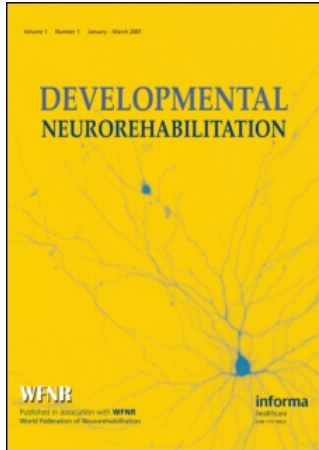


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Physical activity for youth with disabilities: A critical need in an underserved population

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Abstract

The recommended amount of daily physical activity for youth is 60 minutes a day, most days of the week. Youth with disabilities are not achieving this target and are significantly less active and more obese than their non-disabled peers. The combination of the health risks associated with physical inactivity and obesity presents a serious health concern in this population. While there is a small amount of research on interventions aimed at improving fitness among youth with disabilities, the majority of these studies were conducted in clinical settings where most or all of the common barriers to participation were eliminated (e.g. transportation, lack of knowledgeable staff, adaptation of programmes and/or facilities to child's needs). One of the most important challenges for paediatric rehabilitation and healthcare professionals is finding ways to increase physical activity and fitness among youth with disabilities in community-based settings. The use of information technology (IT) to customize physical activity programmes for youth with disabilities offers a promising approach to addressing this important health issue in the future.

Keywords: *Physical activity, youth, adolescents, disability, secondary conditions*

La cantidad recomendada de actividad física diaria para jóvenes es de 60 minutos diarios, la mayoría de los días de la semana. Los jóvenes con discapacidad no están alcanzando este objetivo y son significativamente menos activos y más obesos que los jóvenes sin discapacidad. La combinación de los riesgos de salud asociados a la inactividad física y a la obesidad es una seria preocupación en esta población. Mientras que existe un reducido número de investigaciones acerca de las principales intervenciones orientadas a mejorar el rendimiento físico entre jóvenes con algún tipo de discapacidad, la mayoría de estos estudios fueron realizados en sistemas clínicos donde se eliminaron las barreras de participación más comunes (por ejemplo, transporte, falta de un personal informado, adaptación de programas y/o facilidades para las necesidades del niño). Uno de los más importantes retos para la rehabilitación pediátrica y los profesionales dedicados al cuidado de la salud es encontrar formas para aumentar la actividad física y el acondicionamiento físico en los jóvenes con discapacidad, en escenarios dentro del marco la comunidad. El uso de la tecnología de la información (IT) para establecer en forma individual programas de actividad física para los jóvenes con discapacidad ofrece una estrategia prometedora para manejar este tema de salud tan importante en el futuro.

Palabras clave: *Actividad física, joven, adolescentes, discapacidad, condiciones secundarias*

Introduction

Childhood and adolescence are critical periods when youth with and without disabilities develop self-concept, attitudes and behaviours that they will likely transfer into adulthood [1]. Participation in play, recreation and sport has a profound impact on overall growth and development and are essential elements for a satisfying childhood and adolescence [2,3]. In addition to the psychosocial benefits associated with sports and recreation, many physiological benefits accrue from regular participation in physical activity during childhood and adolescence.

These include increased bone density and lean muscle tissue, better management of body weight, lower risk of high blood pressure in adulthood and reduced feelings of depression and social isolation [4]. Despite these physiological and psychosocial health benefits, the rate of physical inactivity among youth with disabilities is much higher than in youth without disabilities and many experts believe this will lead to a greater number of health complications in adulthood [5–8].

The low level of physical activity among youth with disabilities was recently addressed by the

Council on Children with Disabilities Executive Committee of the American Academy of Pediatrics (AAP). The Council recommended that physical activity participation be increased among youth with disabilities by eliminating societal barriers to participation and by encouraging health professionals to advocate for greater participation in sports and physical activities by all children, including those with disabilities [5]. The Committee also urged paediatricians to emphasize to families of children with disabilities the need to become involved in competitive and recreational sports and physical activities throughout childhood and adolescence.

