


# A grounded theory of adoption and maintenance of physical activity among autistic adults

Autism  
1–15  
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## Abstract

**Background:** Although a growing body of literature has explored the physical activity experiences from the perspective of children on the autism spectrum, the perspective of autistic adults remains largely unheard. Due to this absence of perspective, there exists limited knowledge of the appropriateness and generalizability of current models and theories of physical activity for this population.

**Methods:** A constructivist grounded theory study was conducted to explore the experiences of adoption and maintenance of physical activity from the direct perspective of autistic adults. Autistic adults ( $n=23$ ) from the United States and the United Kingdom were recruited.

**Results:** A total of 29 codes emerged from the coding process. These codes were formed into four broad categories: (1) individual attributes; (2) environmental factors; (3) social relationships; and (4) social experiences. The interconnectedness of these four categories was explored.

**Conclusions:** The findings and presented model highlight the importance of building successful experiences for young children on the autism spectrum, so that they are more likely to continue physical activity into their adult life. Furthermore, findings emphasize the importance of creating noncompetitive, sensory-friendly physical activity experiences for autistic adults that offer flexibility in social engagement.

## Lay abstract

Little is known about how autistic adults experience physical activity. To begin to change this, we interviewed 23 autistic adults from the United State and the United Kingdom about their past and current experiences of physical activity participation. The interviewees told us about how their physical activity experiences were highly influenced by their individual strengths, the setting in which the activity took place, the presence of people to support their physical activities, and the sensory experiences they had while in physical activity. Through these interviews, we were able to create a model that represented the physical activity experiences discussed. Based on the model that emerged from this study, we recommend physical activity opportunities are made available that are noncompetitive, sensory-friendly, and that allow for participants to socialize as they prefer.

## Keywords

autism spectrum disorder, life span development, physical activity, sensory factors, socio-environmental barriers

Autistic adults<sup>1</sup> are at a greater risk for a host of health problems compared to their nonautistic peers (Bishop-Fitzpatrick & Kind, 2017; Cashin et al., 2016; Croen et al., 2015). Physical inactivity is a key, modifiable risk factor for a host of health outcomes. Indeed, physical inactivity is the fourth largest cause of death worldwide (Kohl et al., 2012) and has been linked to an increased risk for cancer,

hypertension, type 2 diabetes, and coronary heart disease (Blair & Brodney, 1999). Participation in physical activity

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(PA) can also decrease an individual's susceptibility to stress and anxiety (Stubbs et al., 2017), decrease the risk for diabetes (Colberg et al., 2016), improve sleep (Saunders et al., 2016), and reduce symptoms of depression (Schuch & Stubbs, 2019). Although research on PA among autistic adults is sparse, research involving autistic youth suggests PA may offer additional benefits for the autistic population (Bremer & Lloyd, 2016; Healy et al., 2018; Lang et al., 2010; Sowa & Meulenbroek, 2012). Additional studies have also found PA participation to result in improved parent quality of life (Toscano et al., 2018), and improved sleep (Brand et al., 2015).

Despite the array of benefits that can be gained from PA participation, levels of PA among autistic adults remain low. Benson and colleagues (2019) compared PA levels between young autistic ( $n=15$ ) and nonautistic adults ( $n=17$ ), using both self/caregiver-report and objective measures. On average, nonautistic adults participated in over twice as much daily moderate-vigorous PA (MVPA) as the autistic sample (15.5 vs 36.8 min). Similarly, significantly more nonautistic adults met the PA recommendations for adults of  $> 150$  min of MVPA per week, compared to the autistic adults (82.4% vs 40%, respectively) (Benson et al., 2019). Moreover, autistic adults are significantly less active than nonautistic children and adolescents (Garcia-Pastor et al., 2019), suggesting the disparity in activity levels between autistic and nonautistic individuals—that is well reported during adolescent years (Dreyer Gillette et al., 2015; Healy et al., 2019; McCoy et al., 2016; Pan et al., 2017; Stanish et al., 2017)—widens as the individual moves into adulthood.

For autistic individuals, accessing and participating in PA may be hindered by a greater array of barriers than face the nonautistic population. Although research with autistic adults is sparse, research with autistic children is gaining greater attention. Research exploring the barriers to PA among autistic children has found that intrapersonal, interpersonal, and community factors play a role in diminished access (Blagrave & Colombo-Dougovito, 2019; Obrusnikova & Miccinello, 2012; Stanish et al., 2017). Autistic children have also engaged in interviews to recall their PA experiences. For example, children (Blagrave, 2017; Healy et al., 2013) and adolescents (Arnell et al., 2018) have had their perspective heard and spoke of the importance of positive PA experiences, but recalled an array of barriers they experienced, including low perceived physical ability, sensory issues, concerns about negative social interaction such as bullying, and anxiety related to participation.

Although the knowledge base on autistic children's experiences in PA grows, much less is known about autistic adults. Nichols and colleagues have begun to address this gap in the literature. Interviews with parents of eight autistic adult children provide an insight into the barriers and facilitators experienced by this population (Nichols et al., 2019). Several factors emerged as being influential;

factors that either facilitated or restricted PA participation. First, parents spoke of their positive attitudes to PA and the availability of financial resources and free time as being factors that led to their adult child being more active. Conversely, a host of barriers to PA was also revealed in this study: parents spoke of their lack of interest in PA and their concern for their adult child's safety as being detrimental to their adult child's PA levels. The parents also listed a multitude of traits of their adult children that they perceived as being reasons for their child's inactivity, such as motor skill delays, aggression, and hypersensitivity. Finally, parents spoke of the importance of the availability of programs and facilities. Whereas many of the parents spoke of how local programs (e.g. Special Olympics) and accessible facilities were critical for PA participation of their adult child, other parents who lived in more rural locations noted that a scarcity of programs for their adult child was a significant barrier to participation (Nichols et al., 2019).

Although the perspective of parents and caregivers has been informative, the perspective of autistic adults requires attention. Autistic adults need to be recognized as the "expert of their own lives" (Caldwell, 2014). Their perspective is crucial for informing the development of interventions and programs to increase PA participation for autistic adults (Nind, 2008). Therefore, the purpose of this study was to examine the lived experiences of autistic adults in regard to their adoption and maintenance of PA throughout their life spans.

## Methods

This study used a constructivist grounded theory design (CGT) (Bryant & Charmaz, 2007; Charmaz, 2006) to capture the lived experiences of PA adoption and maintenance among autistic adults across their life span. Grounded theory is a structured qualitative analytical methodology uniquely intertwined with the data collection process to "generate an inductive theory about a substantive area" (Glaser, 1992, p. 16). CGT adopts many of the key strategies from early versions of grounded theory (Corbin & Strauss, 1990, 2008; Glaser, 1978; Glaser & Strauss, 1967). This specific subdomain of grounded theory allows for the reflexive capture of the language, meaning, and actions of the researchers and research participants by acknowledging the complexity and subtle nuances of the daily lives of participating individuals, as well as situating the research in the social and environmental contexts that occur during data collection (Charmaz, 2017).

