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Stakeholder Perspectives on Physical Activity in Youth with Developmental Disabilities: A Mixed Methods Study

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Abstract

We explored factors associated with physical activity (PA) engagement in youth with developmental disabilities (DD) as they transition out of school. We conducted focus group discussions with 44 youth, families, special educators, and therapists to obtain information on PA levels, barriers to being active, and recommendations to improve PA among youth. Youth preferred activities that are fun, not too challenging, non-competitive, and that promoted interactions with neurotypical peers. Families face the burden of sustaining PA in their adult children after school-age, and experience barriers related to accessibility and affordability of adult-oriented programs, availability of trained personnel, and challenges in balancing multiple work and family-related commitments. Our findings can inform the design of programs to promote PA among youth with DD.

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Youth with developmental disabilities (DD) are a growing underserved population with special healthcare needs (Rimmer et al., 2007; Roux et al., 2017; Zablotzky et al., 2019). In the US, over 1.3 million youth have a disability and the rate of disability increases with age (Erickson et al., 2020). In 2014, the proportion of the population with a disability was 1% in children under 5 years, 5.4% among ages 5-17, and 10.5% among ages 18-64 years (Kraus, 2016). Youth with DD are also more likely to be obese (Courtney-Long et al., 2015; Curtin et al., 2010; Grondhuis & Aman, 2014; Rimmer et al., 2007) and 3 times more likely to be sedentary than neurotypical peers (Lakowski & Long, 2011). A study by the World Health Organization suggested that in the US, in 2016, 72% of neurotypical youth between 11 and 17 years did not meet the recommended physical activity (PA) guidelines of 60 minutes/day (2018 Physical Activity Guidelines Advisory Committee, 2018; Guthold, Stevens, Riley, & Bull, 2020). Along similar lines, more than 80% of youth with disabilities do not meet PA guidelines (Stanish et al., 2023). With an increase in age, individuals with DD are more likely to be sedentary, with a progressive decline in PA levels (Phillips & Holland, 2011; Sung et al., 2022). Previous research has indicated that there are multiple factors at the individual (e.g., awareness about PA programs, motivation to exercise, beliefs regarding importance of PA, and ability level in terms of prerequisite motor, social, and cognitive skills required for PA participation) and environmental levels (e.g., availability of appropriate programs, space, equipment, and trained personnel, family attitudes towards PA, family schedules and finances, and availability of transportation) that contribute to lower levels of PA engagement among youth with DD (Shields & Synnot, 2016; Lakes et al., 2017; Nichols et al., 2018; Obrusnikova & Miccinello, 2012; Srinivasan, Pescatello, & Bhat, 2014; Temple, 2009; Tsai & Fung, 2009; Temple & Walkey, 2007; Frey et al., 2005; Heller et al., 2003; Menear, 2007; Yazdani, Yee, & Chung, 2013; Shields et al., 2012).

Low levels of PA and increased sedentary behaviors are associated with adverse physiological effects including greater risk for high cholesterol, high blood pressure, cardiovascular disease, Type II diabetes, and osteoporosis as well as negative psychological effects including lower quality of life and well-being (Bray & Kwan, 2006; Fowler et al., 2007; Martin et al., 2012; Onyewadume, 2006; Salaun & Berthouze- Aranda, 2012; Wallén et al., 2009). There is a clear need for programs to improve PA participation and inculcate active lifestyle habits among youth with DD, especially following their transition out of schools. However, a majority of past research has focused only on children with DD (Gorter, 2017; Healy et al., 2018; Rimmer et al., 2007; Shields, et al., 2012; Sowa & Meulenbroek, 2012; Srinivasan et al., 2014; Willis et al., 2018). Moreover, exercise programs for young adults have not been entirely successful in reducing weight gain and improving long-term PA habits (Bloemen et al., 2017; Harris et al., 2015; McCoy et al., 2016; Obrusnikova, Iva & Cavalier, 2011; Pan et al., 2016; Stanish et al., 2015; Tyler et al., 2014). A careful examination of the several inter-linked determinants of PA is therefore critical to guide the design of interventions to facilitate long-lasting behavior change among youth with DD.

This mixed-methods study obtained quantitative and qualitative data relating to PA levels of youth with DD close to the transition out of school systems. Unlike prior research that obtained inputs from 1-2 stakeholder groups (Cheak-Zamora & Teti, 2015; Hurley & Burt, 2015; Obrusnikova & Miccinello, 2012; Schleien et al., 2014; Shields et al., 2012; Shimmell et al., 2013; Taliaferro & Hammond, 2016), we obtained a holistic view from 4 stakeholder groups, including youth with DD, their families/caregivers, special educators, and therapists who are all part of the decision-making team. We collected data using surveys and focus group discussions in the following 4 areas: (1) current PA engagement and anticipated PA engagement after

transition out of school, (2) stakeholders' values and beliefs relating to PA, (3) factors (facilitators and barriers) associated with PA engagement, and (4) proposed recommendations to promote PA engagement among youth with DD.

