the dancer?

4. What activities (other than dance) do you enjoy doing?
    1. Prompt: do you swim? Sing? Paint? Garden?
    2. Provides a point of comparison for why an activity is enjoyable and/or what about an activity is enjoyable.

5. Brief casual conversation to 'break the ice' and get comfortable (for interviewees and interviewer) also to familiarize the interviewer with the communication of the interviewee (though this should be established in the pre-interview meeting).
    e.g., have you had a good day today?
    - Note: starting with yes/no questions is helpful

Interviewer: thank you for sharing your photos! I am excited to hear more about each of them. Let's get started…

Question 1 – gathering and understanding the characteristics of dance program.

Interviewer: you've been dancing with _____ for _____ years. What kinds of activities do you do in _____?

A. Prompt: do you start with a warmup? What happens after the warmup?
B. Prompt: do you learn choreography (combinations)?
C. Prompt: what is your favorite music from dance class? And what do you do to that music in class?
D. Prompt: have you participated in any dance performances? (e.g., recitals)

Interviewer: you selected this photo [show on screen], to describe your dance class. Do you remember this photo?

Interviewee: yes/no

Interviewer: I'd like you to take a moment to have a look at it and think about why you chose this photo/image. [pause – allow time to look at the photo]

Interviewer: tell me why you chose this photo to describe your dance class.
Prompt: what is happening in this photo (if it is of their class or of a class)?
Prompt: in what ways is this photo like what you do in your class?

[Note: if time allows, repeat this with the 2nd photo they chose or go to the backup photos and use those as a jumping off point to get to characteristics of the class they participate in.]

[interviewer reminder – take your time between questions]

[natural break here**…]**

Question 2 – understanding what aspects of the dance class are enjoyed and/or not enjoyed)

Interviewer: Moving on to question #2 - You selected this photo [show on screen], to express what you enjoy or do not enjoy about dancing. Do you remember this photo?
[pause]

Interviewee: Yes/No
Interviewer: I'd like you to take a moment to have a look at it and remember why you chose it. [pause – allow time to look at the photo]

Interviewer: Tell me why you chose this photo to represent what you enjoy most about dancing?

PROMPT: How does it remind you of your dance class?
PROMPT: Does it remind you of an activity you do your dance class?

NOTE: If time allows, repeat this with the 2nd photo they chose OR go to the backup photos and use those as a jumping off point to the next question

[NATURAL BREAK HERE…]

Question 3- understanding what tools the teacher may/may not use to adapt movements or to create an inclusive environment.

Interviewer: Moving on to the third question, what does your dance teacher do that helps or prevents your participation, or to feel included/excluded, in the class?

Do you remember this photo? [show on screen],

Interviewee: Yes/ No

Interviewer: I'd like you to take a moment to look at the photo and think about why you selected it for this question.

PROMPT: Does the teacher adapt exercises or activities in the class for you or others?
PROMPT: Does the teacher recognize your successes in class?
Does the teacher help you to be a better dancer in class?
How does the teacher help you to be a better dancer?

NOTE: If time allows, repeat this with the 2nd photo they chose OR go to the backup photos and use those as a jumping off point for the next question

---

Interviewer: We have two questions left – would you like to take a short break?

Question 4 – understanding how dancing changes how we feel about our bodies, and about ourselves.

Interviewer: Only two questions left! You are doing a great job.

Interviewer: Do you remember this photo? [show photo on screen],

Interviewee: Yes/No

Interviewer: I'd like you to take a moment to look at the photo and think about how dancing makes you feel.

Interviewer: Tell me why you chose this photo. [pause]

PROMPT: Does this photo show how your body feels when you are dancing?
Can you tell me more?
PROMPT: Does your body feel different when you are dancing?
How does your body feel when you are dancing? Why?

FOLLOW UP (if they reference how if physically feels): So, dancing makes your body feel [reiterate what they expressed]. Can you tell me more? Why does dancing make you feel that way?

FOLLOW UP (if they reference how it makes them feel emotionally or in reference to the self). So, dancing makes you feel _____ Can you tell me more? Why does dancing make you feel that way?

NOTE: If time allows, repeat this with the 2nd photo they chose OR go to the backup photos and use those as a jumping off point for the next question

[NATURAL BREAK HERE…]

Question 5 – understanding the importance of dance to the individual.

Interviewer: Moving on to the last question.

Interviewer: Do you remember this photo? [show on screen],

Interviewee: Yes Or No.

Interviewer: You selected this photo to show how dance is or is not important to you. [pause]

I'd like you to take a moment to look at the photo and think about why you selected this photo.

Interviewer: Why did you choose this photo to represent the ways dance is important in your life? [pause]

PROMPT: is being able to participate in dance important to you? Why?
PROMPT: what things have you learned through dance?

FOLLOW UP: During the COVID shutdown in your area, were you able to participate in dance? How did it feel to not be able to go to dance in-person? [Tell me what you missed the most about dancing in person.]

NOTE: If time allows, repeat this with the 2nd photo they chose OR go to the backup photos and use those as a jumping off point to the wrap up question.

WRAP UP question: It sounds like your experiences in dance have been _____ (sum up what activities they've talked about).

FOLLOW UP (if appropriate): Am glad that you've been able to continue (some) activities on Zoom. How does being physically active through dance make you feel?

[CONCLUSION]

Interviewer: Before we end the interview, are there any questions you have for me?

Interviewer: Is there anything else you'd like share with me about your dance experiences?

Interviewer: Thank you so much for sharing your thoughts with me and for taking the time to meet with me today!

Interviewer: To follow up - Over the next few days we will type up this interview and will then send it to you (both, if a support person is with them in the interview) by email. We ask that you read through the transcript to ensure that what we have written down reflects your words and thoughts accurately.

Thanks again and we will be in touch! Have a great rest of the day!

[CLICK END MEETING]

APPENDIX F

Table 14

An Overview of the Hybrid-Delphi technique

An overview of the Hybrid-Delphi technique

Stage 1	**Face to face meeting with each group of experts.** • Introduced background, study, and framework to all group members. • Members were given the opportunity for reflection, introductions, and initial thoughts ideas within each group. ***Post-meeting*** • Questions distributed to each group member by email for reflection in advance of focus group (stage 2). Each member asked to compile their responses to each of the three questions. Members were encouraged to be explicit – no longer than 3 sentences within a response. • Members were given 2 weeks to compile their responses.	January-February 2023
Stage 2	**Virtual focus group (1)** • Each question was presented to the group. In a round table fashion each group member was asked to share what they feel were critical highlights from their lists. • Members shared reasoning/justification for statements. • Members had the option to revise, add to, or change their responses throughout the meeting. Each was asked to share their lists back to the RA during the meeting. ***Post-focus group*** • The group responses for each question were collected during the focus group, aggregated, and thematically coded, then shared back to the group for review and/or revision. ○ Shared back to experts through individual shared Excel™ spreadsheets. ○ Upon review members were asked to review and, if needed, revise their own statements. If they felt anything was missing, they could add statements, suggest code/categories, note redundancies, and make suggestions for collapsing statements. ○ Members were given 2 weeks to complete the task.	February 2023
Stage 3	**Virtual focus group (2)** • The reviewed lists and initial comments were combined into one list and shared through Zoom™ prior to this meeting. • During this meeting we reviewed responses for each question for each group. If there were any conflicting comments/suggestions, they were brought up within the group. Members had the option to suggest what statements could be collapsed together or were simply redundant. ***Post-Focus group*** • Based on group input and feedback each list was further reduced by the researcher.	March 2023
Stage 4	**Ranking** Responses for each question are shared back to the expert group for ranking (using Microsoft Forms™). ○ Each member was asked to prioritize their group statements for each question by ranking each statement on a Likert Scale of 1-7. ○ To support flexibility and in consideration of the member's time separate surveys were produced for each question. Each survey took no more than 15 minutes of the members time to complete. ○ Group members were given 1 week to respond. [check email] **Post-survey** • All median mean scores were calculated. • Each set of three lists for each group were ordered according to ranking.	April 2023
Stage 5	**Community expert group review** • Focus groups or 1:1 meetings (in-person or virtual) held with each Community group member to discuss their groups ranked statements, as well as the overall group statements and how the final list might be organized. • The researcher met with members of the Clinical and Dance expert groups to present how the final lists would be centred on the Community groups' recommendations. The Clinical and Dance expert recommendations would be included as strategies for each Community recommendation.	May 2023
Stage 6	**Share Final Lists** • Only those items that were ranked 5 or above ($\geq$ 71%) were included in the final lists. • Each set of three lists for each group were collapsed into three lists in the following manner: 1. Community expert recommendations 2. Dance expert recommendations 3. Clinical expert recommendations. ○ Each statement was included the mean rank(score) for each statement as well as an indicator of which list the statement came from (○ Example (D2; 6.7) = Dance educators list 2; ranked 6.7 • The final three lists were shared back to each of the expert groups by email. At this stage feedback was welcome, but not mandatory.	June 2023

