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## **Navigator Role for Promoting Adaptive Sports and Recreation Participation in Individuals with Disabilities**

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# Navigator Role for Promoting Adaptive Sports and Recreation Participation in Individuals with Disabilities

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## Abstract

### Objective

The aims of the study were to gain a better understanding of the resources, barriers, and facilitators of participation in adaptive sport and recreational activities as a means of achieving physical activity recommendations in individuals with disability and to understand preferences for a patient navigator service to help mitigate the barriers.

### Design

Clinical, academic, and community stakeholders applied a community-engaged research approach to develop online surveys and focus group questions for adults with a disability or parents of a child with a disability to meet study objectives.

### Results

One hundred ninety-eight adults and 146 parents completed the online surveys. Sixteen adults and 18 parents took part in focus groups. Many participants lacked knowledge of available adaptive sport and recreational resources; other barriers were expense, limited number of trained volunteers, and need for instruction. Conversely, persons were facilitated by community, socialization, and words of encouragement/motivation. Participants strongly preferred a patient navigator to be a person active in adaptive sport and recreational or an informative resource-filled website.

### Conclusions

Our findings suggest that physical activity programs including adaptive sport and recreational should be designed to offer people with disabilities opportunities to build social networks and strengthen social support. A patient navigator service could help increase participation in adaptive sport and recreational and physical activity within a community context.

## What Is Known

- Individuals with disabilities experience serious, preventable health disparities and are less likely to be physically active than people without disabilities. Multiple barriers have been reported including lack of social support, negative societal attitudes about disability, low awareness among health and fitness professionals, physical access and transportation

barriers, and poverty. Despite acknowledgment of these barriers, there remain significant gaps to effective action to increase PA among individuals with disabilities.

## What Is New

- Using navigator services provided by a person active in ASR and/or access to an informative ASR website were highly preferred to overcome barriers to participation.

People with disabilities are a large and crosscutting demographic group, making up more than 25% of the US population.<sup>1</sup> Adults with disabilities experience serious, preventable health disparities, including higher rates of obesity, chronic disease (eg, diabetes, cardiovascular disease), and premature mortality and are less likely to be physically active than people without disabilities, although most people with disabilities can engage in some type of physical activity (PA).<sup>2,3</sup> Fifty percent of adults with disabilities report no aerobic exercise at all (vs. 25% of adults without disabilities).<sup>2</sup> Among children and adults with disabilities, physical inactivity has been linked with obesity, preventable chronic conditions, increased pain and disability, poorer psychosocial outcomes (eg, lower self-esteem, social isolation), and loss of independence.<sup>2,4</sup>

Although physical activity is proven to have numerous health benefits for people with disabilities, making a change to their overall health and meeting physical activity recommendations can present extra levels of difficulty. Adaptive sports and recreation (ASR) offers an avenue to promote PA for persons with disabilities.<sup>3</sup> Adaptive sports and recreation refers to “any modification of a given sport or recreation activity to accommodate the varying ability levels of an individual with a disability.”<sup>5</sup> Adaptive sports and recreation, including wheelchair sports (eg, basketball, rugby, soccer), and recreational activities (eg, watersports such as swimming and kayaking),<sup>6</sup> can be either competitive or recreational, for children, adults, and families and for people with physical, intellectual, and/or emotional disabilities. Growing literature shows that participating in ASR programs not only increased the physical activity opportunities for adults and children with disabilities<sup>7</sup> but also can improve quality of life, mood,<sup>3,8</sup> community reintegration, and sense of community<sup>9</sup> in those with disabilities.

In addition to offering various opportunities for increasing PA such as ASR, it is also critical to understand and overcome barriers to participation. Promoting PA among people with disabilities requires consideration of complex, multilevel factors. Commonly reported barriers to PA for people with disabilities include lack of social support, negative societal attitudes about disability, low awareness among health and fitness professionals, physical access and transportation barriers, poverty, lack of cross-sector collaboration, poor enforcement of existing laws and policies (eg, Americans with Disabilities Act), and few data that can be used to advocate for change.<sup>10,11</sup>

Using a community engagement approach, one unique aspect of this study is to engage people with disability as stakeholders to understand their perceived barriers and the benefits/outcomes of PA or ASR.<sup>11</sup> Community engagement research approaches have been increasingly embraced by the disability community, as epitomized in the disability rights slogan “nothing about us without us.”<sup>12,13</sup> Based on patients’ perspectives and preferences, researchers would then develop community action strategies such as using patient navigator.<sup>14</sup>