Methods

Study Design

This descriptive study utilized both focus group and survey methods. The focus groups afford open exchange of perspectives, comparison of multiple view-points, and identification of potential solutions to critical challenges in the field by key stakeholders as subject-matter experts (Barbour & Schostak, 2005; Cheak-Zamora & Teti, 2015; Krueger & Casey, 2000). A follow-up researcher-developed survey was also distributed to obtain additional quantitative data relating to PA in youth with DD.

Theory

Focus group questions (see Table 1) were developed based on theoretical models, i.e., the social ecological model, the PA for persons with disabilities model, and the Youth PA promotion model (McLeroy et al., 1988; Van der Ploeg, Hidde et al., 2004; Welk, 1999), previous literature in the field, and author expertise. The choice of the specific theories was based on their applicability in studying PA engagement among young people, including youth with disabilities. The social ecological model acknowledges that PA behaviors are determined by factors at multiple levels: intrapersonal factors (e.g., knowledge about PA, attitudes towards PA, skills needed for engaging in PA, and prior experiences with PA), interpersonal factors (e.g., social support systems including family, friends, teachers, etc.), institutional factors (e.g., formal and informal regulations at social institutions such as school, workplace, etc. that support behavior change related to PA), community factors (e.g., availability of safe neighborhoods and accessible

and affordable community facilities to engage in PA), and public policy (local, state, and national policies around PA) (McLeroy et al., 1988). On the other hand, the Physical Activity for Persons with Disability Model (PAD) put forth by Ploeg and colleagues relates PA behaviors, participation/functioning of youth with DD, and various determinants of PA behaviors (Ploeg et al., 2004; Blomen et al., 2014). The model identifies facilitators and barriers relating to both personal and environmental levels that influence PA behaviors. Their model accounts for personal factors such as motivation to exercise, beliefs about value of PA and physical fitness, self-efficacy, financial and time-related resources, as well as level of mobility, cognitive, and social communication impairments (Ploeg et al., 2004). Similarly, environmental factors impacting PA performance include social factors such as family beliefs and peer opinions tied to PA, availability of accessible facilities with trained supportive staff and appropriate equipment, as well as transportation options (Ploeg et al., 2004; Pitchford, Siebert, Yun, 2016; Mahy et al., 2010). Finally, the youth PA promotion model (Welk, 1999) based on social-ecological theory, proposes a framework for understanding factors that predispose, enable, and reinforce youth's PA engagement. The model proposes that engagement in PA depends on inter-related psychological determinants of perceived benefits and costs to PA engagement (i.e., "*is it worth it?*") as well as perceived competence (i.e., "*am I able?*"). Moreover, several factors including individual demographics (age, gender, socio-economic status), their fitness levels, access to facilities and spaces for PA, and family and peer attitudes may enable and/or reinforce PA engagement among youth (Welk et al., 1999). In line with these theoretical PA models that significantly overlap with each other, we designed our focus group questions to encourage participants to share their perspectives on multiple factors at the individual, social, and environmental levels that serve as facilitators and barriers to PA engagement in youth with

developmental disabilities (see Table 1 for focus group questions). In addition, we obtained stakeholder input on proposed ideas and recommendations to increase PA engagement among youth with DD.

Participants

A total of 44 participants (see Table 2) were recruited through convenience sampling by contacting educational programs, support groups, and communities of practice. Separate focus groups were held with (1) youth with disabilities (e.g., ASD, CP, ID, etc.) from 13-24 years who were able to verbally communicate and engage in small group discussions, (2) caregivers of youth, (3) educators and paraprofessional school staff, and (4) physical therapists and assistants working with youth with DD. In order to be as inclusive of perspectives of individuals with disabilities with varying ability levels, the study included family members of individuals with disabilities who were limited in their communication abilities. Family members represented the issues faced by the individual and his/her family. Individuals with disabilities were recruited on a volunteer basis resulting in inclusion of only those who were able to express their views. Out of the 12 youth with disabilities who participated in our study, 8 students were still in school. These 8 students were part of a transitional special education program. The remaining 4 students were no longer receiving educational programming. All students had participated in special education programming through public schools. None of the participants dropped out of the study.

Study Procedures

All study procedures were approved by the xxx IRB. Interested participants contacted the researchers. We then set up a phone meeting with them to explain study procedures, confirm eligibility, and obtain consent/parental permission/assent forms. Additional oral consent was obtained at the start of the focus group. All focus groups were conducted virtually via Webex

and involved 3-8 participants (average size: 5 participants). The study was conducted during the COVID pandemic and the chosen method of facilitation was in view of lockdowns and COVID-related restrictions that prohibited in-person interactions at the time. In our experience, for this study, the online mode of focus group discussions actually facilitated broader participation from individuals/families across the state who were otherwise challenged due to availability of transportation or care provisions for their family member with a disability. We conducted separate discussions (~1.5 hours/discussion) with each group, with 2 focus groups conducted per stakeholder group. All discussions were recorded to allow audio transcription at a later time.

