

PARENT PERCEPTIONS OF BARRIERS TO PHYSICAL ACTIVITY FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS

Walaa Khader^a, Aysel Pehlivan^b

^{a,b} *Institute of Sport, Physical Education and Health Sciences, University of Marmara*

Email: walaa_khader@hotmail.com

Abstract

Introduction: Children with Autism Spectrum Disorders (ASD) engage in less physical activity (PA) compared to their typically developing peers. **Purpose:** Our aim was to explore the barriers to participation in physical activity for this group. **Methods:** The method applied in this study was qualitative in nature and the phenomenological approach was used. Data was collected by interviewing. "Purposeful sampling" method and "Criterion sampling" strategy were used. In this study, 15 parents from Jordan with identified criteria were selected and face to face interviews with open-ended questions were asked. "Descriptive analysis" and "content analysis" methods were used to analyze data. According to the **results**, 4 main themes emerged from data: 1. "Community" 2. "Institutional" with 3 sub themes: a. Specialization (coaches and centers), b. certified programs, c. cost; 3. "Environmental", 4. "Family involvement".

Key Words: AUTISM SPECTRUM DISORDER, PHYSICAL ACTIVITY, BARRIERS

1. INTRODUCTION

Physical activity [PA] has been widely researched and numerous benefits have been reported (Canadian Diabetes Association, n.d.,2007; Health Canada, 2004; Jakicic & Otto, 2006; Warburton, Nicol & Bredin, 2006). Regular physical activity is linked to enhanced health and reduced risk for the development of several diseases such as heart disease, stroke, and type II diabetes (Sallis, Prochaska, & Taylor, 2000; Schomer & Drake, 2001; Warburton et al., 2006).

Also it has reported that engaging in regular [PA] improve general emotional well-being (Penedo & Dahn, 2005), mood (McPhail, 2006), and social skills (Terre & Drabman, 1992). These benefits are enjoyed by people of all ages who engage in regular [PA] (Pangrazi, Beighle, Vehige & Vack, 2003). Several retrospective studies have shown that participation in competitive sports in youth increases the likelihood that the individual will remain active in his or her adult years (Perkins, Jacobs, Barber & Eccles, 2004).

Therefore, educating children at an early age about the benefits of being physically active may help to reduce or prevent the tracking of physical inactivity into adulthood. Children with intellectual disabilities, including those with developmental disorders, are at greater risk for inactivity and the health risks associated with a sedentary lifestyle than typically developing children (Pitetti, Rimmer & Fernhal, 1993). Children with autism may have some degree of intellectual disability (Reid & Collier, 2002), as well as difficulty with motor performance (Baranek, 2002; Klin & Volkmar, 1995; Peeters & Gillberg, 1999; Reid & Collier, 2002) placing them in this high risk category.

Autism Spectrum Disorders [ASD] represent a spectrum of conditions with deficits in social interaction, communication, restricted interests and repetitive behavior (WHO, 2006). Autism is one of the most common diagnoses on the Autism Spectrum (Reid and Collier, 2002) and is typically diagnosed in early childhood, usually within the first three years of life (Hewetson, 2002). Children with [ASD] may be at risk for being physically inactive because characteristics of the disability interfere with successful participation in traditional forms of physical activity. It has been suggested that an understanding of potential barriers and facilitators that affect participation by people with disabilities could provide important information necessary for developing interventions that have a greater likelihood of success (Dunn, Andersen, Jackicic, 1998; Humpel, Owen, Leslie, 2002).

Unfortunately, published literature on barriers and facilitators associated with participation in physical activity among people with disabilities is limited (King et al, 2002; Meyers et al, 2002; Rimmer, Rubin, Braddock, 2000). In addition little is known about the types of [PA] in which children with [ASD] participate, and there is no literature reporting on specific barriers to [PA] opportunities in children with [ASD].

The aim of current study was to explore the barriers of PA for children with ASD, as reported by their parents.

2. METHOD :

Study Design

The method applied in this study was qualitative in nature and the phenomenological approach was used. The data was collected by interviewing. “Purposeful sampling” method and “Criterion sampling” strategy were used.

Participants

Face to face semi structured non-depth interviews were conducted with 15 parents of a child between the ages of 6-12 years from Amman (Jordan) , diagnosed with [ASD]. The focus of this study was on children with ASD whose characteristics are fairly consistent and not in a state of rapid change during early childhood.