Patient navigator, an individual who helps guide a patient through the healthcare system, can provide individualized assistance to overcome barriers to participation and connect patients with quality medical and psychosocial care or social services. Although patient navigation programs have primarily been implemented with cancer patients and underserved population including racial and ethnic minorities,<sup>15</sup> they have increasingly been used as a popular and low-cost way to reduce barriers to community participation and healthcare among individuals with disabilities. Examples include those with severe mental illness<sup>16,17</sup> and spinal cord injuries,<sup>18</sup> which extended health care into the community by using community-based navigators.

The purpose of this exploratory study was to understand (1) what people with disabilities view as the most important barriers, facilitators, and outcomes of ASR and (2) what type of patient navigator service they would prefer to mitigate participation barriers. Our approach was to engage the community involved to (1) develop a multidisciplinary research team of clinicians, therapists, researchers, and disability service providers and (2) use a mixed-methods design, answer the following specific research questions:

- What ASR opportunities currently exist in our region?
- What do people with disabilities see as the greatest barriers and facilitators to ASR?
- What outcomes of ASR are most important to people with disabilities?
- What type of navigator service would people with disabilities prefer?
- What tasks should a patient navigator perform?

Given the exploratory nature, we have no previous hypothesis for the findings. Findings will guide future studies to make recommendations to increase physical activity and ASR participation among children and adults with disabilities in similar environmental conditions.

## METHODS

This exploratory study aimed to build a formative understanding of group needs rather than have a single primary outcome of interest per se. The mixed-methods approach<sup>19,20</sup> used in this study integrated quantitative data (eg, an anonymous survey) and qualitative open-ended focus groups. The survey assessed barriers, facilitators, current participation, and preferences among adults who have a disability and parents of a child who has a disability. Focus group data further explored quantitative findings and provided context and personal experiences of individuals with disabilities. Both quantitative and qualitative data can provide validation for each other.<sup>21</sup> All study activities were approved by the institutional review board. Signed informed consent was obtained of all focus group participants.

### Developing a Diverse and Representative Study Team

This project used community-engaged research (CEnR) approach to identify themes regarding a patient navigator to assist patients with enhancing PA through participation in ASR. Community-engaged research occurs on a spectrum spanning five stages: outreach, consult, involve, collaborate, and shared leadership.<sup>22</sup> Our project best aligned with the consult stage in which community and academic partners share information and the community provides feedback.

As the consulting stage of CEnR, our project sought to build on the collaborations that had been developed in previous work<sup>6</sup> with a focus on poising the team to move to the next level of CEnR, “involve.” Adequate representation on the study team was critical to developing the research question, identifying methods that the target population would accept and be comfortable with, and create language for research materials that is clear and meaningful to the participant. In this project, our study team was composed of three different “stakeholders”: (1) community stakeholders including representatives from state or local agencies and community-based organizations that provide services to enhance the well-being of people with disabilities, adults with disabilities, and parents of a child with a disability; (2) academic researchers with expertise in exercise science and public health, respectively; and (3) clinicians who treat patients with disabilities.

Community stakeholders played an equally important role as researchers and clinicians during the whole process of the study. Led by the research team, community stakeholders received the 4-hr introduction orientation with other stakeholders (researchers and clinicians). All members completed bioethics certifications. Community stakeholders led the efforts in participants’ recruitment (eg, word-of-mouth recruitment, disseminated the survey link on their websites and newsletters and invite their clients to participate). Guided by the literature,<sup>23</sup> our engagement was “an engaged process” of actively soliciting the all stakeholders’ knowledge, experience, and expertise in the process of developing/refining survey questionnaires and focus group questions. The team met monthly, rotating meeting locations at the home institution of each representative to foster understanding of each team member’s role and access to resources.

## Survey

Survey questions were developed in collaboration with all team members. The 2008 Physical Activity Guidelines for Americans with disabilities were referenced for survey development. Guidelines state “adults with disabilities, who are able, should get at least 150 minutes per week of moderate-intensity, or 75 minutes per week of vigorous-intensity aerobic activity, or an equivalent”; “aerobic activity should be performed at least 10 minutes at a time, preferably spread throughout the week.” The research team chose to assess frequency of exercise participation of 10 mins or more rather than assess exercise intensity performance. The survey was accessible online through SurveyMonkey. The survey consisted of 20 questions to explore general physical activity and ASR participation.