APPENDIX G

Table 15

Example of how the original statements were collapsed.

Final Statement (for ranking)	Original Statements	Assigned codes
Designing a course to deliberately incorporate adaptive sensory transitions may help to direct and maintain participants' attention. For example, lighting should be adjustable, if possible. Those with sensory disorders should be allowed to become acclimated to sound system, lighting, room temperature, floor feel, etc.	Designing a course to deliberately incorporate adaptive sensory transitions may help to direct and maintain participants' attention. For example, lighting should be adjustable if possible. Those with sensory disorders should be allowed to become acclimated to sound system, lighting, room temperature, floor feel, etc.	Accessible space - sensory considerations; inclusive environments - sensory considerations
	Accessibility of the room, enough lighting, considerations for the audio/sound equipment. Sometimes rooms can be quite loud, so having the tools to adjust, ear plugs etc.	Accessible space - sensory considerations; inclusive environments - sensory considerations

APPENDIX H

Table 16

Strategies for adapting class structure and environment*

1. The Space:
□ Consider providing/loaning noise cancelling headphones, ear buds or foam ear plugs.
□ Ensure that the space is large enough to facilitate personal space for all dancers and assistants.
□ Define a quiet area outside the dance space for persons to go if they need to self-regulate before/during/after the class. Consider including dimmed lighting, seating such as bean bag chairs, and zones of regulation signage.
2. Class sizes:
□ Be mindful of the size and dynamic of a class (considering physical, communication, sensory, and emotional regulation needs) to allow for more person-centred instruction.
3. Accessibility:
□ Dancers using wheelchairs or other mobility devices/aids should be able to enter the building and/or school, studio and/or classroom, have easy access to the washrooms, and move around the class and studio freely and easily.
□ Ensure that building entrances and drop-off locations are accessible and clearly marked.
□ Is the type of flooring compatible with their mobility aids (e.g., carpet)? Are tactile markers available for students with low vision?
□ Discourage the use of perfumes, scented cleaning supplies, or hair products in the building.
4. Consistency and flexibility of instruction:
□ It is critical that the instructor understand the need for and demonstrate flexibility in their delivery of the class and communication.
□ Use a consistent yet flexible lesson plan that considers the complexity of the movement and the amount of energy required throughout the class (e.g., consider your class plan as an outline rather than a strict plan).
□ Communicate change and introduce any new elements in the class to both the dancers and assistants at the beginning of the class or before a transition to prepare them for the transition.
□ Maintain a balance between focused activities (teacher directed movement), improvisation/creativity (movement exploration) and integrate rest breaks to hydrate and recover and/or recharge from the activity.
5. Consider sensory needs and transitions:
□ Reduce visual and auditory information such as fluorescent lighting, mirrors, clutter (e.g., posters, props, etc.) and volume of music can serve as a significant barrier to participation for some individuals.
□ Access to equipment that allows teachers to adjust and/or dim lighting, adjust audio levels, or to amplify their voices (microphone) is recommended.
□ Adjust the traditional expectations of the dance class (loosening of the rules) by allowing natural expressions of joy, nervousness, stress, etc. (e.g., stimming, tics), accepting movement that may not be performed exactly as taught, allowing students to sit if they cannot stand for the duration, to move/fidget during instruction, and understand that some dancers may not be quiet/settle into class.
□ Consider sensitivities to fabrics, fit of clothing/shoes into consideration when deciding costuming and allow families/dancers the flexibility to wear to class what is most comfortable for them.
□ To promote self-regulation/participation consider dancers' sensory processing strengths, needs, and differences related to auditory, visual, tactile, and olfactory senses. For example, provide a visual for the routine they are learning, promote listening to the music for the routine before the class or before practising the choreography in class.
□ Incorporate the use of visual tools such as visual schedules and/or visual timers to provide a sense of predictability, comfort, and consideration for those who require more processing time.
6. Facilitate participation:
□ Be encouraging.
□ Develop a class/studio culture and learning environment that is accepting and welcoming.
□ Consider how you are creating a space, encouraging independence, and advocating for the dancers' needs within the class.
□ Ensure that the dancers' voices are heard when planning activities/choreography. Involve dancers in performance planning to ensure adequate time to process and prepare.
□ Provide or enlist instructional support such as an additional teacher or class assistant to meet the needs of those participants requiring more support.
□ Consider the skills and ability of who is in the environment to support your group (assistants, carers). Consider how they will be engaged in the class.
□ Be mindful of the language used around emotions and regulation. Model and support dancers' learning the range of their emotions and language around how they feel.
7. Observation:
□ Provide options to cover viewing windows (and mirrors) and space for family and others to wait that is outside of the dance space.
8. Communication:
□ To decrease the demand for in-the-moment processing, increase predictability, comfort, and reduce anxiety for all dancers, build in communication strategies to facilitate a welcoming, inclusive environment. E.g., provide a video example of the class before the first class, email upcoming changes to dancers and assistants.

Note. *(*) Strategies as they relate to the items listed in Table 3, Question 1.*

