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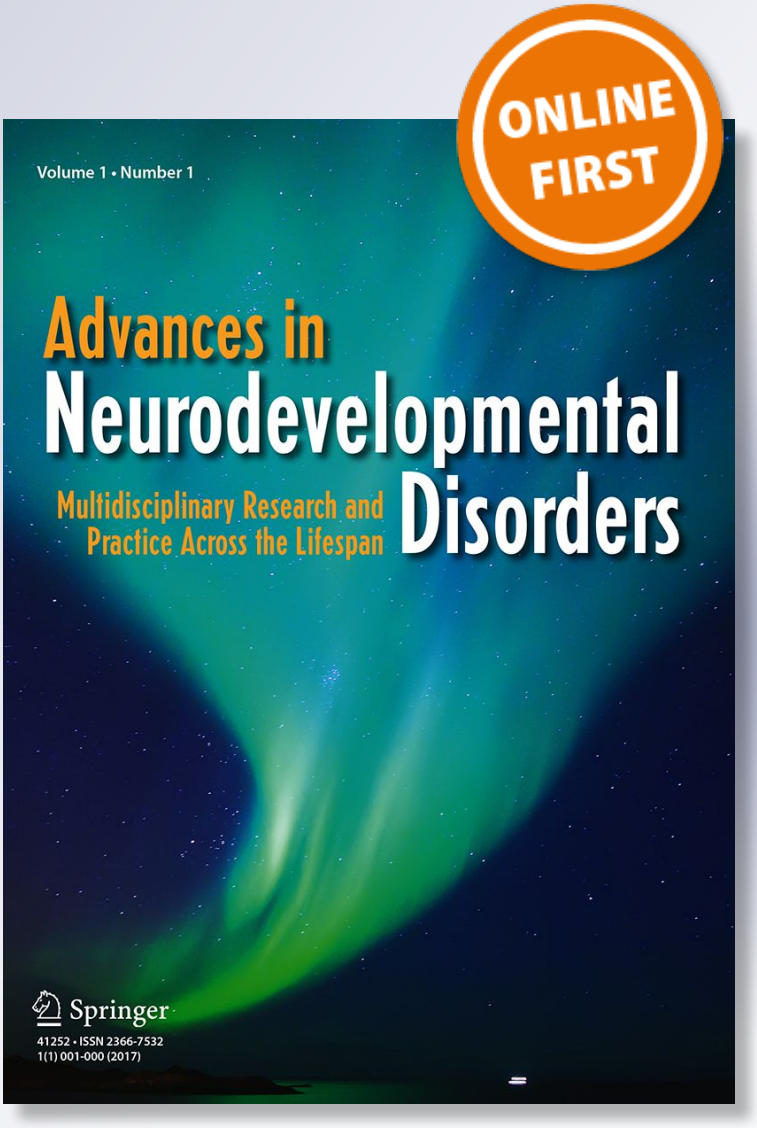
Advances in Neurodevelopmental Disorders
Multidisciplinary Research and Practice Across the Lifespan

ISSN 2366-7532

Adv Neurodev Disord
DOI 10.1007/s41252-018-0094-0



Springer

Advances in Neurodevelopmental Disorders
https://doi.org/10.1007/s41252-018-0094-0

ORIGINAL PAPER

Experiences Participating in Community Physical Activity by Families with a Child on the Autism Spectrum: a Phenomenological Inquiry

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Abstract

Objectives Families with a child on the autism spectrum face challenges to participating in physical activity in the community. Yet, little research has examined these families' experiences and perspectives on such participation.

Methods This phenomenological study used semistructured interviews to collect data from 13 families with a child on the autism spectrum to understand their experiences as a family attempting to access physical activity opportunities.

Results Families discussed four overall themes related to participating in physical activity in the community: (1) safety outside the home, (2) lack of acceptance, (3) behavior affecting the family participation, (4) and limited opportunity for activity.

Conclusions Evidence suggests that physical activity can provide tremendous opportunities to build better connections within the community and improve quality of life, but the barriers discussed by parents in the present study suggest that families and their children on the autism spectrum might not yet have the same opportunities for access or support.

Keywords Autism spectrum disorder · Physical activity · Family relationships · Environmental barriers · Accessibility

Autism spectrum disorder (ASD) continues to gain worldwide attention and is well documented as one of the most prevalent neurodevelopmental disorders in the USA (Fombonne 2009; Lyall et al. 2017; Matson and Kozlowski 2011). According to the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*), ASD is characterized by deficits in social communication and repetitive and restrictive behaviors present from birth (American Psychiatric Association [APA], 2013). The most recent prevalence reports from the Centers for Disease Control [CDC] (2018) estimate that 1 in 59 children in the USA is diagnosed with ASD.

Although a wealth of research has examined populations on the autism spectrum and various stakeholders, an area slow to gain the attention of the broader ASD research community is physical activity (PA). A growing body of literature continues to identify the health benefits of physical activity, and a small swath of that literature has shown that exercise is an evidence-based practice for individuals on the autism spectrum (Dillon et al. 2017; National Professional Development Center on Autism Spectrum Disorder [NPDC], 2015). Still, few studies have conclusively explored whether the benefits of PA apply to populations with ASD (Bremer et al. 2016; Lang et al. 2010; Sowa and Meulenbroek 2011) or whether barriers might exist to impede these populations' access to PA. Strong evidence exists on the determinants of PA among populations without a disability (Meyer et al. 2014), but few studies have focused on this issue for ASD populations (Ayvazoglu et al. 2015; Pan and Frey 2005). Of research that has included populations on the autism spectrum, the focus has been on activity levels (Stanish et al. 2017), beliefs about physical activity (Stanish et al. 2015), or patterns of participation MacDonald et al. 2011). Although individuals on the autism spectrum and their families might experience the same benefits of PA as most individuals, their lived environment creates unique facilitators and barriers to PA. Understanding these nuances will help policy makers, program managers, and frontline workers provide the most beneficial and successful services.