Questionnaire included barriers (knowledge of opportunities, transportation, caregiver availability/participation), preferences for a patient navigator (type, location of service, preferred tasks), current participation levels, and important outcomes of participating in ASR and PA. The survey was designed for adults with disabilities and parents of a child with a disability.

Inclusion criteria were adults (18 yrs or older) with a disability (congenital or acquired) or parent of a child (younger than 18 yrs) with disability, be able to read, and speak English. It applied to both survey and focus group participants. Survey participants were recruited to anonymously complete the survey via a written letter of invitation from a clinician or community partner/investigator. In addition, cards with study information and a link to the survey were distributed throughout the community. The survey was administered from September 2015 to January 2016.

## Statistical Analysis

Likert scale responses were summarized with their relative frequencies. The distributions of responses were summarized by their means and standard deviations. Responses of the parents of a child with a disability to adults with a disability in barriers and preferences to participation were compared using unpaired independent *t* tests. We accepted a *P* value of 0.01 or less to account for multiple comparisons. These statistics were performed in SPSS Version 26 (IBM Corp, Armonk, NY).

## Focus Groups

Focus groups were administered between September 2015 and June 2016. Focus groups were used to build a formative understanding of the subjective experiences, motivations, and barrier/facilitators of adults with a disability and parents of children with a disability in the context of a phenomenological framework. Phenomenology is an approach to qualitative research that focuses on the commonality of a lived experience within a group in a specific situation. The fundamental goal of the approach is to arrive at a textual description of the nature of the particular phenomenon.<sup>24</sup> Under this framework, we were interested in participant's lived experience with physical activity in the community within the context of our questions.

Study team members collaborated to develop focus group questions centered on participation incentives, motivation, barriers, facilitators, and resources. Focus groups were held with two populations: (1) adults with a physical disability and (2) parents of a child with a disability. Focus group participants were recruited through clinic patients, community recruitment, and stakeholder networks. Participants in the focus groups may have also completed the anonymous survey, but this was not a requirement.

A trained member of the research team served as the moderator of each focus group comprising two groups of six and one group of four adults with a disability (16 total) and three groups of six parents of children with a disability (18 total). Another study team member acted as note taker. Focus groups were audio recorded and transcribed. A codebook was developed, as described by DeCuir-Gunby et al.,<sup>25</sup> by members of the study team before coding the transcripts, and included four a priori themes: (1) incentive: a desired outcome, goal, or result of participation; (2) motivation: willingness to overcome participation barriers to achieve an incentive; (3) barriers: circumstances or obstacles that limit the ability to participate or achieve an incentive; (4) facilitator: a person or thing that assists in helping achieve participation; and (5) resources: circumstance, person, thing, or opportunity that enables participation. The analysis was an iterative process involving constant comparison.<sup>26</sup> Trained research team members (MAI, RM, KZ) coded the transcripts independently using NVivo (NVivo 11; QSR International) qualitative data management software, and the study's principal investigator reviewed the coding. During the coding process, the research team held regularly scheduled consensus meetings during which codes were collapsed into themes.

## RESULTS

### Characteristics of Participants

One hundred forty-six parents of a child with a disability (parent survey) and 198 adults with a disability (adult survey) responded to the online survey. Parents completed the survey on behalf of their child, and the reported data are for that of the child, unless otherwise indicated. Demographic



information is described in Table 1. Eighty percent of the children and 83% of the adults were White. Children and adults were nearly equally distributed across the age categories. Binary sex ratio in the child group was 65/35% male/female compared with the equal sex distribution in the adult group. Of children, 37% were wheelchair users versus 18% in adults. Cognitive disability was the most frequently reported type for both the child and adult groups. Among disabilities that result in motor deficits, cerebral palsy and spina bifida were the most frequently reported disabilities in the child group, whereas spinal cord injury and multiple sclerosis were the most frequently reported disabilities in the adult group. Other disability was reported by 23% and 27% in the child and adult groups, respectively. Focus groups (total 34) included 16 adults (3 groups) with a disability and 18 parents of children with a disability (3 groups). We did not ask focus group participants demographic questions although some in the focus groups may have also completed the anonymous survey.

