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# “When We Dance It’s Never Just Dancing...”: Understanding the experiences and perspectives of adult dancers with neurodevelopmental disability

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**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 and aimed to deepen our understanding of their experiences and perspectives on instruction. Interviews were conducted with 14 dancers from across Canada and the United States. 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 culture that supports me as a dancer. 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.

**Keywords:** dance pedagogy; inclusion; disability; lived experience; qualitative; constraints model; instruction; learning environment; adaptive physical activity

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## 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.

## 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 (CP), Down syndrome (DS), 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 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 the role of the instructor, are seen as integral to shaping skill development. Embodied knowledge theory acknowledges that an individual's 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'-that is, dancers who live with NDD-can know the experience of disability within the dance community. 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).

## Objectives

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.

## Materials and Methods

### 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 semi-structured interviews (virtual or in-person). Photo-elicitation was used as a tool to stimulate engagement, direct and foster attention, and conversation around each interview question (Danker et al., 2019; 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 (Danker et al., 2019; 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 dancers' experiences. The interviews were conducted by the first author who was a doctoral candidate.

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 providing support during the interviews (Danker et al., 2019; Lumia et al., 2021). These partnerships encouraged a shared dialogue in which 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). 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).

### **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 A). All natural silences or pauses, in the conversation were embraced to encourage thoughtful responses, facilitate conversation, and support a comfortable interview pace (Kvale & Brinkmann, 2015). 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 (Nowell et al., 2017).

### **Positionality**

As qualitative researchers we reflected on our preconceptions, assumptions, and biases throughout the research process (Holmes, 2020). The interviews were conducted by the primary author who was 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 was a doctoral student 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 with 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.

### **Recruitment**

A purposive sampling process was undertaken through disability organizations across Canada who then shared the information across social media. 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). 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).

### **Power Balance**

Some dancers were current students of, or known to, the first author. 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.

### **Analysis**

An iterative reflexive thematic analysis was used (Braun & Clarke, 2022). Each interview was de-identified and transcribed verbatim alongside the video recordings and shared back to the dancers for their review, amendment, and acceptance (Nowell et al., 2017). Reviewed transcripts were then uploaded to NVivo 12© (Lumivero., 2017) software for analysis. NVivo was used to code, contextualize, and interpret the interview data (Braun & Clarke, 2022). 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 (Nowell et al., 2017).

An inductive analysis was used to reveal the codes grounded in the data. 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 (Nowell et al., 2017). Visualizing the data in this manner transformed the ‘chunks’ of information gathered into more meaningful data (Nowell et al., 2017). Intervention studies involving humans, and other studies require ethical approval must list the authority that provided approval and the corresponding ethical approval code.

## Results

### 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 whose mean age was thirty. Participant characteristics can be found in Table 1. 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 1.** Participant profiles

Participants	(n)	Description
Dancers	14	(Male (M) =9; Female (F) = 5)
Support persons	6	(4 dyads; 1 triad; F=6)
Average age (of dancers)	30	
Average years in dance	12	
<b>Self-reported Diagnoses</b>		
Autism (AS)	7	M=5; F=2
Down syndrome (DS)	5	M=2; F=3
Attention deficit hyperactivity disorder (ADHD)	1	M=1
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 2. 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.

### Themes

#### 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.

**Table 2.** 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 supports me as a dancer	Environment of acceptance and safety
	Tailor Instruction
	Strategies used by instructor

“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).

### 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)

### **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)

### **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 did not 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).

### 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)

### 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 mindset 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 sibling and (wondering) why can't I be like them at this activity (dance) ... like, I want to be like my sibling, 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)

### 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)

### **Inclusive instruction and dance culture supports me as a dancer**

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)

### ***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.

### ***Tailoring Instruction***

Many dancers were not aware of any specific adaptations made to dance movements or steps. Importantly, the dancers also expressed that 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)

### ***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 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)

## **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), 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.

### **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). 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). 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 (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 (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). Based on these findings, when efforts to engage a person-centred and strengths-based approach to dance instruction ~~was~~<sup>were</sup> present, an inclusive dance culture was fostered, and dancers experienced a deep sense of belonging.

### 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.

### **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 (Newell, 1986). Task constraints include strategies used by the teacher and how instruction is given in relation to the capabilities of the dancer. 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 become familiar with 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).

### **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. We acknowledge that

some participants may have experienced, but may not have identified, ‘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 (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 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 dancers who require communication and/or physical assistance in a dance environment.

### Perspectives

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’ lived 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 pre-emptive actions of inclusion in the dance community. This study lends critical insights into the need for dance educators, 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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## Appendix A

### The Interview Guide

#### Before the 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 have they known each other.
  - How often do they attend dance sessions with the dancer?
4. What activities (other than dance) do you enjoy doing?
  - Prompt: do you swim? Sing? Paint? Garden?
  - 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 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

**Question 1** – You've been dancing with \_\_\_\_\_ for \_\_\_\_\_ years. What kinds of activities do you do in \_\_\_\_\_?

- Prompt: do you start with a warm-up? What happens after the warm-up?
- Prompt: do you learn choreography (combinations)?
- Prompt: what is your favorite music from dance class? What activities or movements do you do when you hear your favorite music in class?
- 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?

**Interviewer:** I'd like you to take a moment to have a look at it and think about the reason 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 similar class)?
- Prompt: in what ways is this photo similar what you do in your class?
- [Note: if time allows, repeat this with the second photo they chose or go to the backup photos and use those as a starting point for conversation around the characteristics of the class they participate in.]
- [NATURAL BREAK HERE...]

**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]

**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 in your dance class?
- [NATURAL BREAK HERE...]

**Question 3** - Moving on to the third question, what does your dance teacher do that helps/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 the reason 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?

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

**Question 4** – Do you remember this photo? [show photo on screen]. I'd like you to take a moment to look at the photo and think about how dancing makes you feel. 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 about that?
  - 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 it physically feels): So, dancing makes your body feel [reiterate what they expressed]. Can you tell me more about that? Why does dancing make you feel that way?
  - FOLLOW-UP (if they reference how it makes them feel emotionally or in relation to the self). So, dancing makes you feel \_\_\_\_\_. Can you tell me more about that? Why does dancing make you feel that way?
- [NATURAL BREAK HERE...]

**Question 5** - 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 the reason 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 attend dance in-person? [What did you miss the most about dancing in person?]

**WRAP-UP question:** It sounds like your experiences in dance have been (summarize what activities they have talked about).

- FOLLOW-UP (if appropriate): 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:** Thank you so much for sharing your thoughts with me and for taking the time to meet with me today!

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

[END INTERVIEW]



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