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Published online: 18 January 2019

The physical activity behaviors of families with a child on the autism spectrum are just starting to be explored. In a rare 2005 study, Pan and Frey (2005) found that age and sedentary behavior—not parent PA and support—were significant factors in the PA of youth on the autism spectrum. Their study also found a significant, negative association between sedentary behavior and overall PA—suggesting those who spent more time in sedentary behavior were less active than those involved in active, leisure pursuits—most likely due to limited opportunity (Pan and Frey 2005). Jones et al. (2017) identified several potential "ASD-specific" correlates related to PA, such as symptom severity, maladaptive behaviors, and psychotropic medication. Although substantial evidence is not yet available on these potential correlates, it is reasonable to assume that a child's behavior would affect her or his own PA level and, given the heterogeneity among children on the autism spectrum, it is likely that symptomology will have an impact.

Stanish et al. (2017) provided further evidence to suggest that adolescents on the autism spectrum spend higher amounts of time in sedentary behavior and less time in PA than do peers without a disability. The Stanish et al. (2015) interview data indicated that most participants on the autism spectrum enjoyed PA and recognized the benefits; however, they frequently expressed that they were too busy to do PA, that PA was boring, they feared getting hurt, or that it was too hot or cold to do PA. These findings provide insight into building programs to increase PA among individuals on the autism spectrum, as overall satisfaction and competence when participating in activities is important for an individual's mental health (Stacey et al. 2018); however, more empirical evidence is needed to understand the challenges, barriers, and potential facilitators of PA for individuals on the autism spectrum, particularly because of the great variance between individuals (Jones et al. 2017).

One important factor in understanding the facilitators and barriers to PA is the influence of family members, especially parents and siblings, as children are heavily reliant on these individuals for everyday activities. These internal and external influences can be explored using the socioecological model (Bronfenbrenner 1977). Used in previous studies to understand participation in physical activity by children with a disability (Blagrave 2017; Buchanan et al. 2017; Obrusnikova and Miccinello 2012) and in a research policy brief (Neumeier et al. 2017), this model identifies five barriers and facilitators to participation in activity: interpersonal, institutional, community, public policy, and physical environment. This model is unique because it focuses on the influence of factors at a variety of levels (Joseph et al. 2014) and was used in this study to explore influences on community physical activity for families with a child on the autism spectrum.

Using a socioecological model to examine the factors influencing afterschool PA, Obrusnikova and Miccinello (2012) identified several barriers and facilitators for children on the autism spectrum. Specifically, intrapersonal barriers, such as lack of motivation or interest and impaired attention, comprehension, and motor performance, and intrapersonal facilitators, such as enjoyment in PA, managerial strategies to promote PA, and maximizing success and achievement, were most commonly reported, as opposed to interpersonal or policy factors. Importantly, this evidence suggesting that potential social, motor, attention, behavioral deficits, and narrow interests might contribute the greatest to physical inactivity in children on the autism spectrum (Obrusnikova and Miccinello 2012). Though these findings may center too much on the parents' report, as the greatest interpersonal barrier reported was, "Parents do not have time or energy." Some parents did list the availability or lack of community programs as influencing the child's physical activity. The heavy focus on the intrapersonal behaviors demonstrates a potential hyperfocus on the child's behaviors and disregards the potential ability that an accessible program designed to meet individual needs can have on overcoming those behaviors.

In a mixed-method study, Ayvazoglu et al. (2015) gathered evidence from six families with a child on the autism spectrum; each child's PA was tracked through accelerometers, then each family was interviewed to understand the determinants and challenges of PA participation. Consistent with prior research, their study found that children on the autism spectrum were engaged in PA below the recommended amount and that most parents' levels were also low. However, the authors noticed a trend: As parents increased their PA levels, so did the children, although the relationship was only marginally significant (Ayvazoglu et al. 2015). The Ayvazoglu et al. findings also revealed several potential barriers to PA in children on the autism spectrum, including understanding PA, living with the child, and awareness in school and community settings. Regarding the first barrier, Ayvazoglu et al. suggested that social deficits might play a role in limiting the success in PA. Behaviors exhibited by the child, coupled with caretakers' attempts to "manage" those behaviors, limit the time available to engage in PA for all parties (Jones et al. 2017). Finally, the awareness in the school and community—or most directly, lack of acceptance in those settings—creates limited opportunities to engage in PA.

A small body of literature has discussed, besides barriers, the impacts that ASD has on the ability of a family to pursue leisure and physical activities. Family activity can be affected by the sensory needs of a child on the autism spectrum (Little et al. 2015) and has been shown to increase as children gain more independence (Haegele et al. 2017). These opportunities for activities are vitally important because, when barriers are reduced, PA provides an opportunity for tighter connections to family outside the nuclear unit and to the broader community (Ullrich-French et al. 2012). Family activities can also help improve motor abilities, which are tied to adaptive daily living skills (Schaaf et al. 2011; Travers et al. 2016) and may act as a

moderator of core autism symptoms (Fulceri et al. 2018). Further, evidence shows that families with children on the autism spectrum have lower reported quality of life (Lee et al. 2009) and that mothers experience higher levels of stress (Giallo et al. 2011), areas shown to benefit from regular PA engagement. Better understanding and improved support of increasing family PA might provide opportunities to increase quality of life and to improve health outcomes across the lifespan of this population.