While the AAP report is clearly an important first step in addressing the physical activity needs of youth with disabilities, many barriers still remain concerning access to fitness, sports and recreation programmes offered in many local communities in the US and abroad. Central to this effort is the need for paediatric healthcare providers, researchers, practitioners and family members to understand the magnitude of the problem and to begin to work towards a unified plan for improving physical and programmatic access to physical activity programmes for this population. Paediatric rehabilitation professionals have direct contact with family members of youth with disabilities and can serve as an important channel for encouraging greater participation in physical activity. The focus of this paper is to (1) provide an overview of the disparity in physical activity participation between youth with and without disabilities; (2) discuss results from a small number of fitness intervention studies that targeted youth with disabilities; (3) briefly discuss barriers that impact their participation; and (4) describe a conceptual model for promoting higher levels of physical activity participation among youth with disabilities through the use of information technology.

Low physical activity and fitness in youth with disabilities

Children and adolescents with disabilities have disproportionately lower levels of physical activity and fitness compared to their non-disabled peers [7,10–12]. Data from a national study conducted in Canada comparing the health risk behaviours of 319 adolescents with physical disabilities to 7020 non-disabled adolescents are illustrated in Figure 1 [13]. In each of the three age groups (11–12, 13–14, 15–16 years), youth with disabilities had a 4.5-times higher rate of physical inactivity compared to non-disabled youth. Adolescents with physical disabilities

were twice as likely as non-disabled youth to report watching television for more than 4 hours per day. The researchers noted that the barriers imposed on youth with disabilities may be the primary reason for their lack of participation.

A secondary data analyses of the 2005 Youth Risk Behavior Survey (YRBS) also found that the proportion of students who engaged in sedentary activities (i.e. video/computer games) 3+ hours/school day was higher ($p < 0.05$) for students with physical disabilities (26.6%) compared to those without disabilities (20.4%) [6]. In contrast, the percentage of students who were members of a sports team was significantly lower ($p < 0.05$) for youth with physical disabilities compared to youth without disabilities. Researchers have suggested that as a result of not being able to compete in sports and recreational sports programmes because of their high level of inaccessibility, youth with disabilities may avoid more physically demanding activities that require higher energy expenditure (i.e. soccer, basketball) and are therefore likely to spend greater amounts of time (i.e. after school, weekends) in sedentary behaviours [14].

The low rate of physical activity participation reported among youth with disabilities is of great concern because this health behaviour generally tracks into adulthood [15]. Therefore, higher levels of physical inactivity during childhood and adolescence are likely to contribute to an increased risk of obesity and other adverse health conditions in adulthood [15–20]. In a recent review paper, Rimmer et al. [21] reported that there was a significantly higher rate of obesity among youth with disabilities compared to non-disabled youth and that this higher incidence would likely result in greater health problems in adulthood.

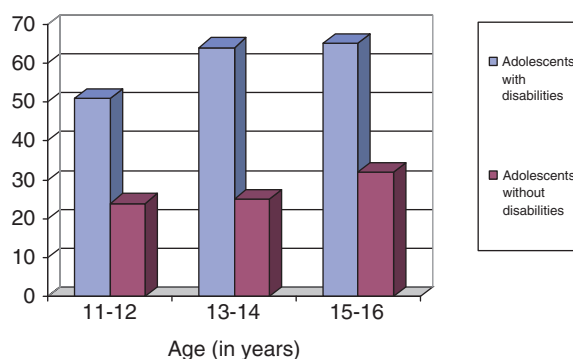


Figure 1. Physical activity levels of adolescents with and without disabilities who exercise once per week or less (OR: 4.50; 95% CI [3.55–5.72]) Steele et al. [8] Data from the Canadian WHO Cross-National Survey Health Behavior in School-Aged Children (HBSC).

Physical activity and exercise programmes for youth with disabilities

Researchers examining the effects of exercise programmes on youth with disabilities have provided evidence that exercise is beneficial in improving strength and cardiovascular endurance [19,22,23] and, in some cases, social connectedness [5]. Exercise is also important in preventing common secondary conditions associated with physical inactivity. Several studies have reported lower levels of pain, fatigue and deconditioning in adult populations with spinal cord injury and multiple sclerosis [24]. Despite these benefits, only 29% of children with physical disabilities classify themselves as being physically active [25] and levels of fitness among youth with disabilities is extremely low [7,26,27].

Most research examining the effects of exercise on youth with disabilities has focused on youth with cerebral palsy [28–48] or mental retardation [7,49]. Collectively, this body of research provides evidence that muscle strengthening programmes resulted in improved function, as measured by gait speed, gross motor abilities and wheelchair propulsion.