The focus group was led by a trained primary facilitator (1st or last author, both females) and 1-2 additional secondary mediators. The last author is an experienced facilitator for focus groups with 40 years of experience working as a pediatric PT. The 1st author is a pediatric PT with 13 years' experience working with children with DD. The primary facilitator led the discussion by describing the research context, posing key questions, providing prompts/probes, summarizing key discussion points, and ensuring equal opportunities across participants. The secondary mediators raised additional questions and took notes of the discussions.

Every discussion began with an introduction of the broader background of the research. We defined PA as follows (Obrusnikova & Cavalier, 2011):

“PA is any structured or unstructured activity where you are [or your child/student/patient is] physically active and moving their body in a way that uses energy, makes the heart beat faster, and makes them breathe heavier. Many times, PA also causes people to start sweating. There are many types of physical activities that people do, such as walking, swimming, running, playing tennis, lifting weights, going to the gym, playing sports, playing physically active games at school, or even doing home chores, yard work, etc.”

Using discussion guides, facilitators posed open-ended questions that welcomed sharing of individual perspectives. Follow-up questions/probes were based on participant responses. After the session, participants filled out a brief researcher-developed survey. This survey included a mix of open-ended and multiple-choice questions to obtain information from stakeholders about current levels of PA engagement among youth. Each participant received a \$30 gift card following participation.

Data analysis

All recordings were transcribed verbatim by 2 trained research assistants. The transcripts were analyzed using a thematic analysis approach (Hunter, 2009) to identify emerging concepts/codes. Trustworthiness of reported data was ensured by giving participants opportunities to clarify their responses during sessions as well as by asking them to fill out follow-up surveys to provide more information and/or clarify information from focus groups. Moreover, trustworthiness was further enhanced by having researchers independently code data and identify themes until data saturation. Concepts/codes were driven by the data and not pre-defined. Quotations representative of emerging concepts/codes were identified, similar concepts were categorized into sub-themes and finally drawn together into broader themes. Transcripts were coded using NVivo software (QSR International). Themes were identified and consensus was established among authors. Transcripts from each focus group were coded separately to ensure that all views expressed in each group were considered. Thereafter, researchers cross-referenced the identified themes across focus groups to compare and contrast stakeholder view-points.

Results

We present results per research question by reporting on student perceptions, then caregiver inputs, and finally feedback from special educators and therapists. Stakeholder surveys provided

information regarding youth's current levels of PA engagement and perceptions about the importance of PA for youth (research questions 1 & 2).

Current levels of PA and anticipated PA engagement following transition out of school

Participating youth with DD engaged in PA around 3-4 days/week, with a large proportion of the day spent sedentary (see Table 3). Youth reported engaging in PA mainly at school and through after-school programs. Some academic programs provided weekly PA opportunities at community-based recreation centers/gyms, as a means of familiarizing youth with options to engage in PA after graduating from school. Outside of school, youth engaged in PA with family members mostly through outdoor activities (hiking, walking pets, etc.) when the weather permitted or through active chores (yard work, cutting wood, etc.). Caregivers also reported seeking private lessons for PA. All special educators and therapists unanimously indicated that their students received a majority of their PA through academic programming and after-school activities. Interestingly, 73% indicated that PA-related goals were not part of the transition plans for their students, unless caregivers advocated for their inclusion.

While still in school, it was hard for youth to anticipate their PA levels following their transition out of school. A majority of youth shared that they would not be active in the absence of encouragement from school staff, attendants, or caregivers, and if PA was not a required part of academic programming. Caregivers expressed anxiety over the scarcity of adult-centric PA opportunities. A parent shared, *"I have seen so many challenges now that my daughter is turning 19. I feel there's less to offer as she gets older. It is quite a project in front of me to set my daughter up for life."* Caregivers felt that it was their responsibility to *"make it happen for their child"* by advocating for PA on their child's behalf, finding trusted programs and trained personnel, and arranging finances, transportation, and equipment to enable their child's PA. Special educators and

therapists acknowledged the huge responsibility on families following children's transition out of school systems. A school-system therapist shared, *"I know for families, one of the biggest fears is ..., my son or daughter is in school right now, but what are we going to do when they don't have that routine, and they turn 21."* Families find it challenging to maintain their child's PA levels and modify existing lifestyle habits, given work schedules and other responsibilities. A principal of a transition program for youth shared, *"I am sad to say that, I don't think we've changed anybody with the exception of the time that they've spent with us, because they go home and live that same life. What usually happens is that we see them in the grocery store a couple of years later, and barely recognize them (they have put on weight)."*

Values and beliefs relating to PA for youth with DD

Youth did not seem to understand the long-term benefits of engaging in PA. Some participants found PA challenging because, *"it [running] was very hard"*, *"I get tired too easily"*, or *"way too fast."* Instead, they participated in activities that they enjoyed and that allowed them to interact with their friends and/or neurotypical peers. All other stakeholder groups were invested in the physical and psychological benefits of PA for their children/students. Several parents emphasized that movement and PA were integral to maintain their child's present level of mobility, functioning, and independence, especially for youth with significant motor difficulties.