## Participants

Following ethical approval, participants were purposefully recruited through university autism clinics and networks. In addition, participants were recruited through online autistic groups by directly contacting page moderators, as

**Table 1.** Participant demographics.

Pseudonym	Gender	Age, years (range)	Diagnosis	Education	Employment	Income (\$)	Marital status	Living situation	Location
Sandra	F	35–44	Formal	College	PT	NR	Married	Fam	UK
Christopher	M	35–44	Self	College	NR	NR	Single	Fam	MI (USA)
Cynthia	F	55	Formal	College	FT	30–49 K	NR	I	MA (USA)
Jack	M	18–24	Formal	HS	U	>10 K	Single	Parent	CA (USA)
Steve	M	55	Self	HS	R	70–89 K	Married	Fam	CA (USA)
Ashley	F	25–34	Formal	College	PT	>10 K	Single	Fam	GA (USA)
Heather	F	35–44	Formal	College	SE	>10 K	Single	I	CA (USA)
Susan	F	55	Formal	College	SE	>10 K	Divorced	Fam	UK
Elizabeth	F	25–34	Formal	NR	FT	NR	Relationship	I	NY (USA)
Jason	M	35–44	Formal	College	SE	90 K+	Married	Fam	RI (USA)
Zebo	M	18–24	Formal	HS	U	>10 K	Single	Parent	TX (USA)
Samuel	M	18–24	Formal	HS	U	>10 K	Single	Parent	CA (USA)
Mark	M	55	Formal	College	R	90 K+	Married	Fam	CA (USA)
Mary	F	45–54	Formal	College	SE	NA	Married	Fam	VA (USA)
Jeffrey	M	45–54	Formal	Some HS	SE	10–29 K	Married	Fam	CA (USA)
David	M	55	Formal	NR	SE	NR	Married	Fam	TX (USA)
Tim	M	18–24	Formal	HS	U	>10 K	Single	Parent	CA (USA)
Jessica	F	25–34	Formal	College	SE	50–69 K	Married	Fam	NY (USA)
Dan	M	18–24	Formal	HS	U	>10 K	Single	Parent	CA (USA)
Robert	M	45–54	Self	College	SE	>10 K	Relationship	Fam	CA (USA)
Nicole	F	25–34	Formal	College	FT	90 K+	Married	Fam	NY (USA)
John	M	55	Formal	College	R	NR	Married	Fam	VA (USA)
William	M	18–24	Formal	HS	U	>10 K	Single	Parent	CA (USA)

F = female; Fam = lives with family (either partner or partner + kids); FT = full-time; I = living independently; M = male; NR = not reported; Parent = living with parent; PT = part-time; R = retired; SE = self-employed; U = unemployed.

well as through social media posts. Finally, a snowball sampling method was used to increase the reach of recruitment through participants' own personal networks. Participants were included if they had a diagnosis of autism or identified as autistic, were 18 years or older, were living independently, communicated verbally, and were willing to participate in interviews. Independent living for this study was broadly defined as living on own or with family (e.g. spouses, partners, or parents) with the autonomy to come or go without restriction.

A total purposeful sample of 23 participants—12 males and 11 females—ranging in age from 18 to 75 years ( $m = 40.45$ ) consented to participate (Table 1). Participants were from diverse educational and geographical backgrounds. Despite a large number of individuals having a college degree, a large portion made less than \$10,000 US annually and the majority worked either part-time or were unemployed—especially those ages 18–24—at the time of interviewing.

Of the participants, 20 had a formal diagnosis of autism, and three were self-diagnosed. Participants who identified as “self-diagnosed” were given the AQ-10 to determine the individual's position on the autism-normality continuum (Baron-Cohen et al., 2001). The AQ-10 is a measurement tool that is used to screen autistic traits in adults with normal intelligence and has been shown to

have discrimination validity and good screening properties (Woodbury-Smith et al., 2005), as well as a limited diagnostic bias (Murray et al., 2017). All self-identified autistic participants met the criteria identified of  $\geq 6$  (Allison et al., 2012) for autism spectrum disorders (ASD).

### Data collection

Data were collected through open-ended, semistructured interviews. Prior to consent and data collection, each participant was provided an overview of the study by their preferred method of communication (i.e. written or oral). Once written consent was obtained, participants were provided an overview of the main interview questions to alleviate any potential anxiety associated with the interview process and to allow participants to prepare. Interviews were conducted using the participants' preferred medium of communication—that is, video interview (Skype or FaceTime), phone interview, or in-person—as identified during the consent process. Interviews ranged in length from 20 min to over 2 h, though the majority took approximately 1 h to complete. Each interview followed a similar format. A predetermined set of main questions were asked in each interview, with follow-up questions and probes used as needed.

**Table 2.** Sample interview questions.

Question
What does being physically active mean to you?
What were your favorite activities to participate in, when you were a child?
a. Why were these your favorite?
Did you prefer activities that involved moving (such as sport) or sitting (such as television)? Why, did you prefer [repeat back preference]?
Did you and your family do any PAs together? If so, can you please describe these activities?
a. How did these activities make you feel?
b. Was there anything you enjoyed or disliked about these activities?
Were there any sports/activities you would have liked to participate in at school?
a. If so, what sport/activities?
b. Why did you not participate in this activity?
c. What made it possible for you to participate?
Looking back, how has your PA level changed over time? Please explain.
Do you consider yourself to be physically active now? Please explain.
a. If yes, what types of PA do you participate in? Typically, how often do you play/do [repeat from above]? For how long?
b. If no, how do you feel about this?
What activities, if any, do you enjoy participating in as an adult?
a. How do you feel when you are participating in these activities?
b. Why do you think you mostly participate in active/sedentary activities (such as ____)?
Are there any activities that you do, but do not enjoy? If yes, why do you do these activities?
a. How do you feel when you are participating in these activities?
Do you usually participate in PA by yourself or with others?
a. Do you rather participating in PA by yourself or with others? Why?
What do you do that has a good impact on your health, if anything?
a. Do you think that PA is related to your health?

PA: physical activity.

### *Interview schedule*

The first and second authors, individually, conducted each interview. Each interviewer had extensive prior experience conducting interviews, including with those on the autism spectrum. Interviews followed a similar format guided by main questions (see Table 2). Prior to the interviews, the authors identified several follow-up prompts to main questions to increase the likelihood of capturing depth in each area of interest. During the interview, probes were used for main and follow-up questions. Interview questions were reviewed prior to the study by three independent experts in the field who have previous experience conducting interviews with autistic individuals. The interview questions followed a chronological order, starting with activity experiences in childhood and concluding with questions pertaining to the adults' current experiences of PA.