APPENDIX I

Table 17

Strategies for Inclusive/Adaptive Instruction

1. Adaptations for different abilities of dancers:
• For dancers who may need physical assistance use a hand under hand approach so that the dancer has control of the movement. • Always ask permission before providing physical assistance.
2. Feedback and direction:
• Be encouraging. • If a student is struggling with a sequence/step, acknowledge their progress. Then suggest a way to improve the step OR provide an adaptation. • Praise your dancers with specificity (‘I like your focus’ vs. ‘good job’ or, for children ‘good job reaching with your hand!’ vs. ’good job’) and use their names often. • With adults, it may be more important to share the whys of the feedback and how this will help the movement.
3. Active vs. Passive Instruction:
• Model the action and energy you want to see from your dancers. • Dance full out, engage your dancers, laugh together. • Include verbal cues in your demonstration.
4. Flexible Instruction:
• Acknowledge dancers' disabilities. Proactively make accommodations and/or adapt the choreography to include their strengths. • Integrate dancers’ voices into ongoing modifications of class planning. For example, asking 'how are things going' during (when appropriate) and after the class, followed by troubleshooting if needed. • Support the autonomy of the dancers by offering opportunities to choose what they would like to do (A or B) and to contribute to the class or the piece of choreography. • Allow for variations on a theme of movement, as opposed to requiring all dancers to look the same. • Allow the exploration of movements on their own before stepping into facilitate or cue movement. • Break down (scaffold) complex movements/activities into smaller steps before putting a movement sequence together, as needed. Use repetition to ensure understanding and 'solidify' movement patterns. • Be open to adapting when and where to pivot instructions in the class (i.e., if you’ve tried something 3+ times and it still isn’t working, try a different approach), and adapt accommodations such as volume of music or lighting, and vary the use of space (e.g., circle, lines, in personal space). • Provide clear proactive transition instructions/cues and expectations. Anticipate and allow for additional wait time and processing time between providing instruction and expecting a response (particularly if the dancer uses AAC; e.g., wait 30-60 sec). • Be very careful if cueing for posture and ensure close monitoring of each dancer. Postural cues can be easily misinterpreted by any individual (including those without NDD) and have the potential to cause harm if not interpreted correctly.
5. Understanding characteristics/experience? of disability:
• Be conscious of the language you choose regarding the dancers' bodies. Be open to modifying the words you choose. Use inclusive language such as 'travel to stage right' vs. 'walk to stage right'. • Normalize alternate methods of communication. For dancers who use AAC instructors should have information on what AAC is and what that might look like in the dance class (e.g., student may communicate nonverbally vs verbally; they may use technology for this or a symbol board or even sign language.). • To ensure adequate instructor preparation, begin collecting information regarding dancer’s abilities, needs, and wants prior to a class starting. Ask dancers/support person what cues or strategies they have found to be helpful in other programs or classes. • Learn dancers' individual personal space preferences (e.g., closeness to other dancers, support personnel, instructor) and tactile preferences (e.g., none, deep pressure vs. light touch, certain locations only if needed, etc.). • Learn dancers’ communication preferences and facilitate a variety of forms of communication in the class (e.g., AAC, ASL, visual communication tools, somatic cues). Ensure there is consistent open line of communication for individuals to update the instructor as needed.
6. Attend to dancers physical and social cues:
• Pay attention to and respond to the somatic (physical, behavioural) cues of the dancers. An instructor’s response to these cues can help to boost or calm the energy of the group. • Be mindful of signs that a dancer requires rest, change in position, hygiene break, sustenance, or medical attention. • Integrate breaks for hydration, regulation, medication needs, and/or accommodation to leave early for pre-scheduled rides. • Check-in with dancers before they join/re-join the class to see how they are feeling and/or how their body is feeling. • Consider using visual aids to help dancers to express how they are feeling (e.g., a visual scale, zones of regulation).
7. Incorporate regulation skills such as breathing exercises.

APPENDIX J

Table 18

Information for Assistants*

1. Be an active assistant:
• How assistants participate in the class has a direct impact on the dancer they assist, as well as the overall energy of the class. If the assistant is not engaged, the student will disengage as well, affecting class participation. • Understand your role as an assistant in the class. Be aware of when to provide support and when to step back to allow independent participation. • The role of an assistant during the class is to support the goals of the dancer, to allow dancers to participate at their own level and in their own time, and to avoid distracting the class as this can interfere with the sensory input/instructions of the teacher. • Assistants should be prepared to act with genuine compassion and awareness, to be able to actively "listen" to the dancers, and to respond mindfully and effectively. • It is important to include and recognize the assistants as participants and encourage their full participation. • Language matters. Clarify current language expectations (what is helpful/harmful) around disability and identity; support the use of pronouns. Understand that identity disclosure is at the discretion of the individual (dancer). For example, do they identify as an autistic vs person with ASD, etc.
2. To dance with, not for:
• It is critical that assistants dance WITH the dancers, not FOR them. Provide instruction to assistants on a support hierarchy such as i) wait and allow independent initiation of movement, ii) gestures to indicate movement/provide physical cueing, iii) verbal prompts/cues. • Assistants should participate in the dance movements as much as possible themselves (modeling the movements). • If/when working with a dancer who uses a power wheelchair ASK if they would like assistance with driving their wheelchair BEFORE assuming control of their wheelchair.
3. Provide support and ongoing learning:
• Include support persons and assistants in an orientation (or meet and greet) with the instructor/s and dancers before the first class. • Respectful and clear communication between the teacher and the assistant is valuable. Teachers must communicate clear expectations to all assistants. • Make sure support persons are aware of the needs of the dancer(s) as identified by them/family/support person (as appropriate), as they will relate to the dance class. • If/when appropriate provide education and/or demonstration on how to safely assist dancers with the movement of limbs, head positions and or body shapes of their partner within the structure of the class. • Regular 'check-ins' between the instructor/s and assistant/support persons are recommended. These can be an opportunity to collaboratively deepen understanding of disability and related behaviours, develop teaching and assisting strategies, and support ongoing development for both parties. • Open a discussion of what biases, preconceptions, assumptions they might bring to their facilitation. Emphasize that its ok to make mistakes, and we will all make mistakes. 'We' are a team - and supporting each other is also important. • Instructors/Schools should consider that sometimes an assistant will just not be a good fit for a dancer/the program, and that it will always be better to go with less support or to work harder to find the right support, than it is to continue with an ineffective or disrespectful support person.
4. Modeling behaviour:
• Assistants are encouraged to get to know the dancer/s they support through informal check-ins before and after the class. • Support persons might need information on how to incorporate themselves into choreography (or if they will be choreographed in) and how to safely rehearse or review at home (if preferred/required).
5. Be Respectful:
• The role of an assistant during the class is to support the goals of the dancer, to allow dancers to participate at their own level and in their own time. • Assistants should avoid distracting the class as this can interfere with sensory input and the instructions of the teacher.
6. Ongoing Learning:
• Consider providing a training session (video/virtual/in-person) to ensure that all assistants understand class structure, their support role, orient them to the environment (e.g., if needing to support in the washroom, if taking a break outside the dance studio, getting a drink of water, etc.) and what sensory tools/places are available. • To encourage ongoing education for assistants (and all participants who do not identify as having a developmental disability) offer resources (handouts, video infographics, an orientation) describing common myths and misunderstandings about disability (physical and neuro-cognitive variants). Emphasize that no one group is homogenous. This may cover all types of NDD diagnoses and behaviours including emotional triggers, physical limitations, and helpful strategies. • Consider providing information/resources for trauma-centred training for both support persons and instructors. • Depending on the needs of the group or dancer encourage ongoing training on dancers' communication strengths and needs (e.g., use of AAC or not).
7. Communication:
• This can be very personal, some dancers have cues that they use at home or at school, if assistants are informed of what these are, then they can likely adapt much quicker and easier to the class. • If working with hard of hearing or DEAF dancers, it is helpful to provide ASL interpreters access to song lyrics for specific choreography in advance of the class. • Open communication between dancers and support persons is encouraged. For adults, acknowledging expertise is important. Lived experience is often downplayed in educational contexts, but the person is the expert in their disability and you, as an assistant, bring a different kind of expertise.

Note. (*) Strategies as they relate to the items listed in Table 3, Question 3.