Although the literature has established lower levels of PA for populations with ASD compared to peers without a disability, more information is needed to understand how to improve the activity levels of individuals with ASD. Given the increasing evidence of the benefits of PA for individuals on the autism spectrum and their family members, and given the emerging research on the barriers to PA faced by these families, this study explored parents' experiences participating in community PA with a child on the autism spectrum, to understand factors influencing participation.

Method

Participants

All research activities were approved by a university institutional review board. Purposive sampling was used to recruit parents from a similar geographic region who shared the experience of raising a child on the autism spectrum. Participants were recruited through emails sent to two local agencies who serve children on the autism spectrum. Interested families responded to the researchers by email or phone, and a follow-up phone call was held to (a) discuss the general overview of the study, (b) answer potential questions, and (c) schedule a day, time, and location for the interview. Participants were not included for this study if (1) there was more than one child on the autism spectrum in the family, (2) the child on the autism spectrum did not have a formal diagnosis, (3) at least one biological parent or legal guardian could not could not participate in the study, and (4) and the participant family could not meet in person for the interview. Parents designated the setting for the interview, and all participants had the interview in their home when their child on the autism spectrum was not present. Families were encouraged to have both parents available for the interview; yet, for a majority (70%) of the families, only one parent participated; of single parent interviews, eight were conducted with the mother-only and one was conducted with the father-only. Four families included both mother and father in the interview.

A total purposive sample of 13 families participated in this study; family characteristics are listed in Table 1. All families were headed by at least one biological parent. Eight (62%) of the families had a child on the autism spectrum in their teens (i.e., 13-16 years of age), and five (38%) families had a child under age 10 on the autism spectrum. Eleven (85%) families had more than one child in their family, although each family had only one child diagnosed on the autism spectrum. No siblings were considered at risk for ASD.

Table 1 Family characteristics

Family	Parent(s) participating	Age of child (years)	Number of siblings
F1	Mother	15	2
F2	Mother	15	1
F3	Mother	4	0
F4	Mother	13	1
F5	Father	7	1
F6	Mother and father	13	1
F7	Mother	9	3
F8	Mother and father	5	0
F9	Mother	13	1
F10	Mother and father	15	3
F11	Mother and father	15	1
F12	Mother	6	1
F13	Mother	16	1

Age of child = child applies to the child on the autism spectrum

The families in this study spanned a wide range of education and employment. All participants were over the age of 30. Education and employment information was collected for all participating parents in the interview. Ethnicity in this study was predominantly Caucasian ($n = 10$), with a few families who identified as Hispanic ($n = 2$) or mixed ($n = 1$) (Table 2).

Procedure

Limited research has examined the experiences of PA in community settings for families with a child on the autism spectrum. To understand the experiences of these families, a phenomenological approach was used. The aim of phenomenology is to understand the experience of participants within a phenomenon and the meaning that the participants' attribute to that experience (Lewis-Beck et al. 2003). Hermeneutic (interpreted by the researcher to gain insight into the experience) in approach, phenomenology is used to understand the perceptions of a participant's experience under a phenomenon and to reduce a phenomenon to its essence (Sparkes and Smith 2014). Phenomenology helps the researcher to understand what an experience is like and "differs from almost every other science in that it attempts to gain insightful descriptions of the way we experience the world pre-reflectively, without taxonomizing, classifying or abstracting it" (Van Manen 1990, p. 9). To capture the essence of the experience of community PA, semistructured interviews were conducted with the parent(s) of a child on the autism spectrum to collect

Table 2 Family demographics

Family	Income	Education	Employment	Age	Ethnicity	Marital status
F1	$30-49,999	CC	PT	< 40	Caucasian	Single
F2	> $90,000	BA	FT(f)/FT(m)	< 40	Caucasian	Married
F3	$30-49,999	Bachelors	Freelance/contract	30-39	Caucasian	Single
F4	> $90,000	CC	FT(f)/SH (m)	< 40	Caucasian	Married
F5	$30-49,000	AA/HS	FT(f)/FT(m)	30-39	Hispanic	Married
F6	> $90,000	Some college	FT(f)/FT(m)	30-39	Caucasian	Married
F7	> $90,000	BA	FT (f)/FT(m)	30-39	Caucasian	Married
F8	> $90,000	CC	FT(f)/SH(m)	30-39	Caucasian	Married
F9	$30-49,000	CC	SH	> 40	Mixed	Single
F10	> $90,000	MA/MA	FT(f)/FT(m)	> 40	Hispanic	Married
F11	> $90,000	MA	FT(f)/FT(m)	> 40	Caucasian	Married
F12	$50-69,000	MA/BA	FT(f)/SH(m)	30-39	Caucasian	Married
F13	$30-39,000	HS	SH	30-39	Caucasian	Single

CC community college, *BA* Bachelor of Art, *HS* high school, *AA* applied associates, *f* father, *m* mother, *PT* part-time, *FT* full-time, *SH* stay at home

information on the family's experiences. Each family completed one interview, and each interview lasted 30 to 40 min. The first author asked follow-up questions if a participant answered too briefly, helping to ensure that a depth of information was garnered from the interview.

Participants were interviewed in person, and interview questions were conducted in the same order for every family, with follow-up questions used to elicit more detailed responses when needed. Member-check meetings were held with five participants to ensure validity of the verbatim transcripts of the interview and to assess the trustworthiness that the themes derived from the data analysis were congruent with how the families perceived their experience.