Less research has been conducted on cardiorespiratory fitness training in youth with disabilities [7,27]. Fragala-Pinkham et al. [50] examined a hospital-based vs. home-based fitness training programme in nine youth with cerebral palsy and other developmental disabilities between the ages of 5–9 years recruited from outpatient clinics and contacts with physical therapists working in a large public school system. Outcomes measures included the energy expenditure index (EEI, [Working Heart Rate-Resting Heart Rate]/walking speed) as a measure of the energy cost of walking, muscular strength, functional and gross motor abilities as measured by the GMFM in the four children with cerebral palsy and the Presidential Fitness Test which includes several cardiovascular, strength and flexibility measures. The group exercise sessions were held for 60–70 minutes 2 days a week for 14 weeks, followed by 12 weeks of home exercise adapted to accommodate the child's functional ability level. Group fitness sessions involved 5 minute warm-ups, 10–30 minutes of aerobic activity, 15–25 minutes of strength training and 5 minutes of cool-down. The home programme included written instructions and videotapes of strength and aerobic training activities that were recommended to be completed twice per week for 3 months. Results of the study found that the group exercise programme had the greatest effect on improving walking efficiency, strength and gross motor function. Programme adherence was also much higher for the group exercise programme

than for the home exercise programme and children and parents reported higher levels of satisfaction with the group exercise programme.

Translating outcomes from clinical or hospital-based programmes to community-based recreational or fitness settings is an important and greatly needed area of research. There are only a few community-based exercise interventions that have been published on youth with disabilities. Fragala-Pinkham et al. [51] examined the safety, feasibility and effectiveness of a community-based fitness programme for 28 children with neuromuscular and developmental disabilities aged 6–14 years. The programme was held at local YMCAs twice a week for 16 weeks and included strengthening, aerobic and flexibility exercises. Strength training activities included use of cuff weights, resistance bands, floor exercises such as pushups and sit-ups and close chain exercises such as wall squats and heel raises. Weights were progressively increased as tolerated by 0.5–1 lb over the course of the programme. Aerobic conditioning included activities such as follow the leader, parachute games, obstacle courses, sports drills such as base running and moving ribbon wands to music. All aerobic activities emphasized continuous movement that began with 10 minutes in the first week and progressed to 30 minutes in the third week with the goal of 75–80% of maximum HR by the fifth week. Participants showed significant improvements in several fitness outcomes including functional mobility, strength (hip abductors, knee extensors, modified push-up, sit-ups) and flexibility (sit and reach test). The authors concluded that children with disabilities could feasibly and safely participate in a community-based exercise programme with the appropriate supervision and guidance by knowledgeable staff.

Darrah et al. [51] also tested the effectiveness of a community-based fitness programme for children with CP that included strength, aerobic and flexibility. Twenty-three children aged 11–20 years trained three times per week for 10 weeks in a programme that included 10–30 minutes of aerobic exercises, 30 minutes of weight training and 20 minutes of flexibility and cool-down activities. Strength training included use of exercise machines and free weights in a circuit programme: shoulder press, lateral pull-down, leg press, biceps curl and hip abduction. Weights were gradually increased when participants were able to perform three sets of 12 repetitions. Aerobic training was not well-described and only characterized as having a tempo and pace necessary for maximizing cardiovascular output with the goal of maintaining a heart rate of 145 bpm. Results indicated significant improvements in strength but not cardiovascular function among the participants and the authors concluded

that progressive resistance exercise was beneficial to this population.

Another community-based physical activity programme titled 'Off the Couch' (OTC) was targeted at children with disabilities aged 8–13 years [52]. The focus of the programme was on individualized activity based on abilities determined through screening of the child's cognitive level, behavioural abilities and gross motor skills. Examples of activities included in the individualized programmes were: warm up sessions involving stretching and exercises such as arm circles, heel lifts, ankle circles, marching and jogging in place, side bends while reaching, sitting with crossed legs and long sitting while reaching forward and to either side. Warm-up activities were followed by ~15 minutes of seated therapy ball activities such as bouncing and marching with lower extremities and a variety of lower extremity exercises. The next phase within the programme varied from step aerobics to individualized aerobic routines and lasted from 7–10 minutes. Strengthening activities were added to some exercise programmes and included use of ankle weights and dumbbells depending on level of ability. Aerobic activities included walking, light jogging, treadmill training and use of a stationary bike/adaptive tricycle. Each programme concluded with 10–15 minutes of group activities such as kickball, volleyball, basketball or parachute golf. A case study involving an 11-year old female with mental retardation and hypotonia indicated this type of individual programming can result in functional and physiological gains as measured with an energy expenditure index (EEI), rating of perceived exertion (RPE), maximum running velocity and the overall daily activity level.