### *Ethical issues and approval*

The standard of ethical research was followed throughout the study. After university ethical approval, each study participant gave written informed consent after receiving verbal and written information. Furthermore, prior to each interview, each participant verbally reaffirmed their consent to participate.

### *Data analysis*

Interview data were transcribed verbatim, then initially coded (Charmaz, 2006) using Dedoose analytic software (Version 8.0.35, SocioCultural Research Consultants, LLC, 2018). A constant comparative method of data analysis (Bryant & Charmaz, 2007; Charmaz, 2006; Glaser & Strauss, 1967; Henwood & Pidgeon, 2003) was used by the researchers to code and analyze the results simultaneously. During the interview process, the first and second authors took analytic notes during each interview and debriefed with each other immediately following each interview. In accordance with grounded theory methodology (Charmaz, 2009; Urquhart, 2012), data were first open coded searching for broad ideas, then to a focused coding stage, and finally a theoretical sampling. The first and second authors coded line by line each of the interview transcripts. Interrater reliability (IRR) was measured using Cohen's kappa (McHugh, 2012). Based on three randomly selected interviews, the first and second authors demonstrated an IRR of 0.90; above the a priori criterion of 0.80.

Following open coding and prior to focused coding, the third author independently confirmed the open codes; all discrepancies were discussed as a group to clarify open codes until consensus was reached. During focused

**Table 3.** Themes, codes and excerpts.

Theme	Code	Excerpt example
Environmental factors	Environmental barriers	"But you know, when it came to school sports, um, I wasn't allowed to do school sports, um, because you're—I mean, when I went to school and if you were in special ed, uh, you weren't allowed to participate in, uh, general educational activities at school." (Jeffrey)
	Environmental facilitators	"We made use of the environment to the best of our ability. And there was no grass and, you know, trees, um, so we did sidewalk games. There were a lot good, uh, lines on the sidewalk, on the pavement, so we had good games that we could play. Um, you know, from the corners of the, the, the limestone squares." (Heather)
	Recess	"I was by myself mostly. I can remember trying to join in and being rejected." (Susan)
	Location	"Yeah. And I love the forests. I love—I love the ocean. I love everything, you know, nature. I didn't like so much the sort of—the, the formal areas." (Robert)
Individual Attributes	Technology	"it still—it tracks my steps, and it tells me if I'm—did a better job, um, some days than other days. And I think that's helped some, um, but I used to look at it more than I do now." (Christopher)
	Body image	"I'll probably actively resist any attempts to get me into their pool because swimsuits." (Jessica)
	Cognitive barriers	"I had some challenge understanding, like, the rules. It was more or less, like, the directions of how the game is supposed to be played that I had difficulty with." (Nicole)
	Health status	"Current health, health level. Well, I always say—and it's probably not true. I always say I'm very healthy." (Mark)
Individual Attributes cont.	Motivation	"it's about pleasure, it's about finding fun" (Jessica)
	Opinions on PA	"I mean, it looks like people want to be on display when they're exercising. That is kind of what the gyms are like." (Susan)
	Perceived competence	"And by the time I was in elementary school, they wanted me to join the swimming team because I was really good." (Elizabeth)
	Physical barriers (personal)	"I'd love for my joints don't ache. Um, I've had pain all my life. I've grown up with it" (Sandra)
Physical facilitators (personal)	Physical facilitators (personal)	"I was good at keeping a rhythm and I have very, very strong legs." (Jessica)
	Mental health	"I exercise and then I don't, like, my depression doesn't go away. But everyone tells you if you exercise and your depression'll go away, and then it doesn't, and then I don't exercise 'cause I'm discouraged." (Christopher)
	Fun or lack of	"It's been quite a while since I played [soccer]. But, yeah, I had a lot of fun playing it." (William)
	Drop out	"I mean, with super competitive games, I can't have fun because all I can think about is winning." (Dan)
Sensory experiences	Defining activity	"I used to [work out]. I can't anymore." (David)
	Mental health	"a great deal of exasperation and annoyance in in exchange for potentially better health." (Jessica)
	Success	"Being physically active, I think of, you know, going out, w-walking, jogging, bike riding, that sort of stuff." (Cynthia)
	Sensory experience	"But it's just become so overwhelming. I—my husband goes to the gym, and I was going with him as a guest for a little while, but I just—it got to the point where I would just start having a lot of anxiety on the way to the gym, so I just stopped going." (Nicole)
Social relationships	Social positive	"I don't have as much of a problem balancing." (Jason)
	Social negative	"I swim, part of it's sensation, biking. I can bike in circles like this. Get a lot out of that." (Mark)
	Masking	"Yoga is so nice 'cause it is so antisocial [laughter]. Like it's, it's just—you know, you walk into a room, you set up yoga mats. All face the same direction. Nobody looks at each other. You don't talk with each other and pretend that other people aren't there. And then the teacher comes in and the teacher doesn't talk to you. The teacher talks to the class, and you can kinda like get through the whole thing without talking to anybody. It's awesome." (Elizabeth)
	Marginalization	"It seemed to be like at the time. And there were other girls that were kind of in the middle. I don't mind going for a walk but let's walk to a bookstore and then go home and read. They may have been around but I just—I couldn't seem to find them or I didn't how to find them." (Steve)
Family attitudes	Bullying	"Honestly uh, I, I just tried to, like, um, um—the stuff any normal kid would do and just try, um, to not draw attention to what, um, uh, I have. Um, but, um, h-ho-honestly, I just tried to act like a normal kid, even though I knew I wasn't." (William)
	Family attitudes	"o, um, I've always been, um, outcast, basically, you know." (David)
	Others attitude, skill, support	"That whole bullying thing. It really degrades a person's thinking. And then you don't wanna do anything. I mean, it's just like at school with me. I, I was scared to death to go out on the playground 'cause I was afraid I was gonna get beat up every day, you know" (Jeffrey)
		"I don't know. I mean, I feel like maybe if they had pushed me more to do, like, more, um, activities, I would be better at them now. I mean, of course, back then, I didn't want to be pushed at it but now, I probably would of" (Dan)
		"If I find a friend to do it with [I'd go to the gym]." (Samuel)

PA: physical activity.