Semistructured interviews are the most frequently used type of data collection method in qualitative research (Krogh and Lindsay 1999). As advised by Bevan (2014) and Smith et al. (2009), questions were broad, open-ended, and asked in the vocabulary of the respondent to ensure access; follow-up questions were asked to clarify or probe for further information when necessary. The aim of these questions was to gain a rich understanding of the experiences of these families and of the barriers they thought affected their family's participation in physical activity. The interview questions are provided in Table 3.

Data Analyses

Interviews were audio taped and transcribed verbatim for analysis. Data were hand coded by the first author using a first-cycle coding method, looking for exploratory categories as described by Miles et al. (2013). Thematic analysis (TA) was conducted following Braun and Clarke's (2006) linear approach: (a) familiarization with the data, (b) coding, (c) searching for themes, (d) reviewing themes, (e) defining and naming themes, and (f) writing up.

Frequencies of themes and subthemes are shown in Table 4. The first author identified subthemes and themes, and the second author reviewed these findings. Any differences in the interpretation were discussed and resolved.

Results

Families who had a child on the autism spectrum discussed their experiences regarding physical activity in the community. The following four themes to PA were identified: (1) safety outside of the home, (2) lack of acceptance, (3) behavior affecting the family participation, and (4) limited opportunity for activity.

Safety Outside of the Home

Safety outside the home was defined as anytime the family described an incident, situation, or environment they perceived as unsafe for their child and was a top concern across all the families in the current study. Many parents in the present study described the fear of their child running away or taking off and the constant need to be vigilant when out in public. Family 3 (F3) shared, "There's only certain parks we can go to because either the equipment is unsafe for him because he wants to try it . . . or he's an eloper so I have to go to parks that can contain him." Even families whose child was older at the time of the interview expressed concerns about wandering and elopement, indicating that the issue still caused anxiety: "He was a wanderer, and so there were serious issues in getting him to stay with us. So, there were just a lot of stressors attached to it" (F4).

Table 3 Interview schedule

1. We will be discussing physical activity within the context of your family unit throughout the following questions. Can you please tell me what the term "physical activity" or "being physically active" means to you?
2. Opposite to that is being sedentary or physically inactive. Can you please describe to us what that means to you as well?
3. Do you think that being physically active is important? If yes: why? If no: why not?
4. What types of activities, physically active or sedentary, do you like to participate in? The other members of your immediate family?
5. Would you describe the members of your family as mostly active or mostly sedentary? Please explain your choice.
6. Do any members of your family participate in organized sports or physical activities?
7. Do you have a gym membership? If yes: how frequently do you go to the gym? If no: do you have a desire to attend?
8. In regard to family physical activity time, what activities does your family engage in together?
9. What do you feel affects the type of activity you as a family engage in?
10. Do you feel that having a child with ASD affects the type of activities your family can engage in together? If yes: how so?
11. (If other sibling/s) Do you feel having a child with ASD affect the type of activity your other child/ren participate in?
12. What is your perception of your child with ASD's motor skills? (Must et al. 2015)
13 Does your child with ASD have siblings? If yes: how do you perceive their motor skills in relation to their sibling? Better? Worse? Please explain. (Must et al. 2015)
14. Are there physical activity experiences that you wish that your family participated in that they do not? If yes: what are those activities & why does your family not participate (time? Safety? transportation?) (Must et al. 2015)
15. Have physical activity experiences been mostly positive, mostly negative, or neutral throughout your life for you personally? Please explain your choice and give examples.
16. Have physical activity experiences been mostly positive, mostly negative, or neutral with your child with ASD? Please explain your choice and give examples.
17. When your family engages in physical activities, what is the usual level of vigor that you reach. For example, light sweat/slightly increased breath, medium sweat/increased breath, heavy sweat/rapid breathing.
18. As a family, do you feel as though you have adequate knowledge of ways to be physically active in this community? If no: what information do you feel is lacking? If yes: where do you mostly get this information?
19. Do you, as a parent, use physical activity as either a) a reward for performing an undesired task or b) punishment for not performing a requested action/behavior? For example: being allowed to go for a bike ride after completing nightly homework (reward) or being made to do push-ups if your child does not eat his dinner.
20. Does your family participate in physical activity with your extended family? Close friends? If yes: what types of activities do you perform with these groups? If no: can you explain why?
21. Is there anything else you would like to share with me/us about your experiences with physical activity?

Families also commented on the constant need to be on alert. F11 felt the need to "over plan everything" and "to see things from every angle." F9 reported,

> Wherever we are at, that's [safety] number one for me. Because having a child that might always, you know, see something or whatever—there he goes. I really do worry. So, I pretty much have to stick with him like glue.

F8 shared a similar sentiment:

> You have to pay attention at all times. So, I think the safety aspect of physical activity—it's different. So, you know, when you have a son or daughter that's 4 of 5 and they're typically developing, you can teach them things like snakes and dogs and things like that. All these things that I think people take for granted. Our child doesn't have the same built-in fear.

F5 shared a similar experience: "He's very—he's very tough. And I think sometimes he'll just push the limits a little further than he probably should."