TABLE 1 - Characteristics of survey respondents

	Parents ( <i>n</i> = 146), <i>n</i> (%)	Adult ( <i>n</i> = 198), <i>n</i> (%)
Age		
3–9 yrs	39 (31.7)	—
10–13 yrs	45 (36.6)	—
14–17 yrs	39 (31.7)	—
Unknown/missing	23	—
18–34 yrs	—	65 (38.7)
35–54 yrs	—	56 (33.3)
55+ yrs	—	47 (28.0)
Unknown/missing	—	29
Sex		
Male	82 (64.6)	83 (50.0)
Female	45 (35.4)	83 (50.0)
Unknown/missing	19	31
Race/ethnicity		
White	102 (79.7)	139 (82.7)
Hispanic or Latino	11 (8.6)	5 (3.0)
Asian or Pacific Islander	5 (3.9)	4 (2.4)
Black or African	4 (3.1)	14 (8.3)
Multiple ethnicity	4 (3.1)	3 (1.8)
First Nation or Alaska Native	1 (0.8)	2 (1.2)
Other	1 (0.8)	1 (0.6)
Unknown/Missing	18	29
Wheelchair user		
Nonwheelchair user	74 (63.2)	82 (54.3)
Wheelchair user	43 (36.8)	69 (45.7)
Unknown/missing	29	46
Self-identified disability type		
Spinal cord injury	4 (2.7)	30 (15.2)
Traumatic brain injury	5 (3.4)	7 (3.6)
Amputee	0 (0)	9 (4.6)
Deaf or hard of hearing	3 (2.1)	7 (3.6)

Blind or visually impaired	5 (3.4)	10 (5.1)
Stroke	3 (2.1)	2 (1.0)
Cerebral palsy	21 (14.4)	9 (4.6)
Spina bifida	10 (6.8)	7 (3.6)
Multiple sclerosis	0 (0)	18 (9.1)
Autism	31 (21.2)	20 (10.2)
Cognitive disability	55 (37.7)	35 (17.8)
Emotion/behavioral disability	15 (10.3)	17 (8.6)
Other	23 (15.8)	27 (13.7)

Parents is parents of a child with a disability younger than 18 yrs who responded on behalf of their child. Adult is an adult with a disability. For self-identified disability type, respondents were able to select more than one diagnosis.

## Survey Findings

### *Adaptive Sports and Recreation—Opportunities and Participation*

Participants' awareness of ASR and participation in ASR and physical activity are shown in Table 2. Approximately 50% of adults with a disability (adults) reported being aware of 0–1 opportunity for ASR. Approximately the other half reported their acknowledgement of 2 or more ASR opportunities with 17.9% aware of more than 6. Similarly, approximately 45% of parents were aware of no more than one opportunity for ARS, although slightly more than half were aware of 2 or more; 6.9% were aware of greater than 6.

TABLE 2 - Participants' awareness of ASR and participation in ASR and physical activity

	<b>Parents (n = 148)</b>	<b>Adults (n = 197)</b>
Awareness of the number of opportunities to participate in ASR, %		
Do not know of any opportunity	20	28.2
1 opportunity	25.5	22.1
2–5 opportunities	47.6	31.8
6 or more opportunities	6.9	17.9
Frequency of participation in ASR, %		
Never	38.6	42.8
A few times a year	25.5	8.8
Monthly	8.3	9.3
Weekly	24.8	30.8
Daily	2.8	8.2
Frequency of participation in physical activity or exercise of 10 mins or more, %		
Never	4.1	10.3
1–2 times per week	40.7	34.9
3–4 times per week	26.2	29.7
>4 times per week	29	25.1

Parents is parents of a child with a disability younger than 18 yrs who responded on behalf of their child. Adult is an adult with a disability.

In terms of self-reported participation in ASR, only 8.2% of adults reported daily participation, although 30.8% reported weekly participation. Less than one fifth reported monthly to a few times per year participation in ASR (18.1%), whereas a large contingent (42.8%) reported never participate in ASR. This pattern for adults was mirrored in the parents with only 2.8% reporting that their child was active in ASR daily and 24.8% weekly. Approximately one third reported monthly to a few times a year participation, and 38.6% reported no participation at all. With regard to self-reported participation in physical activity or exercise of 10 mins or more, one tenth of adults reported never participated. The majority (89.7%) reported at least a weekly participation, ranging from 25.1% (more than 4 times per week) to 34.9% (1–2 times per week). Similarly, few parents (4.1%) reported that their children never participated, whereas 40.7% of parents report participation 1–2 times per week, and 55.2% more than 3 times per week.