Special educators and therapists shared that PA engagement seems to be associated with family values and priorities around PA. One therapist shared, *"I think the bottom line is that activity and fitness for the high school and the adult population is really caregiver driven. It's really dependent on the caregiver and their ability, whether it's time, financial resources, physical strength, all of those things to get someone more active, because I don't think there's a lot of special needs young adults [who] are saying, hey, yeah, I want to go get fit."* Families that were physically

active were more likely to encourage their children to be active by integrating PA into their child's daily routine, advocating for PA opportunities within their child's transition plans, limiting amount of 'sedentary' and 'technology' time, encouraging attendants to get youth to be more active, and making efforts to engage in PA with their child. For other families, PA, although desirable for their child, may not be prioritized given financial and logistical barriers, busy schedules, and other competing responsibilities.

Factors associated with engagement in PA in youth with DD

Stakeholders shared factors related to the individual, the family, and more broadly to the program/institutional and societal level that impact PA in youth with DD (see Figure 1). Youth with DD shared that they were motivated to engage in activities that were “*fun*”, “*not too hard*”, or “*required too much focus.*” Opportunities to exercise with neurotypical peers served as a huge motivation. Some students engaged in PA to improve sport-specific movement skills that would ultimately allow them to engage with peers outside of school. A youth with DD shared that with Unified Sports and Special Olympics she “*could do stuff that average people [without disabilities] could do.*”

Caregivers agreed that motivation was a crucial factor that determined their child's willingness to engage in PA. For instance, a caregiver shared, “*He doesn't really want to do exercise. He wouldn't get on a treadmill or something, unless we make it a contest.*” Moreover, caregivers reported that their child's abilities (motor, social, communication, and cognitive) influenced PA engagement. For youth with significant motor issues, physical exercise presents a challenge with more limited activity choices. Students with ASD may prefer solitary activities compared to group-based PA/sports due to social communication difficulties. A parent discussed her daughter's challenges, “*My daughter actually has had significant behavior issues... I could*

not put my daughter into Special Olympics because she was that aggressive.” Past negative experiences with PA or anxiety/fears may also limit youth PA. A parent of a child with CP shared, “We tried basketball...she was hit on the head, because she does not have a protection reflex. It was bad luck, but it made her afraid of the basketball court. After that she wouldn’t go near it!”

Caregivers shared their efforts to promote PA among youth by advocating for the inclusion of such activities within adult day programs, requesting state funding for one-on-one aides or pieces of equipment/technology to support PA engagement, and finding PA programs within their town/community that accept older students. They highlighted the scarcity of both state-funded and community-based PA opportunities for adults with DD. When community-based PA programs are available, parents had to make significant efforts to enable their child’s participation. One caregiver shared, “...When it works, it’s because parents dedicate time in an already existing, very busy schedule. It also takes some financial investment even when you find activities that are available and when you may not be able to find them, you’re organizing them yourself, you are bringing in people, sometimes you’re paying for them out of pocket. Trying to find someone who also values fitness and is willing to take them [youth with DD] out for walks and do that kind of thing is hard.” Caregivers also shared their challenges in finding safe and trustworthy programs and trained, empathetic, and consistent personnel who could support their child. For instance, a caregiver of a 17-year-old with ID shared, “I definitely have trust issues. My trust issues lie in the fact that my son’s non-verbal. I don’t know if somebody’s done something or not done something. I have to take their word for it.” Another caregiver shared, “...if you don’t have a consistent staff person who you know and trust, it’s hard.”

Special educators and therapists discussed behavioral strategies they used to get youth active, including exercising with them, involving neurotypical peers, using humor and games to

make activities fun, providing external incentives and reinforcement, and challenging students to beat their own record. One therapist spoke about inclusive PA opportunities, *“If their friends are doing it, they are going to do it. Social is so huge for this age group. I think it is the driving force of why they [youth with DD] show up [for exercise].”* As students age, the focus tends to shift from teaching fundamental movement skills to competitive sport engagement in high school; therefore, students with DD often find it hard to keep up with their neurotypical peers in terms of the motoric skills required (speed, agility, coordination, stamina, etc.) and higher-order cognitive skills needed such as decision making, motor planning, problem solving, rule following, and strategic thinking.

Stakeholders discussed challenges that families face relative to access and logistics of PA opportunities. A therapist aptly pointed out, *“... a lot of families might not have access to things like a gym..... or even transportation there, and even when we talk about programming, let's say there's openings for the pool, but it's from 12 to 1. Parents work 12 to 1..... so there's a mismatch within the community, it's also a time commitment if you think about it.”* Moreover, for students requiring additional equipment (e.g., communication or mobility aids), special educators highlighted the challenges associated with continued access to assistive technology that was previously funded through the school system. In light of limited state-provided financial support, families are forced to independently make tough decisions related to spending priorities for their child and may end up not prioritizing PA. Lastly, stakeholders discussed concerns regarding caregiver health/well-being. Families are overwhelmed and overburdened from continually balancing numerous responsibilities pertaining to their child and family along with several other personal and professional commitments. Caregiver burnout in turn can negatively impact their ability to provide optimal care for their child.