Consent Forms for Study Two

Perceptual-Motor Integration Lab
234 Investors Group Athletic Centre
University of Manitoba
Winnipeg, Manitoba R3T 2N2
(204)480-1487

Appendix E

INFORMED CONSENT - Dancers

Highlighting the Voices of Dancers with Neurodevelopmental Disability

Principal Investigator: Jacqueline Ladwig, M.Sc.
PhD Candidate
Faculty of Kinesiology & Recreation Management
University of Manitoba
[redacted]

Supervisor: Cheryl Glazebrook, MSc (PT), PhD
Professor
Faculty of Kinesiology & Recreation Management
University of Manitoba
[redacted]

Research Assistant: Elena Broeckelmann
PhD student
Faculty of Kinesiology & Recreation Management
University of Manitoba
[redacted]

Contact Information: Jacqueline Ladwig, MSc
[redacted]

You are being asked to participate in a research study involving an interview. This form will explain the study and your role as a participant. Please take your time to review this consent form and discuss any questions you may have with the study staff, your friends, family, or someone that you trust before you make your decision. Please ask the study staff to explain any words or information that you might not understand.

WHY ARE WE DOING THIS STUDY? We wish to understand the experience of adults with neurodevelopmental disabilities who participate/have participated in dance programming. Specifically, we are interested in i) understanding the meaning of dance for the dancers; ii) their insights on adapted and inclusive instruction; iii) and their experiences of inclusion and exclusion within dance. **You can choose to do one, some, or none of the activities that we explain.**

WHAT WILL HAPPEN? **This study involves your participation in an interview (virtual on ZOOM or in-person, if Covid-19 restrictions allow). In addition, you will be asked to attend a virtual pre-interview meeting.** If you wish, a friend, family member or trusted (support) person may participate in the meeting and interview process with you. The support person will also be considered a participant in the study.

The following interview will be facilitated by either the Principal Investigator (Jacqueline Ladwig) or the Research Assistant (Elena Broeckelmann).

Photo-Elicitation process: In advance of the interview, you are asked to select two (2) photos in response to each of the five (5) interview questions. During the interview, the photos that you select will be discussed along with the interview questions.

- You will receive the interview questions along with the consent forms.
- The photos you select may be personal photos OR may be images selected from the internet.
- **It is recommended that participants avoid using or taking photos of others.**
- If you choose to take photos of others, you will need to get written consent (permission) from the individuals before they are photographed. A photography consent form will be provided to you.

You will be asked to email your selected photos and/or images with the researchers about three (3) days before your scheduled interview date. If photos of others are used, the assigned photography consent forms must be received with the photos.

The Interview: The selected photos/images will be used to facilitate the interview conversation. Participants may choose to attend the interview in-person OR over ZOOM. The interview will last no more than 90 minutes.

- You will be asked five questions related to your experience participating in dance programming. These questions will help us to better understand your experiences and perspectives of your participation in dance.
- **Participants may ask for a break at any time** and will also be offered a break following each question (approximately every 15 minutes).
- With your consent the interview will be video recorded.
- For Zoom interviews participants are asked to keep their camera open.

Interview Transcript: Within seven (7) days of the interview you will receive a typed transcript of the interview by email. Participants will have 14-days to review, request changes and/or amend the transcript. A reminder email will be sent after 7 days. If no response is received after 14-days, then the researcher will assume that the participant agrees with the detail in the transcript.

WHO WILL KNOW WHAT I DID IN THE STUDY? We will do everything possible to keep your personal information confidential. Your name will not be used at all in the study records. A list of names and addresses of participants will be kept in a secure file so we can send you a summary of the results of the study. All recordings and transcripts will be stored in separate files in a locked cabinet. All files (recordings, transcriptions, and personal information will only be accessible by the investigators and will be destroyed by Dr. Glazebrook seven (7) years after the completion of the study (approximately October 2029). Only Dr. Cheryl Glazebrook, the Principal Investigator, and the student research assistant listed will have access to any lists that contain identifying information.

Support persons are expected to uphold the confidentiality of the individual they are supporting by refraining from discussing the details of the interview with others.

RISKS AND BENEFITS: Some risks include boredom and potential anxiety. While this may be frustrating, the researcher conducting the interview will provide breaks throughout the interview and breaks may be requested at any time. Benefits may include thinking about your experiences in dance and how your participation in dance influences your daily life, or how you see yourself as a dancer. Other benefits include informing the development of recommendations for adapted dance instruction and furthering the development of adapted/inclusive dance programming.

COSTS AND PAYMENTS: There are no costs to participate in this study. Participants will receive a $30 e-gift cards for Amazon. The gift card will be emailed to the participant at the start of the interview (or within 3 days). Those choosing to participate in-person may opt to receive the $30 in cash, delivered on the day of the interview.

CONFIDENTIALITY (publication of study): If the results of this study are presented in a meeting, or published, nobody will be able to tell that you were in the study. Please note that although you will not be identified as the speaker, your words may be used to highlight a specific point. The collection and access to personal information and health related information will be in compliance with provincial and federal privacy legislations. If photos are used for publication or presentations the photos will be anonymized (e.g., faces will be blurred). Knowledge gained from this research will be shared with the academic community through dissemination of the thesis through MSpace, academic conferences, invited presentations (including community organizations), published in peer-reviewed academic journal, or in presentations for other universities. The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

According to Manitoba's Vulnerable Persons Act, all persons who have reasonable grounds to believe that the person is or is likely to be abused or neglected are obligated to report these suspicions to the Department of Family Services. If abuse of a person in care is discovered the PI or research assistant will immediately consult with the Advisor of the research study and contact the proper authorities.

DEBRIEFING: If you would like to know the results of the study please indicate 'yes' on the consent form and the research team will contact you with a summary of the findings in approximately 4 months (10/01/2022). A summary will be mailed OR emailed and, if you wish, an online sharing via ZOOM delivered by the researcher/research assistant.

DO YOU HAVE TO BE IN THE STUDY? No, your participation in the study is voluntary. If you *wish to withdraw* from the study, you are free to do so at any point in time. If you decide to withdraw at any point during the study, you can do so by telling the interviewer you are finished. You can also tell the interviewer if you would like to have your data collected up to that point included in the case series or destroyed.

WITHDRAWAL: If withdrawal occurs at any point in time *before* the interview no compensation will be provided. If withdrawal is received *during or after* the interview a $30 e-gift card will be sent by email within 3 days of the notification OR those who choose to receive the honorarium in cash will receive it at the start of the interview.

WHAT IF I HAVE QUESTIONS? You can ask questions at any time before, during or after the study.

CONSENT SIGNATURES:

1. I have read **all 6 pages** of this consent form.
2. I have had a chance to ask questions and have received satisfactory answers to all of my questions.
3. I understand that by signing this consent form I have not waived any of my legal rights as a participant in this study.
4. I understand that my records, which may include identifying information, may be reviewed by the research staff working with the Principal Investigator and the agencies and organizations listed in the Confidentiality section of this document.
5. I understand that I may withdraw from the study at any time and my data may be withdrawn prior to publication.
6. I understand I will be provided with a copy of the consent form for my records.
7. I agree to participate in the study.

A copy of this consent form has been given to you to keep for your records and reference. This research has been approved by the Research Ethics Board at the University of Manitoba, Fort Garry campus. If you have any concerns or complaints about this project, you may contact any of the above-named persons or the Human Ethics Officer at 204-474-7122 or HumanEthics@umanitoba.ca.

INSTRUCTIONS: Please print the informed consent form, participant information, and COVID consent (for in-person interviews), **complete and sign, then scan a copy to email to the research team at** [redacted]

Participant Name (PRINT) _____

Participant's Signature _____ Date _____

Researcher Signature _____Date _____

PLEASE INDICATE your consent for the audio-video recording of the interview (check one):

□ I agree to the video recording of the interview.

□ I do not agree to the video recording of the interview, and I understand that the audio will be recorded regardless.

PLEASE INDICATE your preference for virtual or in-person interview (check one):

□ I prefer to participate in an in-person interview on the University of Manitoba campus.

□ I prefer to participate in a virtual interview.