Procedure

After study had received ethical approval from the Marmara University Committee, each parent participant in this study in both was interviewed face to face by the researcher, each interview was voice recorded and transcribed. Each participant was interviewed once; as well the interviews were conducted in locations and times that suited the participants. The length of each interview was approximately 40 minutes. The interviewers encouraged free and open responses and did not follow a rigid interview sequence.

Data Analysis

The data was coded according to the themes and descriptive analysis and content analysis were used as qualitative analysis methods in order to analyze and to interpret data. The obtained data was summarized and coded independently and patterns were established.

Result

Barriers were grouped under four general interrelated themes emerged from data: 1) Community, 2) Institutional with 3 sub themes: a. Specialization (coaches and centers), b. certified programs, c. cost; 3) Environmental, 4) family involvement.

Community

Although most of the parents felt that people’s attitudes toward individuals with ASD have improved over the years, some mothers described individual prejudice and negative societal attitudes from people in the community towards ASD children as a barrier to participation in PA. These prejudices and discriminations came from strangers in the street, other sport and recreation program participants, and participant’s parents.

Parents described how the parents of typical children could be openly negative about their child playing with a child with ASD.

“A few mums have said to me “oh my son or my daughter is picking up bad habits from your son”.”

This social prejudice could be attributed, in part, to a lack of knowledge and understanding of individuals with ASD that was depicted in this statement:

“They [parents of normal children] do not want their children to have too much contact with these kids [her son] despite not seeing him.”

Institutional

Institutions which we are talking about are schools for special needs, integrated schools, community institutions, ASD centers and sports clubs. The institutional barrier and facilitator identified by parents were grouped under three sub-themes. (fig.1)

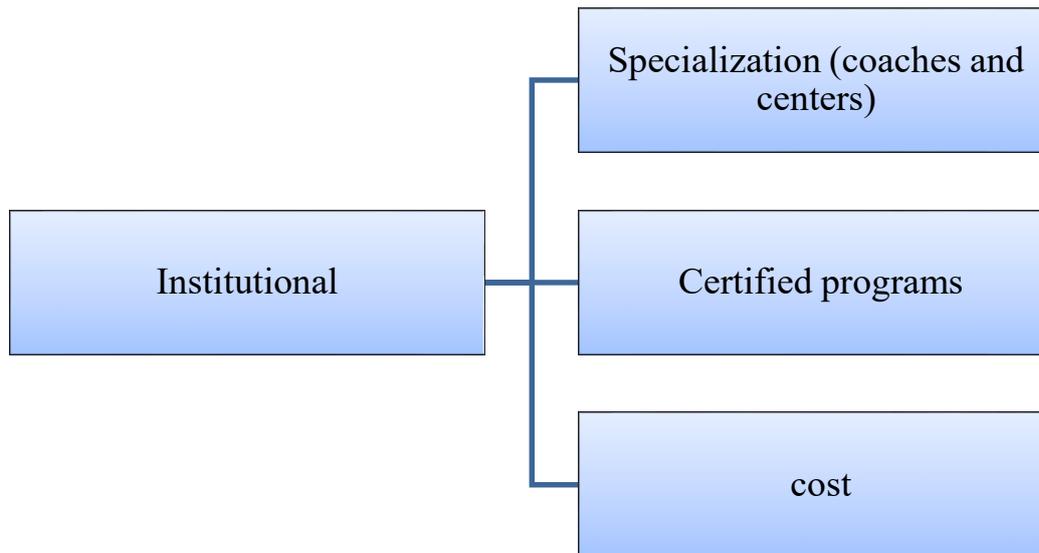


Fig.1: Institutional sub-themes

Specialization (coaches and centers)

Almost all parents were complaining about the lack of the devoted centers for the training of the children with special needs in general and for children with ASD in particular. They tried hard to find institution that would accept their children to participate in some kind of sport, some of the statements of the parents on this subject are as follows:

“I noticed agility and consistency in my child’s moves, and his love to roll forward and backward. I felt that his moves are more like the gymnastics moves. That is why I wanted him to train for gymnastics, but when I searched, I could not find any center or club who would accept my child.”

“... When he sees a basketball game on TV, he sits and watches with intense attention, and he gets excited when the players throw the ball and score. I wanted him to translate his tendencies into playing, but I did not find an adequate place for him to learn this game...”

Moreover, parents complained from the lack of sports coaches who are able to train ASD children since several institutions frequented by ASD children to get the qualification in different areas, either schools, ASD center or societal institutions does not have qualified workers to train children on different sports and physical activities.