Proposed recommendations to promote PA and active lifestyles in youth with DD

Stakeholders provided several recommendations to address barriers to PA (see Figure 2). Youth shared that they would like to participate in enjoyable activities that aligned with their interests/preferences. A majority of youth requested for social support in the form of exercise buddies or people to provide encouragement/feedback. Suggested PA ideas included walking clubs, activity camps, and swimming programs. Youth emphasized incorporating the activity as part of their daily routine to make it predictable and easier for them to sustain in the long-term.

Caregivers suggested providing autonomy and multiple activity choices to help youth self-identify preferred activities. They recommended that programs be adapted and individualized to their child's needs to make them more successful and sustainable. Caregivers requested for an easily accessible, web-based resource directory of age-appropriate programs organized by state to help identify PA opportunities. At a program level, caregivers requested for accessible, affordable, and trustworthy PA programs equipped with qualified and compassionate staff. They suggested developing year-long programs with combined public-private funding and also encouraging adult daycare programs, vocational programs, and/or employers to provide opportunities for youth to engage in PA as part of their daily routine. A caregiver summarized her idea of an ideal program, *“A facility, some place local that would be easily accessible for my daughter in a wheelchair to do multiple things. She particularly doesn't need extremely trained staff, but certainly it would be nice to be able to leave her and have her interact independently with someone else. My dream for her future is to be part of an inclusive community. So, not just people with disabilities, but everybody playing games and choosing what they want to do and having fun.”*

Special educators advocated for early education of families to emphasize the importance of lifelong wellness for individuals with DD. As it is hard to modify lifestyles in young adulthood,

school systems need to work with families from when children are young to ensure family buy-in into PA initiatives and inculcate active family lifestyles. Therapists also shared success stories of working collaboratively with teachers, gym physical education instructors, and paraprofessionals to create programs for their students. For after-school programs, stakeholders requested extended timings and arrangement of transportation to enable families to access facilities beyond work hours. Therapists recommended working with families to find local recreational facilities and ways to address access barriers for youth with DD.

Stakeholders also recommended developing holistic programs focusing on “life skills coaching” and “wellness” beyond a sole emphasis on PA. This involves working with local programs/gyms to expose youth to community-based PA opportunities and teaching them ways to access these facilities (using public transportation, gym equipment, locker rooms, etc.) following the transition out of school. Finally, there is a need for more family support groups to provide opportunities for sharing information, learning from each other’s experiences, and receiving ongoing psychological support during children’s transition out of school. Stakeholders also asked for facilities that offer respite care to offload families for short periods.

Discussion

Our study explored factors at the individual, family, and program levels influencing PA engagement in youth with DD as they transition out of school systems. At the individual level, in line with prior research, motivation emerged as a strong factor influencing PA participation among youth with DD (Bossink et al., 2017; Temple & Walkley, 2007). Youth did not understand the long-term health benefits of PA and instead relied on extrinsic rewards/reinforcement for participation (McGarty & Melville, 2018; Shimmell et al., 2013). Participants unanimously indicated that they were likely to sustain PA they found enjoyable. Another recent study reported

that non-participation in organized PA among young people with disabilities is best predicted by parent reports of not finding activities their child enjoys and their child's lack of motivation and happiness during PA (Papadopoulos et al., 2020). Youth in our study preferred activities that were fun, non-competitive, not too hard or exhausting, and that allowed them to interact with neurotypical peers. Previous work also suggests that social interactions are often the most valuable outcomes following exercise for individuals with DD (Columna et al., 2020; Darcy et al., 2017; Hurley & Burt, 2015; Mckenzie et al., 2021). To effectively address barriers at the individual level, we recommend developing inclusive, individualized, and adult-centric PA programs that provide youth with opportunities to exercise with their friends, peers, and families, and build in multiple activity choices to allow youth to pick preferred activities (Schleien et al., 2014; Shields & Synnot, 2016; Yu et al., 2022).

At the family level, parental involvement and family values/priorities are related to youth trajectories, which is also aligned with previous literature (Papadopoulos et al., 2020; Shields & Synnot, 2016; Shimmell et al., 2013). Neurotypical children initially rely on parents for finding programs and planning the logistics of participation, but they eventually assume responsibility for their own PA (Beets et al., 2005; McGarty & Melville, 2018); in contrast, we and others have found that youth with DD continue to rely on their families for initiating, planning, and sustaining PA (McGarty & Melville, 2018; Mckenzie et al., 2021). Based on our findings, we recommend early education to prepare families to eventually assume responsibility for their adult child's PA engagement following transition out of academic programming. It is indeed well-known that active lifestyle habits acquired early are likely to be incorporated into family routines and sustained in the long term (Hinckson et al., 2013; Valis & Gonzalez, 2017).