The above questions were pulled from a larger interview schedule that contained 48 main questions; some questions included one to three priori probing questions as shown above.



coding, each author independently grouped the open codes by commonalities. These groupings were discussed and manipulated as a group, until the authors reach 100% agreement. During the focused coding process, each author used memo writing to frame their thoughts around each open code. Finally, the authors, using the analytic notes, focused codes, and memos, jointly conducted the theoretical sampling phase. During this phase, authors indexed the codes (Braun & Clarke, 2013), allowing them to manipulate the focused codes about the relationships demonstrated within the data and defined them into categories (see Table 3). Through several theoretical iterations, the categories and subsequent model were further defined until the authors reached 100% agreement.

### Data credibility

To ensure the credibility of the data collection and analysis of this study, several steps were taken. Prior to conducting each interview, the first and second authors bracketed their thoughts, situating their prior assumptions and feelings (Tufford & Newman, 2012). Once data were transcribed, each transcript was sent to the corresponding participant for confirmation of the content of the transcript and allow for further or clarifying detail. Once a preliminary grounded theory was developed, the researchers returned the model to the participants for analysis and feedback. Of the 23 participants, 12 provided feedback on the entire model. Feedback, overall, was positive and confirmatory of the presented model; critical feedback of the model from respondents focused on cosmetic issues such as font size and curvilinear versus linear lines.

### Findings

A total of 29 codes emerged from the thematic open coding process of 1244 excerpts; these codes included body image, environmental barriers and facilitators, motivation, perceived competence, as well as social positives and success. During focused coding, open codes were collated into four broad categories: (1) environmental factors; (2) individual attributes; (3) sensory experiences; and (4) social relationships. Focused coding revealed that each factor impacted individuals both positively and negatively, and each factor was interdependent with the other categories.

Through the theoretical coding process, a cyclical model emerged demonstrating the interconnectedness of the categories discussed by participants. This model—the Grounded Theory of PA Adoption and Maintenance in Autistic Adults—is demonstrated in Figure 1. The following sections will describe the model's phases, while rooting each step within the collected data and connecting referenced data to related categories. All participant names have been replaced by a pseudonym.

### Step 1: selection of activities

Activity selection is the first step in the model cycle. Participants discussed how throughout their life, they made choices regarding what activities to select and which to avoid. The categories of *Social Relationships* and *Individual Attributes* were very prominent within this step.

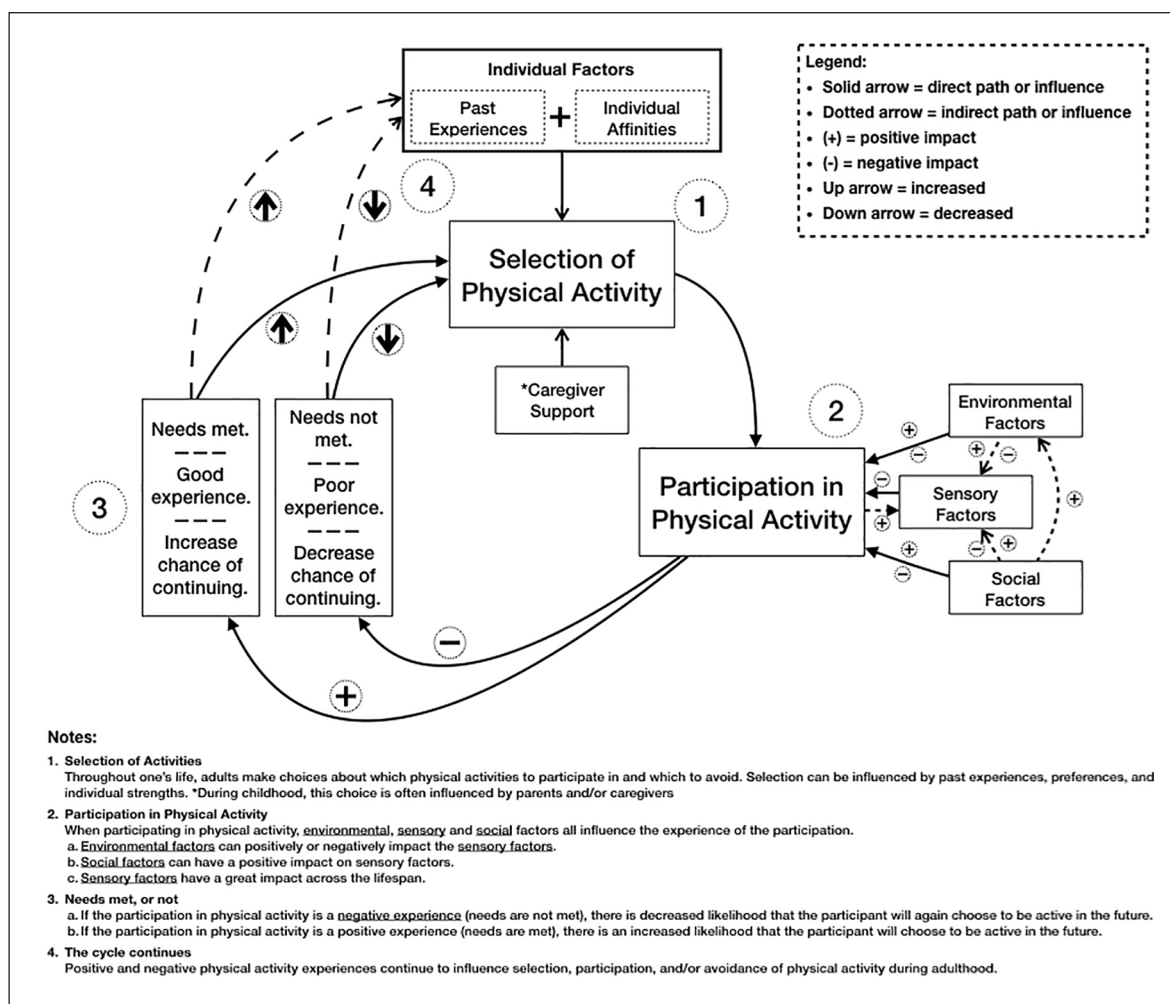
**Social relationships.** Referencing the category of *Social Relationships*, the activities chosen during childhood were strongly influenced—both positively and negatively—by caregivers, siblings, friends, and close relatives. Sandra reflected, positively, that:

We were one, two, three, four, five—sometimes six, uh, [groups] of younger parents, my parents were and other younger parents. And they were, uh, a Saturday evening get together with squash, badminton, uh, yeah, dancing, that kind of thing. So quite well encouraged. And the children had their little games as well. Like, uh, tetherball—what was the right word?