Barriers to participation and task preferences for a patient navigator are described in Table 3. In general, barriers were reported as moderately serious or less for both groups. Nevertheless, “Lack of knowledge regarding ASR opportunities” was rated as the most serious barrier to participation by parents. In contrast, “Expense of activity equipment” was the most serious barrier for adults, and this was significantly different from the parents. Transportation was the one of the least significant barriers in both groups, although a greater barrier for adults.

TABLE 3 - Barriers to participation and preferences for a patient navigator

	Parents ( <i>n</i> = 146)	Adult ( <i>n</i> = 198)	
	Mean (SD)	Mean (SD)	<i>P</i>
	Barriers to participation		
Barriers (1 = no barrier, 4 = serious barrier)			
Lack of knowledge regarding opportunities	2.96 (1.09)	2.73 (1.10)	0.055
Need for instruction	2.46 (0.94)	2.68 (1.12)	0.048
Expense of activity equipment	2.38 (1.10)	2.92 (1.07)	<0.001*
Expense of the activity	2.37 (1.03)	2.64 (1.03)	0.017
Caregiver availability	2.24 (1.11)	2.18 (1.09)	0.618
Transportation	1.58 (0.88)	2.28 (1.17)	<0.001*
Navigator type preference (1 = least preferred, 3 = neutral, 5 = most preferred)	Preferences for a patient navigator		
An individual active in ASR	4.05 (0.86)	4.16 (0.94)	0.267
A website for information and resource	3.70 (1.08)	3.57 (1.38)	0.345
An individual with a healthcare background	3.49 (0.87)	3.46 (1.19)	0.796
An online community I can join as a member	3.38 (1.19)	3.18 (1.40)	0.164
A parent of a child with a disability	3.28 (0.87)	N/A	
An individual/peer with a disability	2.90 (0.85)	3.30 (1.09)	<0.001*
An App I can access on my mobile device	2.84 (1.30)	2.72 (1.44)	0.427
Navigator access (1 = least preferred, 3 = neutral, 5 = most preferred)			

Meet with service provider at the activity of interest	4.01 (1.04)	3.92 (1.19)	0.465
Access this service at my child's school	3.69 (1.19)	N/A	
Access this service through a website	3.59 (1.19)	3.35 (1.40)	0.095
Assess this service through an App on my mobile device	3.06 (1.26)	2.75 (1.44)	0.038
Meet with service provider at my regularly scheduled doctor visits	2.34 (1.31)	2.76 (1.42)	0.005*

Parents is parents of a child with a disability younger than 18 yrs who responded on behalf of their child. Adult is an adult with a disability.

\* $P \leq 0.01$ .

In terms of preferences for a patient navigator, both groups indicated “an individual who is active in adaptive sports and recreation” as the most preferred. Assessing a website as a resource was ranked second in preference also for both groups. However, accessing a navigation service through an app was the least preferred by both groups. “An individual/peer with a disability” was rated low by both groups although preference rated slightly higher by the adults with disability.

With respect to navigator access, both groups rated “Meet with service provider at the activity of interest” as the top choice. One of the least preferred ways to access a navigator was to meet at scheduled doctor visits, with a higher rating again in the adult group. Consistent with preferences was that assessing a navigator service through a mobile App was ranked lowest in both groups.

Table 4 listed top 5 most important health outcomes for participation in ASR for both groups. Both the parents and the adults group reported elements of socialization, physical function, and mental health as important outcomes.

TABLE 4 - Health outcomes for participation in ASR ranked in order of importance (top 5)

Rank	Parents	Adult
1	Build peer friendships	Improve fitness
2	Improve function for everyday tasks	Meet new people
3	Improve overall mental health	Improve function for everyday tasks
4	Improve fitness ability to participate in competitive sports	Improve overall mental health
5	Improve ability to participate in competitive sports	Weight loss

Parents is parents of a child with a disability younger than 18 yrs who responded on behalf of their child. Adult is an adult with a disability.