At a program level, school-based initiatives are needed that can help families identify activity interests of transition-age youth, find community-based recreation programs, recommend strategies to encourage youth involvement in active chores at home, offer advice on healthy meal plans, and develop out-of-school transition plans (Almeida et al., 2020; Yu et al., 2022). In line with previous research, stakeholders recommended that programs provide mandatory disability awareness training to staff to help them better support PA among youth with DD (Mckenzie et al., 2021; Taliaferro & Hammond, 2016; Temple & Walkley, 2007). Caregivers suggested that trained staff work closely with families to tailor programs to individual needs of youth to ensure sustained adherence with PA (Aherne & Coughlan, 2017; Bossink et al., 2017; Yu et al., 2022). We recommend developing multimodal programs involving interdisciplinary team of experts comprising PE teachers, special educators, PTs, dietitians, and school psychologists. Although youth with DD in this transition age desire independence, they may lack prerequisite skills needed to take charge of their own health (Shimmell et al., 2013; Cheak-Zamora & Teti, 2015). School-based life-skill and transition training programs might be a safe place to teach youth self-advocacy and decision-making skills in a step-by-step manner to enable a gradual, supported transition of responsibility from parents and educators to youth. As recommended by stakeholders in our study, such efforts although time-consuming would likely lead to greater independence, improved physical health including engagement in physical activity, and better quality of life among youth with DD into adulthood.

Limitations

We had a relatively small sample size consisting of volunteer participants who valued PA. Not all youth with DD may be represented as we only included individuals who were verbal. We did not conduct discussions with representatives from community-based recreational programs, adult

daycare programs, or state agencies. Future studies should expand the sample size and include other stakeholder groups to obtain a more holistic picture of PA among youth with DD.

Conclusion

Our mixed-methods study explored barriers at the individual, family, and program/institutional level to PA engagement among youth with DD. Stakeholders advocated for health and wellness of youth with DD to be a shared responsibility between families, school systems, communities, and government agencies. Programs for improving PA should be enjoyable, affordable, accessible, and tailored to individual preferences and abilities. Ideally, multiple activity choices should be offered that provide opportunities for interactions with neurotypical peers, and programs should be run by trained personnel who can optimally support PA engagement among adults with DD.

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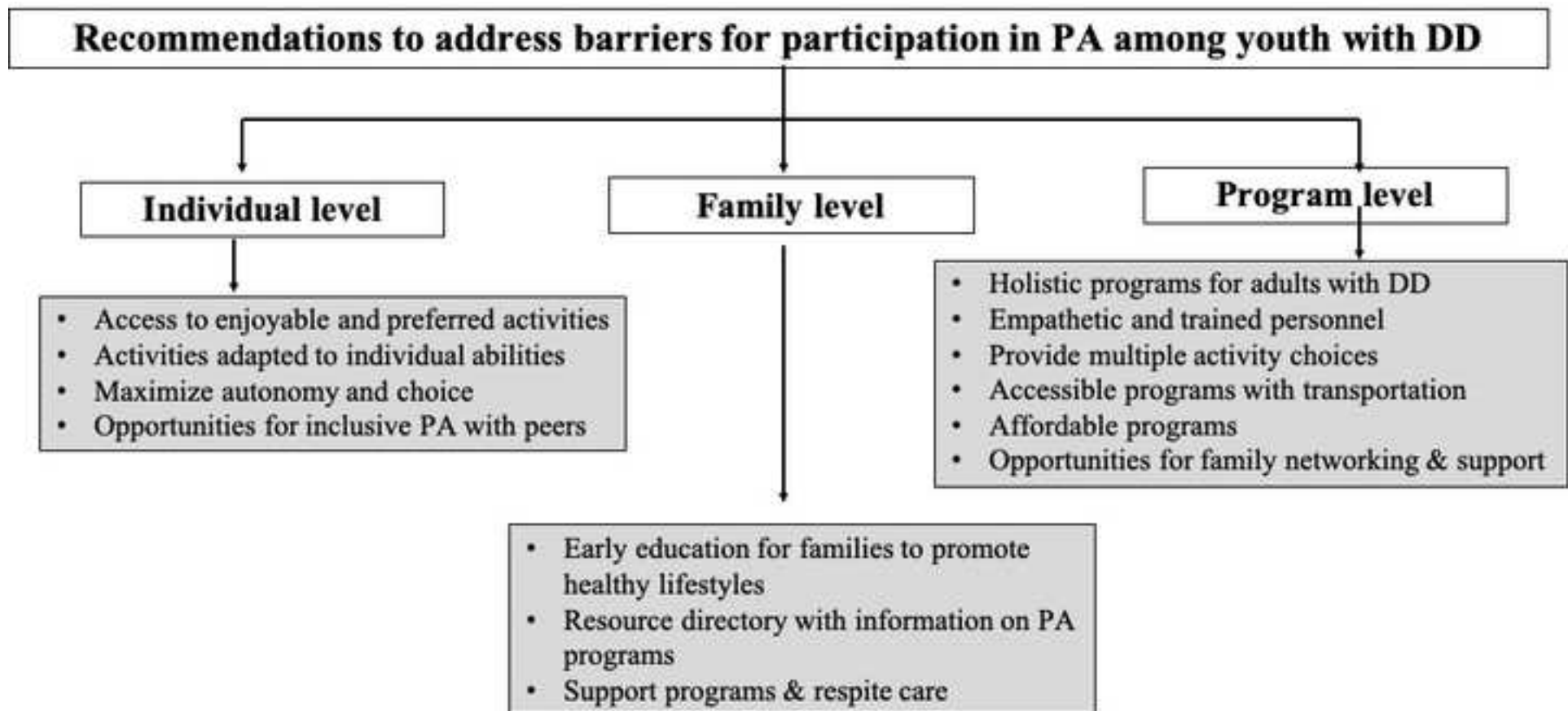
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Figure Legends