Participant Information and Communication

Email: _____

Phone number: _____□ Cellular phone □ Land line

For verification purposes, please provide the full name of the dance program you participate in:

_____

Please provide the full address of the school/organization that provides the dance program:

Name: _____

Address: _____

City: _____ Province/State: _____

Country: _____ Phone #: _____

Email: _____

At various times we may need to reach out to you to schedule meetings or share information. Please indicate your preferred form/s of communication (select all that apply):

□ By Email □ By Phone □ By text (SMS); see following note

Please provide cellular phone number (if not provided above) _____

Do you wish to have a support person or caregiver participate in the interview process with you?

(Please indicate) □ YES □ NO

If yes, what is the name of the support person/caregiver: _____

Email: _____ Phone: _____

SUMMARY OF FINDINGS: Would you like to be contacted with a summary of the overall findings of this study?

(Select one) □ YES (please indicate preferred format below) □ NO

Preferred Format: □ Email □ By mail (please provide mailing address below)

Address: _____

City: _____ Province: _____

Postal Code: _____

UM | Faculty of Kinesiology and Recreation Management

Perceptual-Motor Integration Lab
234 Investors Group Athletic Centre
University of Manitoba
Winnipeg, Manitoba R3T 2N2
(204)480-1487

Appendix E

INFORMED CONSENT – Support persons

Highlighting the Voices of Dancers with Neurodevelopmental Disability

Principal Investigator: Jacqueline Ladwig, M.Sc.
PhD Candidate
Faculty of Kinesiology & Recreation Management
University of Manitoba
[redacted]

Supervisor: Cheryl Glazebrook, MSc (PT), PhD
Professor
Faculty of Kinesiology & Recreation Management
University of Manitoba
[redacted]

Research Assistants: Elena Broeckelmann
PhD student
Faculty of Kinesiology & Recreation Management
University of Manitoba
[redacted]

Contact Information: Jacqueline Ladwig, MSc
[redacted]

You are being asked to participate in a research study involving an interview. This form will explain the study and your role as a participant. Please take your time to review this consent form and discuss any questions you may have with the study staff, your friends, family, or someone that you trust before you make your decision. Please ask the study staff to explain any words or information that you might not understand.

WHY ARE WE DOING THIS STUDY? We wish to understand the experience of adults with neurodevelopmental disabilities who participate/have participated in dance programming. Specifically, we are interested in i) understanding the meaning of dance for the dancers; ii) their insights on adapted and inclusive instruction; iii) and their experiences of inclusion and exclusion within dance. **You can choose to do one, some, or none of the activities that we explain.**

WHAT WILL HAPPEN? **This study involves your participation in an interview (virtual on ZOOM or in-person, if Covid-19 restrictions allow). In addition, you will be asked to attend a virtual pre-interview meeting**. As an invited support person your role is to provide the support you typically provide to the dancer throughout the process, in addition you may be asked for your thoughts in relation to topics arising within the interview as well. Support persons are

expected to uphold the confidentiality of the dancer they are supporting by refraining from discussing the details of the interview with others.

The interview will be facilitated by either the Principal Investigator (Jacqueline Ladwig) or the Research Assistant (Elena Broeckelmann).

Photo-Elicitation process: The dancers will be asked to select (in advance of the main interview) two (2) photos in response to each of the five (5) interview questions. During the interview, the photos that selected will be discussed along with the interview questions.

- The dancers will receive the interview questions along with the consent forms.
- The photos selected may be personal photos OR may be images selected from the internet.
- **It is recommended that participants avoid using or taking photos of others.**
- If dancers choose to take photos of others, they will need to get written consent (permission) from the individuals before they are photographed. A photography consent form will be provided to you.

The dancers will be asked to email their selected photos and/or images to the researchers about three (3) days before your scheduled interview date. If photos of others are used, the assigned photography consent forms must be received with the photos.

The Interview: The selected photos/images will be used to facilitate the interview conversation. Participants may choose to attend the interview in-person OR over ZOOM. The interview will last no more than 90 minutes.

- The dancers will be asked five questions related to their experience participating in dance programming. These questions will help us to better understand their experiences and perspectives of their participation in dance.
- **Participants may ask for a break at any time** and will also be offered a break following each question (approximately every 15 minutes).
- With your consent the interview will be video recorded.
- For Zoom interviews participants are asked to keep their camera open.

Interview Transcript: Within seven (7) days of the interview you (and the dancer you support) will receive a typed transcript of the interview by email. Participants will have 14-days to review, request changes and/or amend the transcript. A reminder email will be sent after 7 days. If no response is received after 14-days, then the researcher will assume that the participant agrees with the detail in the transcript.

WHO WILL KNOW WHAT I DID IN THE STUDY? We will do everything possible to keep your personal information confidential. Your name will not be used at all in the study records. A list of names and addresses of participants will be kept in a secure file so we can send you a summary of the results of the study. All recordings and transcripts will be stored in separate files in a locked cabinet. All files (recordings, transcriptions, and personal information will only be accessible by the investigators and will be destroyed by Dr. Glazebrook seven (7) years after the completion of the study (approximately October 2029). Only Dr. Cheryl Glazebrook, the Principal Investigator, and the student research assistant listed will have access to any lists that contain identifying information.

Support persons are expected to uphold the confidentiality of the individual they are supporting by refraining from discussing the details of the interview with others.

RISKS AND BENEFITS: Some risks include boredom and potential anxiety. While this may be frustrating, the researcher conducting the interview will provide breaks throughout the interview and breaks may be requested at any time. Benefits may include thinking about your experiences in dance and how your participation in dance may influence ones' daily life, or how individuals see themselves as a dancer. Other benefits include informing the development of recommendations for adapted dance instruction and furthering the development of adapted/inclusive dance programming.

COSTS AND PAYMENTS: There are no costs to participate in this study. Participants will receive a $30 e-gift cards for Amazon. The gift card will be emailed to the participant at the start of the interview (or within 3 days). Those choosing to participate in-person may opt to receive the $30 in cash and will receive the honorarium on the day of the interview.

CONFIDENTIALITY (publication of study): If the results of this study are presented in a meeting, or published, nobody will be able to tell that you were in the study. Please note that although you will not be identified as the speaker, your words may be used to highlight a specific point. The collection and access to personal information and health related information will be in agreement with provincial and federal privacy legislations. If photos are used for publication or presentations the photos will be anonymized (e.g., faces will be blurred). Knowledge gained from this research will be shared with the academic community through dissemination of the thesis through MSpace, academic conferences, invited presentations (including community organizations), published in peer-reviewed academic journal, or in presentations for other universities. The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

According to Manitoba's Vulnerable Persons Act, all persons who have reasonable grounds to believe that the person is or is likely to be abused or neglected are obligated to report these suspicions to the Department of Family Services. If abuse of a person in care is discovered the PI or research assistant will immediately consult with the Advisor of the research study and contact the proper authorities.

DEBRIEFING: If you would like to know the results of the study please indicate 'yes' on the consent form and the research team will contact you with a summary of the findings in approximately 4 months (10/01/2022). A summary will be mailed OR emailed and, if you wish, an online sharing via ZOOM delivered by the researcher/research assistant.

DO YOU HAVE TO BE IN THE STUDY? No, your participation in the study is voluntary. If you *wish to withdraw* from the study, you are free to do so at any point in time. If you decide to withdraw at any point during the study, you can do so by telling the interviewer you are finished. You can also tell the interviewer if you would like to have your data collected up to that point included in the case series or destroyed.