Learning new skills in public is challenging, and families in this study expressed the special challenges they believed are specific to their families because of their child on the autism spectrum. F13 talked about the dangers associated with trying to ride a bike on trails in the park. In particular, although her son is capable and follows the park rules, if he sees someone else breaking the rules he has been trained to follow, it can be so overwhelming to him that it becomes a safety hazard for others. Other families echoed concerns with biking safety. F1 stated that their child on the autism spectrum "needs to be supervised because she doesn't pay attention. She just doesn't have the—she doesn't really have the physical ability to, like, stay balanced, pay attention. So, it really limits what we can do together physically." F12 also expressed concerns about biking: "We couldn't all go for a family bike ride, and know he would stay on the sidewalk and be safe." F10 shared biking safety issues as well. F6 shared a tactic that they have to employ to make biking safer for their child on the autism spectrum: "One of us has to walk because she can't be trusted in traffic. So, somebody is walking alongside with her. So even then it's not a full-on family activity. It's difficult."

One family (F7) described safety of physical activity differently. The family's response focused on the issue of safety, or perceived safety, when the child on the autism spectrum is interacting with typically developed (TD) children:

> We went to the gym. We went 3 or 4 days a week because it provided childcare, but then, when [our son] tried to attend on the first and second try, after the second time, they kicked him out because

Table 4 Occurrence of identified themes and subthemes

Theme	Subthemes	Statement of subthemes by family
Safety outside the home	Supervision Fatigue/overheating	F1, F2, F3, F4, F5, F6, F7, F8, F9,F10, F12, F13
	Staff training	
	Not good balance	
	Wanderer	
Lack of acceptance	Survival No judgment	F1, F3, F5, F6, F7, F8, F9, F12, F13
	Programs for ASD (wanting)	
	Better training for staff	
	Extended family acceptance	
	Meltdowns	
	Kicked out of programs	
Behavior affecting the family participation	Overly verbal High volume	F1, F2, F3, F4, F5, F6, F7, F8, F9, F12, F13
	Screaming	
	Hitting	
	Elopement	
	Waiting is hard	
	Meltdowns	
	Motivation	
Limited opportunity for activity	Only 1 day a week Short duration	F2, F3, F5, F6, F7, F8, F9, F10, F11, F12, F13
	Issues with daycare	
	Activities not considered outings as outings because of challenges	
	Crowded places	
	Challenges waiting/self-selecting out if waiting	
	Time and availability	
	Support staff not available	
	Parents not allowed to help	
	Availability of programs	
	Programs not a fit for ASD as they currently exist	
	Needing to rent the whole place to accommodate	
	Only for typical sibling	

> they said he was not safe. He fell on top of another child; they felt he was aggressive because of his autism. So, then we couldn't go to the gym anymore.

The issues described above were consistent across families regardless of the age of the child on the autism spectrum. The perceived barriers were just as much a concern for families who had a 5-year-old as they were for families with a young teenager. It is also important to note that this was consistent across families regardless of the severity of ASD symptoms.

Lack of Acceptance

Lack of acceptance was defined in this study as any time a family member identified feelings of being left out or judged by others. Families in this study described a general feeling of judgment from members in the community who do not have a child on the autism spectrum. Because of this perceived judgment, families would often go to gyms or public places at nonbusy times and avoid places where they thought their child might act out. Family 5 said,

> When you have a child with special needs and is very outspoken and will be very verbal to a higher volume, some people find it really annoying. So trying to find a gym where people aren't gonna—where you're not going to disrupt everyone and management isn't going to come and say something where it's going to offend the parents. So often we'll just self-select out of it.

F3 described an experience of judgment as well:

> We used to go to the mall and play there. And my son would do something and I'd have this group of moms judging me and not even knowing why and it wasn't even—it's not like he hit another kid or something like that. It's just like he might have screamed and thrown himself down. And so, the judgment that's out there, it's limiting. It's hard to want to jump in and play when you feel—when you have a judgment coming.

Families described a general longing for acceptance and wanting people to understand their experience. "You just want to have that feeling of like, getting it, rather than people staring at your kid when your kid's screaming in line" (F8). Families also said that acceptance in a setting (or hearing about it from another family) determined whether they would go to or return to a business or setting. "Depending on where we go or how people treat us while we're there is a huge factor in whether we'll go by or try right away" (F13). Family 9 has attempted to do a lot of activities in the community despite their son's challenges. When on a soccer team for TD children, she described her experience: "There wasn't a lot of support to have kids [like him] on the soccer team. I was like, why do I do this to him?" Echoing the experience of safety in the previous theme, the experience of acceptance and fear of meltdowns was shared across family experiences regardless of age and symptom severity.

Behavior Affecting the Family Participation

Behavior affecting the family participation was defined as any mention of a behavior by the child on the autism spectrum deviating from the social norm or disrupting an environment in a way that caused discomfort to the family or those involved. All parents reported that their child on the autism spectrum's behavior affected the type of activity that their family could participate in. This behavior could be related to sensory concerns or behavior challenges commonly associated with the autism spectrum, such as a need for sameness and routine (Miller et al. 2015) or problems with transition (Cheak-Zamora et al. 2015; Williams 2015). F5 described their experience with their child as:

> [affecting] everything. You have to consider everything, swings, animals—there is a lot that prevents us from going places and doing things that other families would just do on a normal basis. Just because . . . there's a large amount of screaming, and maybe if he's hitting his head or something . . . that may be something other people find alarming.

F6 shared similar behavior experiences. Their family discussed how they must manage going about visiting places and the amount of effort it takes to make an outing with the family successful.

> [It's] contingent on how she deals with it. Her safety and behaviors. To the extent that, when we go to an amusement park, we have her in a wheelchair because she could have a meltdown where we have to remove her and if we're at the back of an amusement park—having to carry a kicking, screaming, biting child out 2 miles just isn't going to work.