“I wished I could find a club that would train my child to swim... I searched a lot to find a personal trainer, but I could not find any so far.”

“The reason why the sports clubs always refuse to accept my child is because they lack trainers qualified to deal with ASD children”.

Some Parents talked about the incapability of many concerned institutions to serve children with special needs generally, and ASD children specifically, and that appears obvious from what one parent has said about one of the inclusion schools his son goes to:

“For our children (ASD), the Gym represents a scary place, it has much sound and noise and has high lighting, and I think that all the environment in the Gym needs adjustment to meet the needs of our children.”

Certified programs

The certified programs in the institutions act as a barrier against the child’s ability to attain optimal levels PA where some parents report that their children do not receive physical education that accommodates their needs at integrated schools. That is depicted in this statement:

“Special education teachers could not give physical education for children with autism in my son’s school.”

My son’s teacher at school told me that the activities in the physical education class are limited to footing in the outside court, and jumping on the trampoline.

A number of parents complained about the lack of physical activity programs in ASD centers and/or about the quality and quantity of PA, where three parents reported that ASD centers which their children attend do not provide PA programs, while the rest of the parents reported that the average time allocated for PA at special needs schools does not often exceed 40 minutes. Besides that, most of them were not systematic.

Also few parents in stated that the Special Needs schools their children go to adopted a program for swimming twice per week, where they rent a pool outside the school since theirs was not ready. Despite the big positive effect on the children, as the parents

explained, this activity did not last for a long period due to the poor coordination and the lack of coaches and the non-readiness of the pool in winter.

I should state that a number of parents said that the existence of the sports education class in the institutions their children frequent plays an important role in increasing their physical activity level, and without their presence, no PA would be available for the children to do when they go home.

3.2.3 Cost

"It comes down to affordability" was a key consideration for families and sports. While cost represents a barrier to the participation in physical activity that affects children with ASD, there was an additional burden for families of a child with ASD given the extra expense of caring for a child with ASD, a reduced income as parents often worked less and the need for one-on-one attention.

"I'd put my son in half a dozen activities...., but by the time you pay for speech therapy, behavior modification programs (...) there's not a lot of money left over."

Parents also talked about the transportation cost and the higher wages for ASD sport coaches compared to whose coaching normal children.

"Center [gymnastics] is too far from my house... I cannot pay a lot for the transportation, in addition, the training costs already high."

"Personal trainer [swimming] takes a lot of money..... I reduced the days of training."

Family involvements

The family plays a big and essential role in easing or hardening their ASD children's participation in physical activity, and that is what many parents who were interviewed confirmed. Many of parents explained the lack of time, energy and patience to support their ASD children in the physical activity, and that appears clear in the following :

Firstly: ASD children need a lot of attention and care from the parents, especially if they belong to the full-time working category or have other in-house responsibilities, for example:

"He likes riding the bicycle in front of the house, and he needs me around him, but most of the time I am busy preparing food"

Secondly: The most of providing transportation to the physical activity programs might be difficult for many parents, and most of the time, the main reason the child does not join some activity is because no one could pick him to the training place, like:

"My husband and I work, and when we go back from work, I am busy preparing food then helping my children with their homework, and we do not find time to pick (...) to the club."

Thirdly: Parents should adapt with the lack of incentives and the opportunities of success in their ASD children's physical activity, which could cause frustration to some parents, and therefore avoiding subscription in the physical activity as it appears in what a parent said:

"I found it hard for my ASD child to practice any physical activity, when I compare him to his ordinary siblings, I notice a big difference."

Fourthly: Parents bear the burden of searching for coaches, programs and physical activities that suit their ASD children, and that consumes a lot of time and effort.

Environmental

Number of parents complained about the lack of parks and this affects physical activities which can be practiced by the normal child generally and the ASD child particularly.

Also the residence of the family in small flats has a role in decreasing the move and activity of the child as some parents cited.

"Playing football at school decreased his excessive activity inside the house, which hardly has a room for our movement, imagine the case for a child with excessive activity."

3. DISCUSSION

Certified programs

It is known, according to the theoretical literature, that every ASD child is a special case and does not resemble other ASD children (Cooper, Heron and Heward, 1987; Lord and McGee, 2001). This apparently acts as a barrier in the selection of different physical activities for most parents in this study because that the specific characteristics of each child were the most influential in the choice of physical activities. It was clear through the parents' responses in interviews that what fits child autism is not necessary to fit another child, for example, one mother said that football is the ideal sport for her son which develops his social skills, while another parent illustrated that football did not succeed with her child: "he was unable to acclimate to the team environment, and it was very difficult for him to follow the rules of the game as they require a lot of coordination". This shows that (one size doesn't fit all), concerning the planning approach for PA for children with ASD.