Jason reflected that, “my parents also helped with a lot of those things,” and that, “A lot of it was the support of my siblings, uh, helping me and trying new things out . . . it was a lot of support from them.” This support, or lack of support, during early years was seen across multiple participants. Participants reflected on these early experiences and the necessity of support to surpass barriers to activity and overcome a lack of access to PA spaces. Jason further highlighted the importance of this relationship by stating that, “It was a lot of support from my parents of saying, “No, you can’t. You can’t just sit at home.”; a common situation reported by many of the older participants. Nicole recalled,

One of my best friends had played soccer, and every time I went to her house, we played soccer. And finally, I remember her saying, “Why don’t you sign up for soccer? You’re so good at it.” Like, I was really—I-I was a really fast runner, and it never even occurred to me that—“yeah, that I could take something that I enjoyed and actually make it more of a structured thing.” So, I took her advice.

Conversely, participants discussed how if their experiences in an activity as children were negative, the selection of that or a similar activity as adults was less likely. Sometimes, this appeared as lacking access to the activity—Mary recalled, “When I wanted to play with other people, they just wouldn’t have me.” Primarily, these negative experiences originated from poor accommodations by those leading the activity or negative interaction with peers participating in these activities. Heather shared, “the general consensus that was if you weren’t making the game better, just sit out.” This led individuals to assume a lower perceived competency in the skills necessary for that activity. Mary, reflecting on several situations, said:



**Figure 1.** The grounded theory of physical activity adoption and maintenance in autistic adults.

There were times when if I did something—even if I really did something right physically, actually managed to catch a beach ball that was being thrown, I would be told that this wasn't any good 'cause if I could do it once in a million times, I should be able to do it always. Or I—if I was very good at something that was not physical, I was really disdained because I was told that basically, I had no right to be great in some things and so disgustingly horrible in others.

Jeffrey said, "It really degrades a person's thinking . . . then you don't want to do anything."

As individuals aged, social relationship continued to be important in the selection of activity, as well as for enjoyment. Jack stated, quite succinctly, "It's usually more fun with others than just do it by myself." Though, as some adults referenced, finding social groups as an adult is difficult and can decrease chances or motivation to be physically active. Christopher said:

Socializing really helps me, [sic] and that's a beauty and it's a bane because it's, like, I feel like I have to be social to get

exercise. And I should really be doing it, like, alone, but I just—it's a lot harder to do alone.

For Jason, "If it's not social, if it's not mental, if it's not physical, it falls apart. Like I can't—I've tried to do certain ones without doing the others." Although these social interactions and supports may look different from nonautistic social engagement, in regard to selecting and PA, autistic individuals benefited from social supports.

**Individual attributes.** In addition to the *Social Relationships* that shaped an individual's uptake of PA, many individuals discussed factors related to themselves—or their *Individual Attributes*—that ultimately impacted their PA choices. Jessica, reflecting on childhood experiences, stated:

I was poor at every activity that the team did except for rowing, so any kind of socializations, the, the calisthenics, the jogging, the, you know, whatever. The—I was not good at it. I was good at keeping a rhythm and I have very, very strong legs.

Most participants discussed the complexity of these *individual attributes* as having the potential for both positive and negative impacts. Robert said, “I was always a good runner and [sic] cyclist because I had [sic] years of that and, and hiking in the mountains. [sic] I had done that, you know, a lot before.” He, also, “lack[ed] upper body strength and, uh, and tone for sure—muscle tone.” Yet, because he had perceived strengths in running and cycling, those outweighed the perceived lack of upper body strength and, “helped [Robert] feel better about [him] self, and become more so—develop better coordination.” In addition to influencing the choice of activity, perceived competencies impacted choices within physical activities. Susan stated that:

My preferred place to play was the left wing in hockey. But, I mean, I’m right-handed. And it meant that everybody was on one side of me. I was left on one side. And I only had to concentrate on one side instead of all around me.

By “playing to one’s strengths,” participants felt they could improve the likelihood of their overall success, allowing them to select activities where they also may have some weaknesses. In certain instances, this resulted in “aging out” of certain activities. Elizabeth, for example, not wanting to swim competitively said she, “just took swimming lessons over and over again up till, like the highest level,” until she was too old to register.

## Step 2: participation in PA

Once an autistic individual selected a PA and begun participating in that activity, a multitude of factors shaped the nature of their participation. These factors are encapsulated in the categories of *environmental factors*, *sensory experiences*, and *social relationships*. The impact of these factors varied across participants, impacting some participants in certain areas more so than others; yet, each participant mentioned various aspects of each category. In addition, these factors had a direct or indirect influence over one another, and synergistically impacted the individual’s participation experience. Those influences were often interconnected, making it difficult to parse out any one factor that was singularly dominant in a given scenario.

**Sensory experiences.** When discussing sensory factors, several were mentioned that strongly influenced the individuals’ level of enjoyment in PA. Most commonly, though, sensory experiences in PA were recalled with sadness and frustration. For example, Jessica discussed how the noise level in a PA environment limited the time she was willing to spend in the environment, “I didn’t really wanna spend that much time in a place that was very loud, and I also had just kind of—it, it doesn’t necessarily occur to me to join those, those group activities.” Similarly, an unpleasant sensory experience of the PA itself affected the choices that David made regarding exercise; he stated: “You know,

. . . I-I can’t do sit-ups and stuff because that’s so disorienting for me. It makes me nauseated.” The importance of the activity itself as a factor that affected the individual’s sensory experience was reinforced in our refinement of our model. A previous drafted model of Figure 1 only considered the sensory factors as external (i.e. in features of the environment) and negatively impacting the PA. After discussing with participants, some mentioned that the PA itself could provide a sensory experience, such as swimming having a positive impact on the sensory experiences of individuals or sit-ups in the instance of David.

When considering the experiences of autistic individuals regarding PA and the various influential factors, it is easy to look at this model and find one’s self regardless of diagnosis status. Yet, it is important to recognize how such areas have a unique impact on an autistic individual versus a nonautistic individual. In one case, Nicole discussed an instant of sensory overload during a team activity:

[There was] a lot of verbal commands all at once. Like shouting from the sidelines is very confusing. Some of my teammates would be shouting one thing, and my coach would shouting the other, and I just kind of—. . . , like, I still remember one game, I just stood in the middle of the field and didn’t move. I can carry on a conversation with you as long as I don’t make eye contact. Because . . . one will disrupt the other. So we have these very fragile, uh, pathways trying desperately to integrate all day long. And they’re shaky.

And it appears that these sensory experiences also affected Nicole’s PA choices in adulthood as she discussed how, as an adult “it’s just too loud, too overwhelming—I just can’t deal [with the gym].” Occasionally, issues with the sensory experiences could be a result of social norms—Heather, in discussing why yoga is an appealing activity for her, said, “Yoga is so nice ‘cause it is so antisocial [laughter]. Like it’s, it’s just—you know, you walk into a room, you set up yoga mats. All face the same direction. Nobody looks at each other and pretend that other people aren’t there. Then the teacher comes in and the teacher doesn’t talk to you. The teacher talks to the class, and you can kinda like get through the whole thing without talking to anybody. It’s awesome.”<sup>1</sup> Yoga offered her the opportunity for social engagement while being physically active but did not require certain social norms such as an eye contact that would otherwise cause sensory overload. The PA setting and those experiences within it may be what cause an autistic individual to become overwhelmed, often forcing individuals to choose between being active and being comfortable.