WITHDRAWAL: If withdrawal occurs at any point in time *before* the interview no compensation will be provided. If withdrawal is received *during or after* the interview a $30 e-gift card will be sent by email within 3 days of the notification OR those choosing to participate in-person who opt to receive the $30 in cash and will receive the honorarium on the day of the interview.

WHAT IF I HAVE QUESTIONS? You can ask questions at any time before, during or after the study.

CONSENT SIGNATURES:

1. I have read **all 7 pages** of this consent form.
2. I have had a chance to ask questions and have received satisfactory answers to all of my questions.
3. I understand that by signing this consent form I have not waived any of my legal rights as a participant in this s study.
4. I understand that my records, which may include identifying information, may be reviewed by the research staff working with the Principal Investigator and the agencies and organizations listed in the Confidentiality section of this document.
5. I understand that I may withdraw from the study at any time and my data may be withdrawn prior to publication.
6. I understand I will be provided with a copy of the consent form for my records.
7. I agree to participate in the study.

A copy of this consent form has been given to you to keep for your records and reference. This research has been approved by the Research Ethics Board at the University of Manitoba, Fort Garry campus. If you have any concerns or complaints about this project, you may contact any of the above-named persons or the Human Ethics Officer at 204-474-7122 or HumanEthics@umanitoba.ca

---

INSTRUCTIONS: Please print the informed consent form, participant information, and COVID consent (for in-person interviews), **complete and sign, then scan a copy to email to the research team at [redacted]**

Participant Name (PRINT)_____

Researcher Signature _____ _____Date _____

PLEASE INDICATE your consent for the video recording of the interview (check one):

☐ I agree to the video recording of the interview.

☐ I [illegible] interview, and I understand that the audio will be recorded regardless.

Participant Information and Communication

Email: _____ _____

Phone number: _____ _____ phone Land line

PLEASE INDICATE your preference for virtual or in-person interview (check one):

 -person interview on the University of Manitoba campus.

At various times we may need to reach out to you to schedule meetings or share information. Please indicate your preferred form/s of communication (select all that apply):

 By Email By Phone By text (SMS); see following note

Please provide cellular phone number (if not provided above) _____

WHO WILL YOU BE SUPPORTING?

Please indicate below the name of the person (dancer) you will be supporting throughout this study:

_____ _____

SUMMARY OF FINDINGS: Would you like to be contacted with a summary of the overall findings of this study?

(Select one) YES (please indicate preferred format below) NO

Preferred Format: mail (please provide mailing address below)

Address: _____

City: _____ ___ Province: _____

Postal Code: _____

Consent Forms for Study Three

UM | Faculty of Kinesiology and Recreation Management

108 Frank Kennedy Centre
University of Manitoba
Winnipeg, Manitoba R3T 2N2
(204)474-8773
cheryl.glazebrook@umanitoba.ca

Appendix F

INFORMED CONSENT – community experts

A Collaborative Approach to Adaptive Dance:
A Delphi study engaging expert clinical, dance, and community perspectives

Principal Investigator: Jacqueline Ladwig, MSc
PhD Candidate
Faculty of Kinesiology & Recreation Management
University of Manitoba
[redacted]

Supervisor: Cheryl Glazebrook, MSc (PT), PhD
Professor
Faculty of Kinesiology & Recreation Management
University of Manitoba
[redacted]

Research Assistants: Elena Broeckelmann, MSc
Faculty of Kinesiology & Recreation Management
University of Manitoba
[redacted]

Contact Information: Jacqueline Ladwig, MSc
[redacted]

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information. Throughout this consent process you are encouraged to consult with a trusted person and the research team is available to answer any questions about participation.

Why are we doing this study? We are conducting a study on how and in what ways dance instruction may be adapted for persons who have neurodevelopmental disabilities (NDD). For this study we are

gathering the opinions of three groups of experts to compile a list of guidelines with input from the clinical and dance professions as well as from the community of persons with neurodevelopmental disabilities and those who support them. **We are asking you to participate in this study as a community expert.**

What will happen? This study involves your participation as a community expert **in an introductory meeting/focus group and three focus groups that will occur through a UM Zoom account**. In addition, the remainder of the study will take place through approximately 3-4 rounds of email communications. The study is estimated to occur from **November 2022 and March of 2023**.

If a participant chooses, they may also have a trusted support person with them during the interview to assist with communication and/or understanding, and to provide reassurance. The focus groups will be conducted by the Principal Investigator, Jacqueline Ladwig. The research assistant, Elena Broeckelmann, will also be present to take detailed notes.

In the introductory focus group the three questions will be provided and accompanied by background information, followed by a discussion of the research topic. In a second focus group you will be asked to share and discuss your responses to three questions. In a third focus group the responses will be reviewed by the group. Then you will be asked to participate in two rounds of reviewing and ranking responses through email (Delphi rounds). **Community experts will also be asked to participate in a final focus group at the end of the study.** The focus groups will be recorded and transcribed through UM Zoom; further transcription will be completed by the PI. Each focus group will be 1 to 1.5 hours in length and breaks will be provided throughout the focus groups. The remaining email communications involving the reviewing and ranking of guidelines will take approximately 2-6 hours of your time.

Following the third focus group and after each of the two Delphi rounds each expert will be given approximately 2-3 weeks (as determined by the amount of information to review and rank) to respond. Reminders will be provided. If communication and/or responses not been received from a given expert by the given deadlines, it will be assumed that they are unable to continue with the study and they will be withdrawn as an expert.

WHO WILL KNOW WHAT I DID IN THE STUDY? We will do everything possible to keep your personal information confidential. Your name will not be used at all in the study data records. Consent forms will be kept separate from the study data. A list of names and contact information will be kept in a secure file so we can send you a summary of the results of the study, if you wish. Once transcripts are verified all recordings will be deleted and transcripts will be stored in digital form on secured drives and an external hard drive kept in a locked cabinet. All files (transcripts and personal information) will be accessible by the PI, RA, and the advisor (Dr. Cheryl Glazebrook). In case a reviewer requires specific details all de-identified transcripts and associated data will be stored for 7 years, after which all files (digital and hard copy) will be destroyed by Dr. Glazebrook seven (7) years after the completion of the study (approximately November 2029).

All participants are asked to uphold the confidentiality of the participants by refraining from discussing the details of the interview or who is participating in the study with others.

To minimize possible conflict of interest between the PI and Community Experts who may be current students of PI, their participation, or choice not to participate in this study, will have no bearing on their treatment in the class. Participation will not be disclosed in the class setting.

RISKS AND BENEFITS: There are no physical risks to participating in the focus groups. Focus group members will be asked to keep the information provided and discussed in the groups confidential; however, a potential risk that might exist would be that information about a participant might be discussed outside the group by other participants and be traced back to them. **Breaks will be provided and offered throughout the focus groups. Participants may also choose to have a trusted support person with them during the interview to assist with communication and/or understanding, and/or to provide reassurance**. Long term benefits include the sharing of this study with the larger dance and research community, informing the development of recommendations for adapting dance instruction and furthering the development of adapted/ inclusive dance programming.

COSTS AND PAYMENTS: There are no costs to participate in this study. You will receive a small honorarium in the form of an Amazon e-gift card sent to you through email, as a thank you for your time ($30).

CONFIDENTIALITY (publication of study): If the results of this study are presented in a meeting or published, nobody will be able to tell that you were in the study. General descriptors (ie., community expert 1, dance educator 2) will be used in place of your name. Please note that although you will not be identified as a speaker, your words may be used to highlight a specific point. The collection of and access to personal and health related information will be in agreement with provincial and federal privacy legislations. Knowledge gained from this research will be shared with the academic community through dissemination of the thesis through MSpace, academic conferences, invited presentations (including community organizations), published in peer-reviewed academic journal, or in presentations for other universities. The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

According to Manitoba's Vulnerable Persons Act, all persons who have reasonable grounds to believe that the person is or is likely to be abused or neglected are obligated to report these suspicions to the Department of Family Services. If abuse of a person in care is discovered the PI or RA will immediately consult with the Advisor of the research study and contact the proper authorities.