## Focus Group Findings

Five major themes emerged as common themes among focus groups with both adults with disabilities and parents of a child with disability. They include incentives, motivation, barriers, facilitators, and resources emerged in analysis of data from focus groups. Focus group findings further explored the quantitative findings and provided context and personal experiences of individuals with disabilities.

### *Incentive*

Adults with a disability cited participation incentives as maintaining function, getting stronger, social bonding, and connection with other individuals with a disability, improved mental health, and empowerment (Quotes “If I find somebody, even friends that are very critical or really down on me, I’m like, I do not need you in my life. I need happy uplifting people.”; “What makes me choose a sport is how much fun it is.”) Within the context of social connection, peer support and “learning tips and tricks” emerged as an important incentive (quotes “I think what really influences me is the bonding because... we all bond because of the MS. But I just wanna get better. And I know exercise is so powerful.”). The opportunity to “compete” and “being challenged” were important incentives among individuals whose primary participation was in team-based adaptive sports events (quotes “I participate in adaptive sports because I love it. I love to push my body to the limit. I love to compete.”). Parents emphasized the importance of community building as an incentive as well as health benefits but did not mention competition (Quote “The reason my son enjoys it, is cause he likes the team aspect of being like... exercise with other people).

### *Motivation*

Adults with a disability cited peer encouragement as a motivator to overcome participation barriers (Quote “... they [peers with a disability] encouraged me so strongly that I decided to come [to the fitness center] and I’m so glad.”). Parents cited the social aspects of participation as main motivation for them to encourage their child to participate (Quote “Being active in other sports is therapy also. It is fantastic socially.”).

### *Barriers*

Adults with a disability described that a lack of knowledgeable volunteers at community-based exercise facilities was a barrier to participating in ASR and strongly emphasized barriers in the built environment such as the need to navigate stairs, bathrooms, and parking (Quote “I do not know where I’m supposed to find a volunteer.”). Additional barriers included feeling fatigued or overwhelmed regarding trying to fit ASR into an already busy life, depression, and anxiety regarding having a disability, expense of activities (especially regarding ASR events where specialized wheelchairs are required), and managing interactions with able-bodied people. Parents of a child with a disability echoed that of adults with a disability but included differences in activities they thought were interesting versus activities their child was interested in as a barrier to participation.

### *Facilitators*

Adults with a disability reported that spaces that had easily accessible and usable environmental features (elevators, bathrooms, etc.) facilitated participation, having other individuals with disabilities in attendance, using “compassionate words” that advocated inclusive environments on an event or fitness center webpage, and having a physician that supported their participation. Parent’s said, “good, well-trained volunteers” as a significant facilitator, location of the event/facility, and “feeling welcome” as key facilitators to participation (Quotes “TRAINED staff ha ha right? Cause then like you say that um someone who knows how to deal with her behaviors. Someone who is trained and willing to work with them and understands where they are coming from and does not get frustrated or overwhelmed. And I think training is a big piece of that. If they do not have training, everybody loses.”).

## Resources

“... physician knowledgeable about adaptive sports and recreation or even just how to exercise with a disability...” was discussed as a key resource by adults with a disability, as well as understanding how to make and track goals to identify progress. Adaptive equipment (adaptive sports equipment such as specialty wheelchairs, and basic adaptive fitness equipment) was another key resource for adults with a disability and parents of a child with a disability. Established adaptive programs (ballet, soccer, softball) staffed by trained teachers/coaches emerged as a key resource among parents of a child with a disability.

## DISCUSSION

Using community engagement approach, this study engaged people with disability as stakeholders to explore their attitudes, participations, perceived barriers, and benefits/outcomes of PA and ASR in an upper Midwest/Great Lakes metropolitan area. Both adults with disabilities and parents of children with disabilities were included as stakeholders. In addition, we examined participants’ preferences for a patient navigator—a necessary and critical precedence to develop community action strategies.

The mixed design allowed us to compare and validate findings from quantitative surveys and qualitative focus groups. From the survey results, participants identified “build peer friendship or meet new people,” “improve fitness,” as well as “improve mental health” as their top 3 health outcomes for ASR participation. The quantitative data about their outcome expectations were supported by findings from the focus groups where both adults with a disability and parents with a disabled child cited the social aspects of participations (ie, build friendship, connect with others, social bounding) and improving mental health as primary incentives that motivate them for PA or ASR participations. Our findings were consistent with the literature that participation in ASR programs provided people with disabilities opportunities to build social networks, experience freedom and success, and feel a sense of normalcy when comparing themselves with others without disabilities.<sup>5</sup> Our findings suggest that physical activity programs including ASR should be designed to offer people with disabilities opportunities to build social networks and strengthen social support. These people-centered programs can also help individuals improve mental health.