**Environmental factors.** Considering the influence of *environmental factors*, for Jason, success was inexplicably tied

<sup>1</sup>This revised quote was added after the article’s original OnlineFirst publication. The original quote was “So I can carry on a conversation with you as long as I don’t make eye contact. Because two—one will disrupt the other”.



to the perception of an activity as “fun.” Jason specifically highlighted the outdoors as a space that he liked to participate in PA—which was shared by a plurality of participants—because, “I’m, you know, jumping across rivers, or creeks, or areas. I’m like going into the water. Like it’s just—that’s my idea of fun.” In addition, the environment, in seemingly small ways, can have a great impact on an individual’s experience. For many participants, one particular negative aspect of a space could be enough to overwhelm the “good” aspects of a space. Elizabeth, for example, stated:

[name removed], that was a really nice gym. Like it was small and like—it did have a big running track that I didn’t use, but like it was a normal gym. But the way the machines were organized was so that they all kinda—I d—I don’t know how to describe it without drawing a picture, but none of—the machines weren’t facing each other in a way—that you were—you couldn’t see each other’s faces when you were using the machines—like in a way that people weren’t like—it didn’t feel like we were looking at each other.

Nicole further demonstrates how, despite many aspects of a space “working” for them, one particular piece of gym etiquette could ruin an otherwise good experience. For Nicole, it was important that individuals, “wipe down the equipment. I don’t like the feeling of, like, the slimy, like, sweat that people leave behind. So it’s just—it gets that—it’s very overwhelming for me.” When considering creating the optimal environment for increasing the likelihood of success for autistic individuals, participants made it clear that these measures need to be individualized but small things should not be overlooked.

**Social relationships.** Similar to the experiences in Step 1, autistic adults found encouragement to continue PA through their own social network. This often resulted in PA that was less competitive and more accommodating. Christopher said, “when the sports were less competitive, the barrier to entry was lower, um, so it would just go, like, “We’re all—we’re all playing basketball in this recess lot. Um, you know, just come on.”” For Jessica, even into adulthood, her parents remain an important social support for maintaining PA; “They try to exercise multiple times a week. So, I’ll be scheduling an exercise date, um, for each of them.” For her this meant, “I’ll get to spend time with them and we will also exercise for probably an hour or something.” Though, it is important to recognize that some individuals are more comfortable with smaller groups or even one-on-one. David said trying to converse with more than one person, “make [him] dizzy just trying to listen.” When asked, “Why hiking and camping were his favorite activities?” he said, “the fact that probably I’m not around a bunch of people,” then laughed.

### Step 3: needs met, or not

Through the influence of the various factors mentioned above, the third step of the model focuses on whether individuals persisted in an activity or not. Each participant identified a set of needs that, in many circumstances, coalesced to influence their perception of a successful experience. For example, if needs were unmet, the potential for a positive experience in that activity was limited. Yet, needs were not uniform across participants; one factor that was negative for one participant may be of no consequence to another. Furthermore, it is important to highlight that all the positive and negative experiences do not occur in isolation.

**Negative experiences.** PA is one part of the whole that is an individual’s day. If a participant was overwhelmed prior to the PA experience, or as they start their PA pursuit, this impacted how elements of the PA environment or task impacted their experience. This led some to choose to stay clear of PA if they knew it took a certain level of mental or physical energy that they did not have available. For example, considering her own personal health status, Heather stated, “If the conditions weren’t a barrier, I would be very—I imagine I would be very active.” David, reflecting on sensory issues, said “I can’t breath without fee-feeling overload. I can’t—any kind of movement at all—I-I mean, just watching a video—the movement from a video causes visual overload for me.” Furthermore, in referencing her own individual attributes, Cynthia said:

I have terrible executive functional skills, which means my time management stinks, my organization stinks, and I think if I was better at staying more organized and better at organizing my time, I probably would be more inclined to do more things.

When considering the complexity of PA engagement, Susan highlighted how a particular activity (i.e. swimming) is cost-prohibitive; yet even if it wasn’t, she would still have to check ahead if the pool wasn’t “too wild or noisy.” For some participants, balancing the added demands of certain activities—even with appropriate supports—lead to dropping out from the activity. William mentioned that he, “wish[es] I [he] could’ve carried on the sports, but I j—I just got burned out.”

One reason for dropping out of activity was the increased prevalence of “competitiveness.” For many participants, this was overwhelmingly a point at which they would self-exclude themselves from an activity. Jason shared that:

Swimming was a really big thing. Man, I loved it. It was the coolest thing. I actually ended swimming because it became competitive. That happened like right around with or sixth grade. . . . It’s kind of sad, but [sic] essentially, I was just like, “I don’t wanna compete anymore. I just wanna do this for fun.

Jeffery, when asked about why he stopped playing sports, said, “I was like, ‘Well, what’s the point? You’re not gonna let me play in the game. There’s no point in me continuing to hurt myself, uh, to benefit your team. It’s just not gonna work.’” William said, “Yeah. Um, farm league, that was, uh—that was little league baseball so more serious. Um, so after that, I didn’t really participate in sports anymore.” Even when participants were involved in activities with adequate social support, ultimately, competitiveness ruined activities for most autistic participants. Christopher said:

Well, the people were accepting and includings . . . I think there’s kind of a metamorphosis that happens in junior high where people get more competitive and, and, um, like, harsher, um, towards people who are different. And I think that—and I’ve read that in other autism, autism people have said that on other communities. And I think that, that sticks permanently, like, uh, though I think it’s probably worse now.

**Positive experiences.** In many instances, participants highlighted how an accepting and inclusive social environment led to increased success and continuation of PA. Dan describes this clearly: “I mean, I’ve chosen a lot of times not to be inactive, but of course, if there was somebody that wanted to do something with me, I would be active more.” For some, acceptance of who they were or the individual differences they possessed impacted greatly their experience. Robert shared that many people were not “tolerant” of him and didn’t accept that he was different; he said, “I just want to be . . . [but] I get frustrated every not and then [because] they treat me like, like I’m a criminal or a delinquent.” William stated that he was bullied from, “literally, elementary school all the way up to my freshman year,” and had little support from family who said, “it was all my fault.” Robert shared, in reference to his enjoyment of surfing, “At school, everybody—teachers always yelling at you and kids bullying you. But when you’re in the water or even skating a ramp, I mean, you’re just—you’re free to learn what you want, to express yourself.”