So the responsible for the PA programs need to recognize that ASD children may have a range of challenges that make their involvement difficult, and be prepared to make these programs flexible and adjustable as necessary and these are often poor motor skills, low motivation (Koegel, Koegel and McNeerney, 2001; Reid, O'Connor and Lloyd, 2003) and the difficulty in planning and

generalization (Ozonoff, Strayer, McMahon and Filloux, 1994; Renner, Klinger and Klinger, 2000). In addition, all the fathers in the study pointed to the lack of adequate programs, separate or integrated in the institutions to provide the necessary support to meet the special needs of their ASD children (Dwyer, Needham, Simpson and Heeney, 2008; Reid, 2005).

Coaches:

The barrier that almost all parents complained about is the lack of trainers who are able to provide PA services for ASD children, where results showed that there is need these classes of trainers. Perhaps the work done by the University of Hong Kong to add a new academic department in 2005 which is specializes in training staff providing PA services to people with special needs such as sport leaders and coaches is an example that can be applied in Universities. Trainers working with children with autism should be able to understand and grasp the needs of ASD children. The ability of the coach to determine those needs, allowing him to focus on the strengths and weaknesses of each child and that therefore lead to improved skill level and understanding of the sport and, more importantly, enable the trainer to provide a supportive environment for the child to participate in the PA (Yanardag, Yilmaz and Aras, 2010). Fennick and Royle (2003) stated, "Training of activity coaches needs to become a lengthier process to establish trust with families and to acquire more extensive information about individual children" (p. 25). The training can include the training of trainers on topics such as understanding the causes and effects of autism, behavior and tendencies of children with ASD, barriers that could affect the participation of children with ASD as well as the practical training with children (Autism Speaks, 2013)

Cost :

The family choice of PA for the ASD child is affected by the cost (Brockman ,Jago ,Fox, Thompson , Cartwright , Page, 2009). Where many parents reported that physical limitations constituted a major impediment to the participation of children in the PA ,therefore it was noticeable that almost all children in the sample were involved in low-cost or even free physical activities , especially that the families of ASD children usually have other costs of interventions or other therapies which ,if compared to the cost of PA are very high.

Family involvements:

It seems that in the present study ,parents need to practice PA and set aside time to explore different PA opportunities possible for their ASD child to participate in (Brusted, 1993; Sallies, Prochaska, Taylor, 2000). Research has also shown that the preliminary upbringing received by children with special needs by parents pose a substantial effect on the child's behavior regarding the PA (Levinos and Reid.,1991) while the data concerning the influence of parents on PA are different or mixed (Sallis at al., 2000) but there is convincing evidence that parent's support has a clear and significant impact on the child's PA where the children who get family support and encouragement have high levels of physical activity (Davison, 2004; Welk, Wood and Morss, 2003; Smith, 2005; Trost, Sallis, Pate, Freedson, Taylor and Dowda, 2003) .This is consistent with the results of the current study.

Environment

Parents complained about the lack of such parks and gardens ,which limits the movement of children and represents an obstacle in participating in various PA ,especially if the family lives in a small size apartment .This makes such parks and playgrounds a pressing need and this is consistent with the findings of (Burton and Davis, 1996; Davis and Burton, 1991; Davis and Van Emmerk, 1995).

4. CONCLUSION

As the long-term consequences of PA can lead to serious secondary health problems among children with ASD, understanding the factors that influence participation in PA is important to help design successful interventions and strategies that increase their level of engagement in activity from an early age.

Activity selection for children with ASD appears to be individually-based and dependent on each child's unique characteristics, needs, preferences and goals. One common theme repeats throughout: ASD represents a spectrum of abilities, needs and preferences and therefore necessitates a spectrum of possibility with regard to PA. What fits autism child is not necessary to fit another, the ideal form of PA for a child with ASD is that which works best for that child.

Parents have to overcome barriers caused by the characteristics of their child's disability, such as motor, social, attention, and behavioral deficits, as well as a lack of resources or PA programs that will accommodate the unique needs of children with ASD. Attention also needs to be paid to barriers related to peers and parent support. Although some outdoor play environments offer important PA opportunities for children with ASD, they are not always affordable and safe.

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