SUMMARY OF RESULTS: If you would like to receive a summary of the results of the study please indicate 'yes' on the consent form (pg 5) you will be contacted with a summary approximately 4 months after the data collection is complete (June 2023). The summary may be mailed, emailed or, if you wish, shared via a virtual meeting.

DO YOU HAVE TO BE IN THE STUDY? No, your participation in the study is voluntary. If you wish to withdraw from the study, you are free to do so at any point in time. If you decide to withdraw you can do so by notifying the Principal Investigator by email of your withdrawal. Please note that you may request that your contributions and data collected during the three focus group sessions be removed.

However, please note that due to the nature of the Delphi process contributions and data collected after the third focus group cannot be removed or deleted.

WITHDRAWAL: If withdrawal occurs at any point in time *after consenting to participate in the study* and a $30 e-gift card will be sent by email within 3 days of the notification. Due to the nature of the study the removal of contributions and data collected cannot be facilitated *after the third focus group, the Delphi rounds (email), nor the completion of the study*. Therefore, the deadline for withdrawal is following the third Focus Group (approximately January 1, 2023).

WHAT IF I HAVE QUESTIONS? You can ask questions at any time before, during or after the study. As part of the informed consent process community experts will be encouraged to meet with the PI or RA, depending on potential conflict of interest, to facilitate the process of asking questions, or for clarification.

CONSENT SIGNATURES:

1. I have read or have reviewed with a trusted person **all 5 pages** of this consent form and **answered the questions on page 5**.
2. I have had a chance to ask questions and have received satisfactory answers to my questions.
3. I understand that by signing this consent form I have not waived any of my legal rights as a participant in this s study.
4. I understand that my records, which may include identifying information, may be reviewed by the research staff working with the Principal Investigator and the agencies and organizations listed in the Confidentiality section of this document.
5. I understand that I may refrain from answering any questions during the focus groups.
6. I understand that I may withdraw from the study at any time and my data may be withdrawn prior to publication according to the conditions outlined above.
7. I understand I will be provided with a copy of the consent form for my records.
8. I agree to participate in the study.

A copy of this consent form has been given to you to keep for your records and reference. This research has been approved by the Research Ethics Board at the University of Manitoba, Fort Garry campus. If you have any concerns or complaints about this project, you may contact any of the above-named persons or the Human Ethics Officer at 204-474-7122 or HumanEthics@umanitoba.ca.

Continue to next page...

INSTRUCTIONS: Please print the informed consent form, participant information, complete and sign**, then scan (or screen capture) and attach to an email to the research team at** pmi_lab@umanitoba.ca**.**

The focus groups will be recorded. Please indicate your consent for the type of recording below:

☐ [illegible]

☐ [illegible]only to the audio recording of the focus groups.

Participant Name (PRINT)_____

P[illegible]_____ _____ Date _____

Researcher Signature _____ _____Date _____

Please also respond to the following questions.

1. **Select which of the following applies to you:**

I identify as a [ ] support person who works with person who has a NDD in a dance class

[ ] person who participates in dance and has a NDD

2. An EMAIL ADDRESS is required for participation in this study.

Your preferred email address: _____

3. **REMINDERS:** Please indicate your preferred method of correspondence for receiving reminders regarding tasks and focus group sessions:

☐ Email only

☐ Text Provide phone number: _____ _____

☐ Phone Provide phone number: _____ _____

4. SUMMARY OF FINDINGS: Would you like to be contacted with a summary of the overall findings of this study? ☐ YES ☐ NO

☐ By Email only

☐ [illegible]

_____

UM | Faculty of Kinesiology and Recreation Management

108 Frank Kennedy Centre
University of Manitoba
Winnipeg, Manitoba R3T 2N2
(204)474-8773
cheryl.glazebrook@umanitoba.ca

Appendix E

INFORMED CONSENT – clinical and dance experts

A Collaborative Approach to Adaptive Dance:
A Delphi study engaging expert clinical, dance, and community perspectives

Principal Investigator: Jacqueline Ladwig, MSc
PhD Candidate
Faculty of Kinesiology & Recreation Management
University of Manitoba
[redacted]

Supervisor: Cheryl Glazebrook, MSc (PT), PhD
Professor
Faculty of Kinesiology & Recreation Management
University of Manitoba
[redacted]

Research Assistants: Elena Broeckelmann, MSc
Faculty of Kinesiology & Recreation Management
University of Manitoba
[redacted]

Contact Information: Jacqueline Ladwig, MSc
[redacted]

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Why are we doing this study? We are conducting a study on how and in what ways dance instruction may be adapted for persons who have neurodevelopmental disabilities. For this study we are gathering the opinions of three groups of experts to compile a list of guidelines with input from the clinical and

dance professions as well as from the community of persons with neurodevelopmental disabilities and those who support them. **We are asking you to participate in this study as a clinical or dance expert.**

What will happen? This study involves your participation as a clinical or dance education expert in **an introductory meeting/focus group and two focus groups that will occur through a UM Zoom account**. In addition, the remainder of the study will take place through approximately 3-4 rounds of email communications. The study is estimated to occur between **November 2022 and March of 2023**.

If a participant chooses, they may also have a trusted support person with them during the interview to assist with communication and/or understanding, and to provide reassurance. The focus groups will be conducted by the Principal Investigator (PI), Jacqueline Ladwig. The research assistant (RA), Elena Broeckelmann, will also be present to take detailed notes.

In the introductory focus group, the three questions will be provided and accompanied by background information, followed by a discussion of the research topic. In a second focus group you will be asked to share and discuss your responses to three questions. In a third focus group the responses will be reviewed by the group. Then you will be asked to participate in two rounds of reviewing and ranking responses through email (Delphi rounds). The focus groups will be recorded and transcribed through UM Zoom; further transcription will be completed by the PI. Each focus group will be 1 to 1.5 hours in length and breaks will be provided throughout the focus groups. The remaining email communications involving the reviewing and ranking of guidelines will take approximately 2-6 hours of your time.

Following the third focus group and after each of the two Delphi rounds each expert will be given approximately 2-3 weeks (as determined by the amount of information to review and rank) to respond. Reminders will be provided. If communication and/or responses not been received from a given expert by the given deadlines, it will be assumed that they are unable to continue with the study and they will be withdrawn as an expert.

WHO WILL KNOW WHAT I DID IN THE STUDY? We will do everything possible to keep your personal information confidential. Your name will not be used at all in the study data records. Consent forms will be kept separate from the study data. A list of names and contact information will be kept in a secure file so we can send you a summary of the results of the study, if you wish. Once transcripts are verified all recordings will be deleted and transcripts will be stored in digital form on secured drives and an external hard drive kept in a locked cabinet. All files (transcripts and personal information) will be accessible by the PI, RA, and the advisor (Dr. Cheryl Glazebrook). In case a reviewer requires specific details all de-identified transcripts and associated data will be stored for 7 years, after which all files (digital and hard copy) will be destroyed by Dr. Glazebrook seven (7) years after the completion of the study (approximately November 2029).

All participants are asked to uphold the confidentiality of the participants by refraining from discussing the details of the interview or who is participating in the study with others.