Figure 1: Stakeholder-identified barriers to engagement in PA among youth with DD

Figure 2: Stakeholder-identified recommendations to address barriers to PA engagement among youth with DD



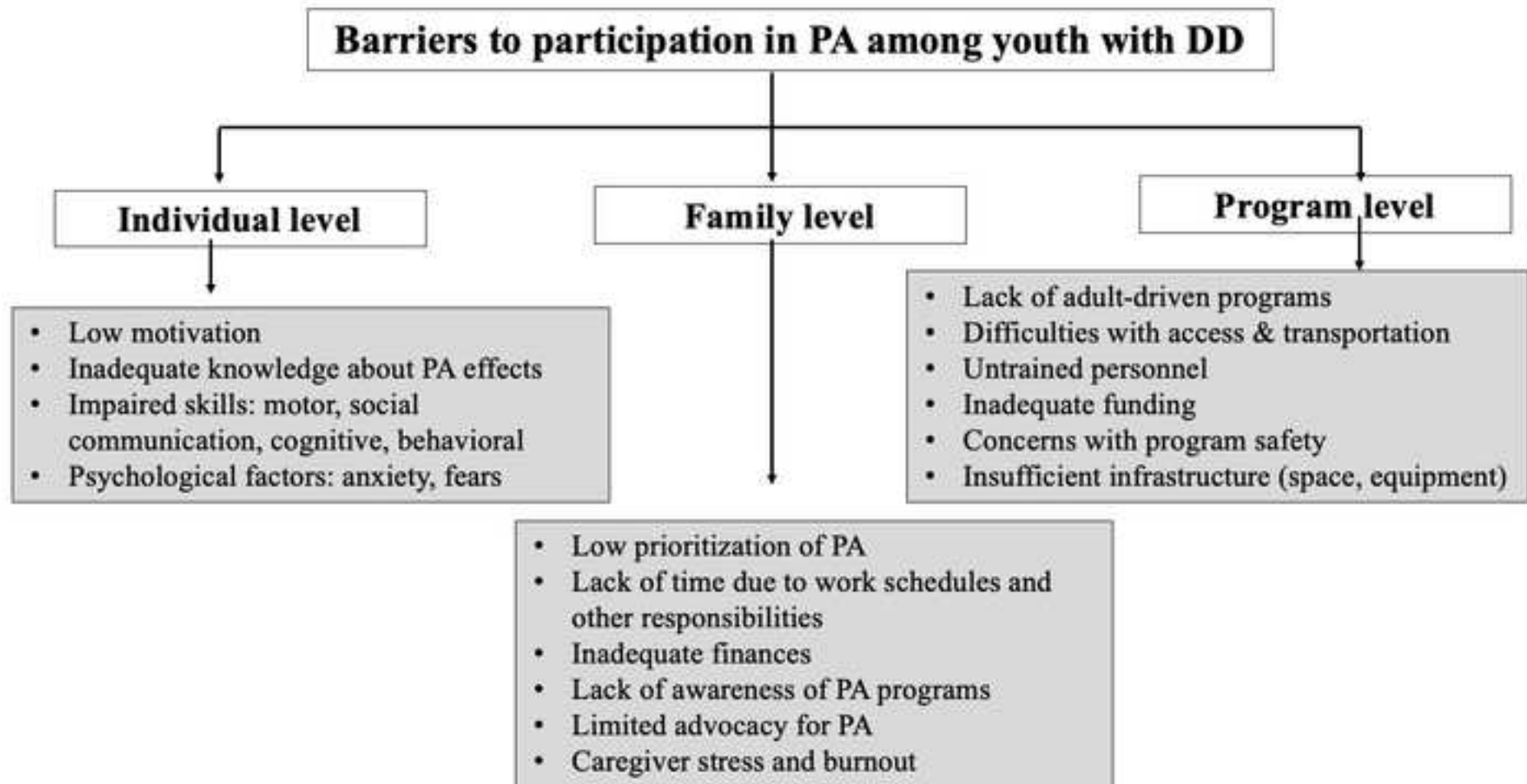


Table 1: Focus group topics and exemplar questions for different stakeholder groups