This behavior also dictates the amount of planning that goes into a family outing or the expectations before an event. F8 described their experience:

> It's definitely high stress. We're constantly just trying to keep him happy and in a calm place. And we really try to do everything a typical parent does. But it's a lot of work, and you know, sometimes you leave happy and sometimes you leave going, "My goodness! Why did we do that?" Trying to do typical things and then [it] just not, not working out—and it's overwhelming to him. And we think he should be interested in an animal at the zoo, but that's not what he's interested in. So, things like that can make it hard.

Waiting in lines is an event that can trigger behaviors as well (F7, F8). Families described the hardship and stress placed on the family when waiting in lines at the grocery store, amusement park, and waiting to take a turn in an athletic event with peers, such as baseball. The fear of this behavior happening in one of these settings is another barrier that will prevent families from participating in "normal" family functions and families described the need to "divide and conquer." Often, parents must split between the child on the autism spectrum and their sibling (F6, F7). Because they could not attend the gym with their child on the autism spectrum, F7 would have the parents take turns working out, while the other parent sat in the car with the kids. Other families commented on outings and behavior as well; for instance, F4 reported:

> It's really hard for us to get him out there, and then once we get out there we know we have to really restrict how far we go in so that we can make it back out without it being a negative experience for him and for all of us. So, we mentally have to gear up to do that.

Family 7 shared similar feelings when siblings want to go to the park and play, but the behavior of the child on the autism spectrum is impacting how long the family can stay: "He just wants to run away [at the park], and we end up chasing him and end up leaving, so it doesn't really work out a lot of the time." Finally, F3's experience summarized plainly many families inferred thoughts: "We don't go to places that have too many people; he doesn't do well in crowds." Although this theme is not a direct reflection of physical activity, the skills needed to participate in community PA are mentioned by parents repeatedly. For example, waiting in line, walking, and taking turns all require a minimal level of understanding and function. It could be argued, for some of these families, that basic day-to-day functions feel like physical activity and that the notion of participating in anything more structured would seem like a barrier to being active. To avoid potentially biasing the participants' responses, the researchers allowed the families to explore their experiences through their own definitions of physical activity (see Table 5).

Table 5 Family definition of physical activity

Family	Definitions
1	"Moving your body on a regular basis, daily basis for a minimum period of time. 30 minutes to an hour or whatever. Just being physically active."
2	"Any sort of movement. Whether it's walking the dogs, going on a hike, going to the gym, if you have a mall person walk in the mall, head to the city doing some street walking pretty much any movement I consider physical activity."
3	"Physical activity would be anything that is not sitting on the couch. So anything outside, anything that gets your heart rate up."
4	"Any type of movement that stimulates your brain and body."
5	"Playing, running, jumping. Any sort of I guess fast paced movement."
6	"Anything that gets you moving."
7	"Up and moving. Outside, being active, not sitting. At least that's what it means to me."
8	"Moving anything…usually outdoors. Anything where your gross motor skills are moving."
9	"Being in shape and being physically able to carry out your day. Not just sports or going to a gym, but being able to carry out your day."
10	"Getting out. Doing something consistent."
11	"Exercise, stress relief, enjoyment, fun things."
12	"A certain number of minutes that gets your heart rate up, it could be intense."
13	"To get exertion. To use energy."

Limited Opportunity for Activity

Limited opportunity for activity was defined as any mention of programs or experiences not fitting the child's needs and/or the family itself being a challenge to participation or causing the child to "opt out." Families who have a child without a developmental disability engage in PA more easily than families who have a child with a disability engage in leisure activity (Solish et al. 2010). Parents of children without disabilities report that their participation is associated with greater health-related quality-of-life outcomes (Vella et al. 2014). Although families in this study understood the importance of being physically active and desired to do this in a community setting, they reported many challenges attempted to engage in PA. Family 13 shared the lack of programs for her 16-year-old son and how often they, "have to go play at the gym when the toddlers are playing," because there not appropriate programs for his age group. However, families in this study frequently participated in more individualized activities with their immediate family in the community or activities that were sensory in nature in their home, as shown in Table 6.

Families frequently discussed issues around availability of programs as well as training of staff. These families often participated in programs that were specific to individuals with a disability and as such were offered within a larger program for the public in a limited amount of time. Examples were an aquatics program that only had one class per week for children with a disability and a gymnastics program that only had one slot per month. Also, families shared that, when they had to choose between allowing their TD child to participate in an activity or accommodating the child with autism, they

Table 6 Family activities

Family	Reported activities
1	Swimming, walks, dancing (at home to music)
2	Archery, swimming, walking dogs
3	Trampoline, walking in park, hiking
4	Swimming, walking outdoors, scooter
5	Trampoline, walking outdoors, swimming
6	Swimming, biking, fencing
7	Swimming, trampoline
8	Walking in park, swimming, trampoline, bike riding, ball play
9	Walking in park, ball play, tag
10	Horseback riding, taekwondo, swimming
11	Bike riding, swimming, gym, baseball
12	Swimming, walking, trampoline
13	Swimming, biking, hiking

frequently had to choose the latter, primarily because the child's behavior while waiting presented challenges. As described by Family 6, "Our daughter [not on the autism spectrum] wanted to do swim team. We researched it and decided we wouldn't do it because there is no way our other daughter [on the autism spectrum] could sit and observe by the pool and not get in. She wouldn't understand it. So, we didn't do swim team." Family 7 also reported discouraging their daughter [not on the autism spectrum] from swim team, "because it was one more thing on top of what our son [on the autism spectrum] needed, and he couldn't understand just sitting and watching." Additionally, staff often lacked the training or awareness to include the child on the autism spectrum in an activity with TD children or children with other disabilities. Even when their child on the autism spectrum could attend a session at a program, then the difficulty became "what to do with the TD child?" because there often was not a concurrently running program for the TD child to attend.