Although as many as two of five adults with a disability and parents of a child with a disability reported that they (or their child) never participate in ASR, indicating a low participation rate in ASR, the rates for never participate in PA for >10 mins were higher among adults with a disability (10.3%) and parents of a child with a disability (4.1%). The differences may suggest that the population surveyed may not be active through organized ASR opportunities. Rather, they may be lightly to moderately active through shorter bouts of physical activity participations. This highlights the need for multiple approaches to promote physical activity both through ASR and other lifestyle PA strategies.

Although as health outcome expectations from surveys were largely supported by focus group results, there was evidence that the survey may have missed salient elements that discourage participation in PA or ASR in both parent and adult groups, for example, lack of knowledgeable volunteers. Nevertheless, activity expense including specialized equipment was highlighted in both the focus groups and survey responses. Program expenses should therefore always be considered in future program development. Survey questions were developed by content experts from the community

including people with disabilities. Despite content expert development, the survey used failed to capture the lived experiences of people with disabilities especially those of a personal or interpersonal nature, for example, fatigue, managing interactions with able-body people, or personal and child expectations.

A patient navigator service could help increase participation in ASR as well as other lifestyle PA within a community context. It was found that adults and parents strongly preferred a person who is active and knowledgeable in ASR as a patient navigator. Access to a website for information and resource was the second highest navigator preference for both groups. This finding was in stark contrast to an “app,” which was rated the least desirable. Although significant advancements have occurred in digital media, including apps, blogs, virtual spaces, and social networking, a low preference for an app serving as a patient navigator was noted in this study. Our result is interesting given previous work that highlights the importance of an app and technology to home-based PA among individuals with disabilities.<sup>27–</sup>

<sup>29</sup> This contrast in app preference may be attributed to differing cultural beliefs and values of the community for mobile technology compared with previous work, lack of accessibility due to physical limitations operating a mobile device, limited use of telecommunication support for apps, or lack of familiarity with an interactive app (eg, Bluetooth fitness trackers, virtual reality interactive technology).

The present findings should appropriately be interpreted within the context of limitations. First, study was limited by the near exclusively White participants. We are unclear whether our recruitment efforts did not reach a diverse population, whether persons decided not to participate, or both. Regardless, engaging participants of color from underserved communities is critical as this population can experience even greater than average disparities. In addition to racial biases, another selection bias is that not all persons with disabilities may have been represented, for example, rheumatoid or osteoarthritis, muscular dystrophies, etc. However, approximately 25% of our sample did identify with an “other” category with respect to disability type. Unfortunately, we do not know the representation of this “other” group. A third limitation is that this study did not engage the children themselves. Parents were targeted as they provide the primary support for children to participate, yet their perceptions could be different from that of their child. This was a concern also expressed by parents during focus groups. Engaging youth directly as partners is necessary to develop services that effectively meet their needs. Fourth, given the nature of our anonymous online survey offered through various channels, it is difficult to know who was invited to the survey and who was not. Lastly, although survey questions were developed by content experts, we did not assess psychometric properties of our survey tools. Subsequent outcomes research will make use of validated questionnaires to assess attitude or behavior change to a developed intervention.

## CONCLUSIONS

These study results reveal a desire for improved dissemination of physical activity and ASR resources. Enhancing knowledge of PA guidelines and available ASR opportunities within the provider community is a fundamental step in moving forward, combined with accurate and easy to use web-based resources. More research is needed to develop effective, hypothesis-based clinical intervention(s) to increase participation in PA for adults and children with disabilities. Future studies integrating a patient navigator as a person or a navigator system combined with strategies, which provide encouragement and motivation to participate in adaptive PA, leverage partnerships to increase the number of

experienced volunteers available for adaptive recreational programs or events, and target initiatives to build bidirectional communication and sustainable partnerships between patients, community stakeholders, and clinicians are potential tactics to promote greater physical activity participation in individuals with disabilities.

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