Exemplar questions	Stakeholders
Current PA and PA after transition out of school	
What kinds of PA, if any, do you/your child/your students/clients engage in? How often? How long? With whom?	Y, C, TP, T
Is PA part of your student' IEP? What PA opportunities are offered to students at school?	TP
Once you/youth transition out of school, how does your/their PA change?	Y, C, TP, T
Values around PA & fitness	
How important is it for you/youth with DD to exercise on a regular basis? Why?	Y, C, TP, T
How does exercise make you/youth feel? Do they like or dislike it?	Y, C, TP, T
What is the reason that you/your child does exercise?	Y, C
Factors influencing PA engagement	
It is recommended that people exercise at least 30 minutes/day. How difficult would it be for you to do? OR (to get youth with DD to meet the standards)?	Y, C, TP, T
What makes it easier for you/youth to exercise every day? What makes it hard?	Y, C, TP, T
Recommendations for an ideal program & strategies to improve PA engagement	
What kinds of PA do you recommend for youth? How many days/week? For how long?	TP, T
How do you encourage youth to be physically active?	C, TP, T
We want to create a program to help young people with DD exercise regularly. What should the program look like?	Y, C, TP, T
What kinds of PA do youth like to participate in? What kinds do they not like? Why?	Y, C, TP, T
What resources are needed to get youth to be more physically active?	C, TP, T

Note: Y: Youth with DD, C: Family/Caregivers, TP: Teachers/paraprofessionals, T: Therapist

Table 2: Demographic characteristics of participants

Characteristic	Youth with DD	Caregivers	Teachers/paraprofessionals	Therapists
Sample size	12	9	12	11
Participant age in years: Mean(SD); Range	19.92(0.90); 19-21	51.11(4.65); 44-60	40.5(11.64), 27-58	55.33(9.57), 34-67
Gender	6M,6F	1M (Father), 8F (Mothers)	3M, 9F	11F
Age of youth with DD in years: Mean(SD)	19.92(0.90)	18.56(4.07)	-	-
Age range of youth with DD in years	19-21	13-24	6-22	3-24
Diagnoses of youth	ASD (8), LD (1), CP (2), DD (1)	ASD (3), CP (2), DS (2), ID (2)	ASD, CP, ID, DS, LD, ADD, ADHD, ODD, Genetic disorders, Emotional disturbances	ASD, CP, ID, DS, DCD, MD, LD, DD, Genetic disorders, Seizure disorder, Ataxia, VI, Cancers, Brain tumors, Multiple disabilities, TBI, Metabolic disorders
Co-morbidities	ADHD (2), ID (2), Anxiety (2), VI (2)	ID (2), Anxiety (1), Seizures & scoliosis (1), Asthma (1), Spinal fusion (1)		
# of students/clients on caseload	NA	NA	Educators - 1-14, PT - 20, OT - 80 students	6-40 students
Role/Setting	Self	Parent of child with DD	Special Educators (5), Paraprofessional (2), Tutors (2), PT (1), OT (1), Program Assistant (1) in school setting	11 school system PTs, 1 home PT, and 1 PT in acute care setting

Note: ASD: Autism Spectrum Disorder, CP: Cerebral Palsy, ID: Intellectual Disability, DS: Down Syndrome, LD: Learning Disability, ADHD: Attention Deficit/Hyperactivity Disorder, ADD: Attention Deficit Disorder, DD: Developmental Disability, ODD: Oppositional Defiance Disorder, DCD: Developmental Coordination Disorder, MD: Muscular Dystrophies, TBI: Traumatic Brain Injury, VI: Visual Impairment

Table 3: PA engagement in youth with DD as reported by different stakeholder groups

# of days/week that youth exercise at least 30 minutes/day	Youth with DD	Caregivers	Teachers	Therapists
1-2	45.45%	11.11%	30.77%	45.45%
3-4	45.45%	55.55%	38.46%	45.45%
5-7	9.09%	33.33%	30.77%	9.09%
Time spent sedentary (Mean(SD) in hours)	Youth with DD	Caregivers	Teachers	Therapists
Weekdays	9.45(7.37)	8(3.81)	4 hours per school day	
Weekend days	11(8)	7.83(4.11)	-	-
Importance of PA for youth	Youth with DD	Caregivers	Teachers	Therapists
Not at all important	9.09%	0%	0%	0%
Somewhat important	45.45%	11.11%	21.43%	18.18%
Extremely important	45.45%	88.89%	71.43%	81.81%
Locations of PA programs	Youth with DD	Caregivers	Teachers*	Therapists
Home	72.73%	77.78%		36.36%
Gym/Fitness center/community recreation centers	72.73%	11.11%		45%
School/After-school programs	45.45%	44.44%	100%	100%
Parks/trails	9.09%	22.22%		
Sports/playground/ swimming pool	9.09%	0.00%		81.81%
Physical Therapy	18.18%	0%		
Local camps/clubs	0%	11%		54.54%
Other (Personal trainer, private activities)	0%	44.44%		
Exercise partners	Youth with DD	Caregivers	Teachers*	Therapists
Alone	27.27%	33.33%	15.38%	18.18%
Friends	27.27%	11.11	69.23%	45.45%
Family	27.27%	55.55%	0%	72.73%
Teacher/tutor/staff	9.09%	44.44%	61.54%	81.81%
Therapists and paraprofessionals	27.27%	18.18%	23.08%	
PCA/aides	0.00%	18.18%	0%	27.27%
Others (babysitter, coaches)	0.00%	18.18%	0%	18.18%
Missing	9.09%	0%	0%	0%

* Teachers were asked about student's PA during their school day