Although individuals on the autism spectrum are reported as being at higher risk for drowning than their TD counterparts (Committee on Injury, Violence, and Poison Prevention 2010), 11 of the 13 (92%) families in this study used swimming as a regular family activity. This activity frequently took place at the home of either the immediate family or close family friends. No families participating in this study reported participating in organized swimming. It is important to understand that, for the families in this study, even activities that were listed as team sports, such as baseball, were usually a home activity, such as playing catch or practicing pitching and hitting with a family member. All families expressed a desire to be more involved in PA with community groups but that, under current conditions, expanding beyond the reported activities (Table 6) would be too stressful or challenging. It is also important to note that, although the participants' communities offered organized sports for all of the ages—and that some of these programs, such as T-ball, aquatics, or adapted archery were specifically created for individuals with a disability—the families still found the barriers to participation too great to overcome.

Discussion

It is not enough to tell families who have a child with a disability that they need to be physically active; these families need to be—and to feel—supported (Galpin et al. 2017). The aim of the present study was to understand how parents of a child on the autism spectrum experience participation in community PA. The results add to the growing understanding of the potential barriers that families confront when attempting to be physically activity in their own community. An overarching theme in the findings was that families that have a child on the autism spectrum confront multiple barriers outside of their own control to participating in community PA, specifically, safety outside the home, lack of acceptance in the community, behavior affecting the family participation, and limited opportunity for activity. This general finding is consistent with extant research on families that have a child with a disability in general (e.g., Buchanan et al. 2017; Colombo-Dougovito 2017; Obrusnikova and Miccinello 2012) that have used the socioecological model to understand factors influencing participation in PA. While previous research has highlighted several areas that may facilitate or limit physical activity, multiple studies (Ayvazoglu et al. 2015; Jones et al. 2017; Obrusnikova and Miccinello 2012) center the issue around the behavior of the child as a predominant barrier. While one theme from this analysis was centered on the behavior of the child, uniquely, these results highlight other areas of concern, such as lack of acceptance or limited program, that play an equal or more significant role. In fact, many of the behavioral barriers discussed, such as limited turn-taking and elopement, can be counteracted by appropriate accommodations and understanding staff.

Finding Acceptance

Overall, the predominant struggles identified by families in this study appear to continue into adulthood for many individuals on the autism spectrum. A systematic review of social participation for adults on the autism spectrum (Tobin et al. 2014) identified limited access to social interaction and social experiences as themes for this population. If these families could receive support from the community to participate more in PA, they would not only receive the health benefits of exercise but also would likely strengthen their social relationships within the community. The latter is important because, among various other benefits, community connections are related to reduced stress, which has been shown to be particularly high in families (Brei et al. 2015; Galpin et al. 2017) and individuals on the autism spectrum (Simonoff et al. 2008).

Improved social connections and support might also help families find acceptance from—and feel more accepted by—community members, which may help to reduce the stigma of autism that families and individuals encounter, either implicitly or explicitly, in a variety of settings. Community support can facilitate the adjustment to a new, potentially more satisfying lifestyle (Stacey et al. 2018), with community activity leading to greater competence and continued participation, in addition to increased opportunity for social interaction and growth (MacDonald et al. 2013). Additionally, acceptance within the community might help abate other themes identified in the present analysis, such as safety concerns and limited opportunities for participation in community PA. Further, building acceptance and understanding of autism by those not directly impacted may allow for better programing development and

decisions, thus reducing the impact of any singular behavior on the family's PA engagement within community settings.

Finding a Pathway to Engagement

Physical activity has the potential to provide a pathway to community engagement and acceptance given the right support. Increasing opportunities for families to be active could help children form habits that carry over to later years (Haegele et al. 2017) and improve the likelihood of positive life satisfaction (Franke et al. 2018). Increased accessible opportunities could also limit some of the barriers faced by adults on the autism spectrum (Taliaferro and Hammond 2016), heighten engagement with community and other societal environments, such as school (Buchanan et al. 2017), as well as limit potential individual barriers, such as sensory issues. By creating strength-based supports and opportunities for activity for children on the autism spectrum, families will be less likely to feel socially isolated and have feelings of reluctance to engage in physical activity (Marggraff and Constantino 2018). Nichols et al. (2018) further demonstrate the positive impact of accessible opportunities on engagement in PA. Nichols et al. (2018) demonstrate that while accessible programs do not extinguish all the barriers faced by individuals on the autism spectrum, programs designed to meet the needs of individuals (such as Special Olympics) can help reduce overall impact of any individual behavior or sensory issue.

However, another finding of note in the present study was that, even when programs were designed for children with a disability, families of a child on the autism spectrum often stated that they were still "too much" for their children on the autism spectrum. This finding provides preliminary evidence of a need for purposeful, individual adaptations to programs for children on the autism spectrum, as opposed to homogeneous disability or, even, "autism friendly" environments. For example, parents in the present study reported that the water was too reflective for their child during the day, so they had to bring their child swimming at peak times (e.g., mornings or evenings), which led to longer wait times, a particular challenge for parents of children on the autism spectrum. The busier times also made it more difficult to obtain instruction and to receive attention from support staff who were trained specifically for children on the autism spectrum. Policy makers and program managers who are trying to make their programs more disability friendly would do well to add and even prioritize training for ASD because, too often, staff lack adequate training and knowledge to meet the needs of this population (Dillenburger et al. 2016).