For some, the benefits of PA on mental health were the reason to persist. Mark mentioned that, “when I feel depression, if it’s there, I go swimming, and it usually lifts,” and Ashley stated that being physically active helps, “reduce anxiety and stress.” Yet, it is also important to highlight that benefits from PA are not universal nor do individuals often feel benefits after a single bout of exercise. Christopher related that sometimes he exercises and his “depression doesn’t go away,” yet, “everyone tells you if you exercise and your depression’ll go away. Then it doesn’t and then I don’t exercise ‘cause I’m discouraged.” While presenting a summation of the experiences of the participants in reference to their needs being met or not, it is important to highlight that there was no singular negative or positive experience that emerged from the collected data.

#### **Step 4: continuing of the cycle**

The last step of this model suggests that every experience in PA, whether positive or negative, influenced the autistic adult’s future PA choices. For some, negative experiences decreased the likelihood of participating in certain types of activities. Jessica, when discussing past PA experiences, said, “so my experience might be tainted somewhat by the fact that I was bullied in, in elementary school. Like, perhaps, if that hadn’t happened, I would’ve been more inclined to do team sports and things like that.” For Tim, this meant starting small and building successes. He said that he’s been doing a walking class and trying to “reach three miles an hour” which is “still very difficult for [him].” For many adults, their patterns of PA have changed over time. For Mark, his activity has, “changed some, but not a lot probably.” He was an avid swimmer and played lots of basketball; so despite living in multiple cities as an adult, he was always able to find the activities he had an affinity. Yet, despite many participants dropping out or being excluded from certain physical activities as children, there was not a single participant that did not participate in some form of PA as an adult. For some, after years of trying different activities, they have settled on walking or hiking (often in a small group or with pets) like John. As an adult, he said like to “go for walks” which he does more often than when he was a child. Others kept trying different activities (e.g. yoga, swimming, weightlifting, soccer) using their prior experiences as a guide for selecting new activities or settings to be physically active. This seems to be rooted, for many, in experiences that were positive or provided “good” experiences. Elizabeth recalled that she has memories of, “always moving when [she] was little,” and that she, “was happier and did not have the same, like, level of sensory problems.” A benefit from PA that she has noticed is absent in adulthood due to more limited engagement.

#### **Discussion**

In recognition that PA behavior, and the associated influential factors, may differ among autistic adults compared to nonautistic adults, this study sought to develop a grounded theory describing the process by which autistic adults adopt and maintain PA participation. The emergent model from this grounded theory analysis represents the PA experiences of 23 autistic adults across their life spans. Although aspects of the model parallel our understanding of PA participation in nonautistic adults, several unique components were apparent. For example, differences were apparent relating to the influence of individual, social, sensory, and environmental factors on PA selection and participation for autistic individuals. The findings from this study supply a foundational model to understand the PA participation of autistic adults across the life span, address the gap in knowledge pertaining to

PA among this population, and serve to inform research and practice in this area.

### *Importance of social support and the effects of negative social interactions*

Contrary to the belief that autistic individuals lack social motivation (Chevallier et al., 2012), social relationships were recalled as being important to the PA experiences of adults across their life span and were often sought out in support of PA goals. Supports of both family and friends were very important during childhood years or with new activities as represented in Step 1 of the model. This mirrored recent qualitative findings in families of adolescent and adult children on the autism spectrum. Blagrove and Colombo-Dougovito (2019), in looking at barriers to community PA engagement in families with at least one autistic child, suggest that community acceptance and social supports are vital for continued engagement. Similarly, Nichols et al. (2019), in interviewing parents, found that support from parents and community organizations can be beneficial to the continued engagement of autistic individuals. In the present sample, the perceived importance of these supports from caregivers generally decreased with time and with more positive experiences. Yet, even in adulthood, some participants shared that they wished they had someone to participate with, such as attending a yoga class or walking in the park, and that this would help them better engage if they were currently struggling with their motivation.

In the present study, most adults—even from a young age—described a desire to participate in collaborative, noncompetitive activities which impacted, ultimately, their choice and support within a given activity as seen in Steps 1 through 3. When considering the plurality of offerings of PA for adults, most activities are competitive even without formal competition. As a society, team sports and competitive activities are centered. PA opportunities such as basketball, volleyball, soccer, baseball, and even kickball are all framed on competition. Few opportunities exist for individuals to participate in activity, together, without competing against each other. Given the desires of most autistic adults in this study to participate in noncompetitive activity, even if many other areas of need are met, they may still have a lack of options to engage in social PA. To meet the needs of the autistic community, in addition to providing opportunities that are sensory-friendly, organizations (i.e. local recreation departments, fitness centers, athletic organizations) should deemphasize the competitiveness of activities and instead emphasize the social aspect of the activities.<sup>2</sup>

Despite the desire to have social experiences in PA settings and the positive impact that a social network could have on the participation of autistic individuals, negative social experiences were often devastating to the PA engagement of the autistic adults in this study. Early experiences with bullying either in school or in community PA

discouraged participants from engaging in PA later in life, and the narratives that they were told in their younger years by adults or other children formed the lens through which they saw their bodies and their ability levels well into their older adult life. These negative experiences reflect the bullying experiences recounted by children with ASD interviewed about their engagement in PA (Blagrove, 2017; Healy et al., 2013), and stresses the importance of addressing bullying in PA settings. Brewster and Coleyshaw (2010) reported similar findings with autistic youth and outdoor leisure activities, with many children wanting to go outdoors, but having a limited network to do so or having negative social experiences that caused them to withdraw from future outdoor pursuits. Even with support as an adult from spouses/partners, friends and family members, when exposed to bullying in PA settings as a child, the autistic adults in this study were rarely able to get past the negative dialogue regarding PA that had been internalized—often choosing to not participate in the activities in which they had the worst social experience.

### *The environment: facilitating or impeding participation?*

This study, for the first time, provides an insight into the relationship between PA experiences and the physical environment among autistic adults. Most commonly participants recalled how they had negative sensory experiences in response to aspects of the environment such as loud noises, lights, and certain textures. Participants discussed in Step 2 how they were sometimes overwhelmed by disorganization and excessive numbers of people within a PA environment. The physical environment has long been recognized as a crucial factor in the provision of effective multilevel PA interventions (Alfonzo, 2005; McCormack & Shiell, 2011; Sallis et al., 2006). Environments that are stimulating and congruent with the needs and preferences of certain populations are an essential determinant of PA.