RISKS AND BENEFITS: There are no physical risks to participating in the focus groups. Focus group members will be asked to keep the information provided and discussed in the groups confidential; however, a potential risk that might exist would be that information about a participant might be discussed outside the group by other participants and be traced back to them. **Breaks will be provided and offered throughout the focus groups.** Participants may also choose to have a trusted support person with them during the interview to assist with communication and/or understanding, and to provide reassurance. Long term benefits include the sharing of this study with the larger dance and research community, informing the development of recommendations for adapting dance instruction and furthering the development of adapted/ inclusive dance programming.

COSTS AND PAYMENTS: There are no costs to participate in this study. You will receive a small honorarium in the form of an Amazon e-gift card sent to you through email, as a thank you for your time ($30).

CONFIDENTIALITY (publication of study): If the results of this study are presented in a meeting or published, nobody will be able to tell that you were in the study. General descriptors (ie., clinician 1, dance educator 2) will be used in place of your name. Please note that although you will not be identified as a speaker, your words may be used to highlight a specific point. The collection of and access to personal and health related information will be in agreement with provincial and federal privacy legislations. Knowledge gained from this research will be shared with the academic community through dissemination of the thesis through MSpace, academic conferences, invited presentations (including community organizations), published in peer-reviewed academic journal, or in presentations for other universities. The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

According to Manitoba's Vulnerable Persons Act, all persons who have reasonable grounds to believe that the person is or is likely to be abused or neglected are obligated to report these suspicions to the Department of Family Services. If abuse of a person in care is discovered the PI or RA will immediately consult with the Advisor of the research study and contact the proper authorities.

SUMMARY OF RESULTS: If you would like to receive a summary of the results of the study please indicate 'yes' on the consent form (pg 5) you will be contacted with a summary approximately 4 months after the data collection is complete (June 2023). The summary may be mailed, emailed or, if you wish, shared via a virtual meeting.

DO YOU HAVE TO BE IN THE STUDY? No, your participation in the study is voluntary. If you wish to withdraw from the study, you are free to do so at any point in time. If you decide to withdraw you can do so by notifying the Principal Investigator by email of your withdrawal. Please note that you may request that your contributions and data collected during the three focus group sessions be removed. However, due to the nature of the Delphi process contributions and data collected after the third focus group cannot be removed or deleted.

WITHDRAWAL: If withdrawal occurs at any point in time after consenting to participate in the study the $30 e-gift card will be sent by email within 3 days of the notification. Due to the nature of the study the removal of contributions and data collected cannot be facilitated after the third focus group, the Delphi rounds (email), nor the completion of the study. In addition, the nature of the focus groups prevents the removal of individuals from the video recordings. Therefore, the deadline for withdrawal is following the third Focus Group (approximately January 1, 2023).

WHAT IF I HAVE QUESTIONS? You can ask questions at any time before, during or after the study. As part of the informed consent process experts will be encouraged to meet with the PI or RA, depending on potential conflict of interest, to facilitate the process of asking questions, or for clarification.

CONSENT SIGNATURES:

1. I have read **all 5 pages** of this consent form and **answered the questions on page 5**.
2. I have had a chance to ask questions and have received satisfactory answers to my questions.
3. I understand that by signing this consent form I have not waived any of my legal rights as a participant in this s study.
4. I understand that my records, which may include identifying information, may be reviewed by the research staff working with the Principal Investigator and the agencies and organizations listed in the Confidentiality section of this document.
5. I understand that I may refrain from answering any questions during the focus groups.
6. I understand that I may withdraw from the study at any time and my data may be withdrawn prior to publication according to the conditions outlined above.
7. I understand I will be provided with a copy of the consent form for my records.
8. I agree to participate in the study.

A copy of this consent form has been given to you to keep for your records and reference. This research has been approved by the Research Ethics Board at the University of Manitoba, Fort Garry campus. If you have any concerns or complaints about this project, you may contact any of the above-named persons or the Human Ethics Officer at 204-474-7122 or HumanEthics@umanitoba.ca.

Continue to next page...

INSTRUCTIONS: Please print the informed consent form, participant information, complete and sign **then scan (or screen capture) and attach to an email to the research team at** pmi_lab@umanitoba.ca**.**

The focus groups will be recorded. Please indicate your consent for the type of recording below:

☐

☐

Participant Name (PRINT)_____

Researcher Signature _____ _____Date _____

Please also respond to the following questions.

1. **Select which of the following applies to you:**

I identify as a [ ] Clinician who works with, or has worked with, persons who have an NDD

[ ] Dance educator who works with, or has worked with, persons who have an NDD

2. An EMAIL ADDRESS is required for participation in this study.

Your preferred email address: _____

3. **REMINDERS:** Please indicate your preferred method of correspondence for receiving reminder regarding tasks and focus group sessions:

☐ Email only

☐ Text Provide phone number: _____ _____

☐ Phone Provide phone number: _____ _____

4. SUMMARY OF FINDINGS: Would you like to be contacted with a summary of the overall finding of this study? ☐ YES ☐ NO

☐ By Email only

☐

_____

Ethics Approval – Study Two

University of Manitoba | Research Ethics and Compliance

Human Ethics - Fort Garry
208-194 Dafoe Road
Winnipeg, MB R3T 2N2
T: 204 474 8872
humanethics@umanitoba.ca

PROTOCOL APPROVAL

Effective: April 28, 2022 Expiry: April 27, 2023

Principal Investigator:	Jacqueline Ladwig-Davidson
Advisor:	Cheryl Glazebrook
Protocol Number:	HE2022-0075
Protocol Title:	*Re-imagining Traditional Dance Instruction and Pedagogy: Engaging an Ecological Lens for the Adaptation of Dance for Persons with Neurodevelopmental Disabilities*

Jonathan Marotta, Chair, REB1

Research Ethics Board 1 has reviewed and approved the above research. The Human Ethics Office (HEO) is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* - TCPS 2 (2018).

This approval is subject to the following conditions:

i. Approval is granted for the research and purposes described in the protocol only.

ii. Any changes to the protocol or research materials must be approved by the HEO before implementation.

iii. Any deviations to the research or adverse events must be reported to the HEO immediately through an REB Event.

iv. This approval is valid for one year only. A Renewal Request must be submitted and approved prior to the above expiry date.

v. A Protocol Closure must be submitted to the HEO when the research is complete or if the research is terminated.

vi. The University of Manitoba may request to audit your research documentation to confirm compliance with this approved protocol, and with the UM *Ethics of Research Involving Humans* Ethics of Research Involving Humans policies and procedures.

Ethics Approval – Study Three

University of Manitoba | Research Ethics and Compliance

Human Ethics - Fort Garry
208-194 Dafoe Road
Winnipeg, MB R3T 2N2
T: 204 474 8872
humanethics@umanitoba.ca

PROTOCOL APPROVAL

Effective: November 9, 2022 Expiry: November 8, 2023

Principal Investigator:	Jacqueline Ladwig-Davidson
Advisor:	Cheryl Glazebrook
Protocol Number:	HE2022-0284
Protocol Title:	*A Collaborative Approach to Adaptive Dance: A delphi-study engaging expert clinical, dance, and community Perspectives*

Jonathan Marotta, Chair, REB1

Research Ethics Board 1 has reviewed and approved the above research. The Human Ethics Office (HEO) is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* - TCPS 2 (2018).

This approval is subject to the following conditions:

i. Approval is granted for the research and purposes described in the protocol only.

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v. A Protocol Closure must be submitted to the HEO when the research is complete or if the research is terminated.

vi. The University of Manitoba may request to audit your research documentation to confirm compliance with this approved protocol, and with the UM *Ethics of Research Involving Humans* Ethics of Research Involving Humans policies and procedures.