Although certain behaviors of the child were identified as barriers to PA for families, it is often the lack of trained staff or access to opportunities that amplify potentially problematic behaviors. Despite its newness as a topic area in the literature, exercise is continuing to emerge as a positive program and intervention tool to encourage PA (Dillon et al. 2017) and may provide a great amount of benefit (Healy et al. 2018) for individuals on the autism spectrum and their families. However, simply knowing the benefit of PA and the importance of engaging in PA is not enough for families to access these benefits and, ultimately, it is not enough to have programs that are listed as disability or "autism friendly," yet are implemented without the input from families or individuals on the autism spectrum. Families and individuals on the autism spectrum must be included by program directors, managers, and staff in the development process because, despite the often unique needs of children on the autism spectrum, accessibility is often the biggest hurdle to engagement. Systematic modifications, including feedback from all stakeholders, are needed to ensure that the environment is friendly and accessible for families and their child on the autism spectrum. Without reducing the barriers for access, families will continue to struggle to access community physical activity regardless of frequency or severity of the behaviors of the child.

Limitations and Future Research

At the time of this writing, this study offers one of the few insights into what impacts community PA engagement for families that have a child on the autism spectrum. However, several limitations to this study should be noted. First, small sample sizes limit the generalizability of the findings to other populations. However, qualitative data are meant to be thick in description, and there are no concrete criteria to determine saturation other than the researchers' judgment. Measures were taken to ensure saturation to the best of the researchers' ability, including follow-up questions, uninterrupted interview periods, and recruiting families until the same themes continued to reoccur with no new data being presented. Still, only one main interview was conducted for each family. This could have affected the type of information gathered by the researchers. To increase the opportunities to capture more detailed information from families, future researchers might find it advantageous to conduct multiple interviews over several sessions. Multiple data points would also avoid the burden of a long single interview and would allow the researchers to check for corroborative or contradictory information gained from previous responses.

Furthermore, the experiences of these families might capture a rather affluent perspective. The most recent statistics place the poverty line in California at $24,000 (Public Policy Institute of California 2017); however, all participants in this study were well above this line. These families, arguably, had more resources to access PA opportunities than their peers from socioeconomically disadvantaged backgrounds. Yet, despite their affluence, families in this study still faced issues of access and acceptance in the community. Future studies should aim to

capture the experiences of a wider range of families, with a focus on the experiences of families that face financial and other challenges that could impact their ability to participate in PA.

Another limitation to this study is the absence of a minority voice. Of all states in the USA, California has the third largest Hispanic population, at 39% (Governor's Budget Summary 2016). However, only 15% ($n = 2$) of the participants in the study were Hispanic and only 23% ($n = 3$) of the participants identified as not Caucasian. Evidence suggests that no significant racial variations exist in the prevalence of ASD (CDC, 2016), but minority populations are underrepresented in ASD research (Hilton et al. 2010; Thomas et al. 2007). Future studies should aim to capture the voices of minority and other underrepresented backgrounds because their experiences might reveal unique experiences, challenges, strengths, and solutions. This study also relied on the families to provide their own definition of physical activity, and the researchers never presented a definition to the families. This might have influenced the participants' interpretation of this key term might differ from the overriding perspectives in the professional community; potentially limiting comparison to previous literature. How physical activity is defined should be considered in future inquiries, as there may be a lack of congruence between the definitions of physical activity of families and the academic community.

A final limitation of this study is that families in this sample were from a rural community in Northern California, an area that offers ample opportunities for families to participate in outdoor activities, such as hiking, biking, and swimming. The weather is also mild, with a long season of outdoor recreational availability, with many lakes and rivers shaping part of the region's culture. Future studies should examine the experiences of families on the autism spectrum in more urban areas and compare this experience to their more rural counterparts. Also, preferences for activities can vary by culture, region, or both, and although the experiences of the families in this study might be true for their area, families in other parts of the country and the world are likely to have different experiences with community PA.

Barriers to family participation in PA identified in this study can be understood through the lens of the socioecological model. Safety in the community (physical environment), lack of acceptance (interpersonal), behavior affecting family participation (interpersonal), and limited opportunity (community) each layer on influences that can make accessing physical activity in a community setting more challenging. If families are facing barriers to participation when their child on the autism spectrum is young, and this child does not have the same opportunities for activity as their TD peers, these barriers may continue into adulthood. Further, the physical activity environment around the family has the potential to overcome individual barriers to activity. For example, a program that exists in the community—that is appropriately staffed and designed to include children on the autism spectrum that also provides opportunities for TD siblings—has the potential to overcome any behavior individually demonstrated by the child on the autism spectrum. By increasing the understanding of barriers, policy makers, program managers, and frontline workers might be able to begin to improve inclusion in physical activity within community settings at an earlier age, thus creating opportunities for families and individuals to establish patterns that may continue into adulthood, allowing individuals to lead potentially healthier, more active, and independent lives.

Author Contributions AJB led the design and execution of the present study, as well as performed the initial data analysis; she collaborated in writing the paper and editing the final manuscript. AMCD collaborated in the design and analysis of the study; he collaborated in the writing of the paper and editing the final manuscript.

Compliance with Ethical Standards

Conflict of interest The authors have no conflicts of interest to declare.

Ethics Statement Chico, California State University provided the IRB approval for the study; this study has been performed in accordance with these ethical standards. All participants gave their informed consent prior to their inclusion in the study.

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