The nature of the environment–PA relationship is not generalizable across all populations; however, for example, the influence of the physical environment for adults (Moran et al., 2014) differs from that among children (Davison & Lawson, 2006). Research with children on the autism spectrum suggests that the environment plays a unique and impactful role in their PA participation; physical barriers (e.g. lack of or unsafe equipment) and facilitators (e.g. the presence of exercise equipment and facilities) have been identified as being influential (Obrusnikova & Cavalier, 2011). Children on the autism spectrum have also spoken about their aversion to a host of environmental features that impede upon enjoyable PA participation, including loud noises, uncomfortable temperatures, and visual distractions (Blagrove, 2017; Healy et al., 2013). The characteristics of the environment–PA relationship that was revealed in the current study suggest a similar



significant environment–PA relationship exists for autistic adults. How the PA shapes PA for autistic adults clearly requires further study and careful consideration in PA program planning for this population.

### *Motivation to be active*

Each step of the presented model demonstrates the factors that contribute to the autistic adults' motivation to participate in PA. Unsurprisingly, the activities that adults were successful in as children were often activities they felt comfortable participating and engaging in throughout adulthood. Furthermore, contrary to studies involving autistic children and teens that report that individuals engage in less PA as they age (R. A. Jones et al., 2017; Stanish et al., 2017), the autistic adults in this study recognized the importance of PA and continued (or wanted to continue) active pursuits when they experienced success as seen in Step 4. Yet, for many autistic individuals, co-occurring conditions, such as dyspraxia (McAuliffe et al., 2017), obesity (Must et al., 2017), and hypermobility (Baeza-Velasco et al., 2018), make engagement in PA more strenuous and/or painful than their nonautistic counterparts. Participants in this study highlighted this concern; several participants reported co-occurring conditions that made participation in PA demotivating due to pain, weight impeding movement, joint and muscular skeletal issues, and motor planning impairments.

In addition, autistic individuals have reported having heightened sensory experiences in certain situations or settings (Jones et al., 2003; Robertson & Simmons, 2015; Robledo et al., 2012). Often, little attention is given to these alternative sensory experiences within PA settings (Blagrove, 2017; Healy et al., 2013; Yessick, 2018). This study, seen in Step 2, stresses the previous findings of sensory issues impacting on PA participation among autistic individuals. All participants reported some form of sensory influence when attempting to participate in PA that either positively or negatively impacted their continued involvement. Sensory visual experiences during team sport, the volume of music in fitness centers, or certain smells impacted participants' choice to participate in physical activities. Conversely, environments that were more neutral sensory experiences such as the outdoors or activities that provided positive sensory feedback (e.g. swimming) were found to have the opposite effect.

### *Situating the present model*

Features of the emergent model reflect other theories used to explain PA participation. The findings of the current study, for example, lend credence to the use of ecological models that recognize that multiple levels of influence act upon our behaviors. This was very apparent in the current study's findings. Influential factors were multifaceted, with interpersonal, intrapersonal, social, and environmental factors all

shaping PA participation. Moreover, influential factors were interactive. The environment regulated the sensory factors, the social factors sometimes offset the negative influence of the environmental factors, and so on. It is apparent from the current study that multilevel, highly individualized interventions are required to promote PA among autistic adults.

This study also demonstrated a process of PA participation that is cyclical in nature. Participants recalled a process of selecting activities, experimenting with activities, and reselecting activities throughout their lives. The transtheoretical model (TTM) (Prochaska & DiClemente, 1983) provides an obvious comparison. The role of the TTM's "decision-making balance" (Marshall & Biddle, 2001) was particularly evident in this current study's data. In the phases of "selection of PA" and "participation," participants continuously weighted the pros of PA participation (e.g. socialization, health benefits, positive sensory experiences) with the cons (e.g. negative social interactions, competitiveness, negative sensory experiences). As is delineated in the TTM, the choices made in continuing, relapsing, or modifying PA behaviors was shaped by this decision-making balance.

Uniquely, this model adds sensory factors as an integral part of the PA experience of autistic individuals that is interwoven throughout PA engagement. Previous articles that have discussed "theoretical frameworks of sensory consequence" (Tse et al., 2018, p. 1667) looked at movement as a product of the need for sensory feedback, or with authors promoting the use of PA to diminish stereotypical movements (Lang et al., 2010). This study identifies sensory factors as inherently embedded in the mechanism of engagement. Thus, through participation in PA experiences, sensory feedback within a PA and its setting can be both a barrier and a facilitator to engagement.

### *Limitations*

Several limitations of the current study should be noted. First, this study only included autistic adults who communicated verbally. Yet, research has estimated that 25%–30% of autistic children (Anderson et al., 2007; Lord et al., 2004; Norrelgen et al., 2014) do not develop functional language—to the authors' knowledge no estimations exist for adult populations—and those who communicate via means other than verbal communication are traditionally excluded. PA experiences of individuals who communicate in ways other than verbal communication may be different than the adults in the present sample; thus, limiting the transference of this model. Future research should consider how those who communicate by means other than verbal communication experience PA participation. Second, the frame of experiences, and thus the data that were collected, was limited to the questions posed by the researchers. Efforts were made to ensure questions captured broad experiences; however, there remains the possibility that certain aspects of the experiences of participation in PA are not included. Finally,



it is important to highlight that all the included participants were physically active (based on their own definition of PA) on a regular basis to some degree. The recruitment procedures and the nature of the study purpose may have attracted autistic individuals that had a greater interest in PA, ultimately, omitting those who engage in little to no PA. The experiences and views of autistic individuals who engage in no PA or low levels of PA should be sought in future research.

## Conclusion

This grounded theory captures the PA experiences of 23 autistic adults through the analysis of their account of past and current experiences with PA. This model highlights the importance of building successful experiences for young children on the autism spectrum, so that they are more likely to continue PA into their adult life. Furthermore, it emphasizes the importance of creating noncompetitive, social experiences for individuals that offer flexibility in social engagement and accept the differences one might have in their social interaction. In addition, the PA experiences an autistic individual has can be positively or negatively influenced by other people in the environment and the sensory factors that exist therein. It also suggests that each experience is very specific to each individual and can vary from day to day, as PA does not happen in isolation of the rest of an individual's daily experiences. As a theory, this model needs further testing to understand how each area impacts an autistic individual's experience and persistence in certain activities. Through this model and continued research that includes hearing the authentic experiences of autistic adults, researchers and practitioners may be better equipped to provide recommendations for making PA more accessible and enjoyable.

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## Notes

1. The authors purposefully chose to use identity-first language in respect of the participants included in this study and in concordance with a plurality of autistic adults (Kenny et al., 2016).

2. It should be noted that the “social aspect” in this context does not require engagement with others; simply cohabiting the same space for recreation or participating in parallel activities created a sense of connection and motivation that many autistic adults in this study needed.

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