Disappointingly, there is very little exercise/fitness research involving youth with disabilities that has been transferred from the clinic to the community [51]. The lack of effective community-based exercise programmes for youth with disabilities limits opportunities for improvements in health and function in their respective communities. Fragala-Pinkham et al. [51] noted that developing community-based fitness programmes for youth with disabilities is a substantial challenge because of the lack of adaptive exercise equipment, appropriate fitness assessments, lack of transportation and adequate and knowledgeable staffing.

Barriers to physical activity in youth with disabilities

Children and adolescents with disabilities participate in very little school-based physical activity, are much less likely to participate in healthy physical activity

after school and are far more likely to be sedentary on the weekends [52]. While youth without disabilities have almost endless opportunities to obtain regular bouts of physical activity during informal play, transportation (e.g. riding bike to school) and structured and unstructured sports and recreation programmes [53], youth with disabilities have substantially less access to these same opportunities [54]. Aside from an occasional *special* recreation programme offered in a small number of communities, most youth with disabilities are not afforded the same opportunities to participate in sports and recreational activities as their non-disabled peers [55].

Physical inactivity among youth with disabilities is often linked to physical, programmatic and attitudinal barriers that limit sport and recreation opportunities within their communities [5,27]; Common physical barriers include playgrounds and ball fields that are inaccessible to youth who use wheelchairs (e.g. grass surfaces, climbing apparatus with no ramps) and common programmatic barriers include not having the necessary staffing or support to accommodate the child during the activity or not having knowledgeable staff who understand how to adapt the game or sport to meet the child's needs [52].

High level competition and emphasis on winning are substantial attitudinal barriers that make it less desirable for coaches and directors of community sports and recreation programmes to accommodate youth with disabilities. Many parents of children with higher athletic skills often want their child to excel in sports and therefore dissuade inclusion of youth with disabilities in community sports programmes. Parents of youth with disabilities often want to protect their child from participating in competitive activities that may result in failure or verbal abuse by other children.

The school environment is not much better when it comes to increasing participation in physical activity and sport among youth with disabilities. Physical education teachers limit opportunities for youth with disabilities who are mainstreamed into their classes because competition often dominates the class time and non-disabled youth are not encouraged to include youth with disabilities on their teams. Likewise, these youth often engage in very little physical activity during the school day because of various barriers associated with participation that include inaccessible facilities, lack of staff knowledge on ways to adapt programmes for the individual and lack of interest among the administration in addressing access issues associated with sport and physical activity for youth with disabilities [5,56].

Building an infrastructure for delivery of tailored physical activity programmes for youth with disabilities: PEP-for-Youth

There is a great need to identify successful strategies for increasing physical activity participation among youth with disabilities that can overcome the numerous barriers that prevent their participation in various community sports and recreation programmes. We have begun developing a framework using information technology (IT) to facilitate the transfer of clinical outcomes into community-based programmes for youth with disabilities. The data-driven and highly individualized support structure that can be provided through information technology allows personalization and relevance of information to the end user (i.e. youth with physical, cognitive or sensory disabilities) that is difficult or impossible to achieve through pre-printed materials [57]. Information technology can also be used to rapidly manipulate extremely large datasets of information required to generate customized protocols for the target population.

One has begun developing an internet-based platform for increasing physical activity among youth with disabilities referred to as *PEP-for-Youth* (PEP stands for *Personalized Exercise Programme*). The *PEP-for-Youth* intervention model (Figure 2) addresses specific barriers to physical activity that adolescents with disabilities often encounter as a

result of not being able to participate in typical school or community-based sports and recreation activity programmes. It is also based on empirical studies that suggest interventions may be more effective if they focus on personalized exercise behaviours that are individually and culturally appealing and are implemented in a setting of the person's own choosing [57–59].

As shown in Figure 2, the *PEP-for-Youth* intervention model can be used by a healthcare provider, therapist, family member or instructor to customize a physical activity programme for youth with disabilities in a more systematic framework. The professional who implements the programme is referred to as a PEP wellness coach. The first step in the process involves the PEP wellness coach conducting a *needs assessment* in the area of physical activity. By assessing a combination of factors, including the youth's motivational level (readiness to change), physical activity profile, health and mobility limitations and barriers to participation, a programme can be developed that meets each youth's specific needs, interests and circumstances. Next, the PEP wellness coach develops a personalized physical activity programme that begins with setting realistic goals that match with the child's needs assessment data and the availability of physical activity programmes in his/her community. Some of these programmes are identified through the

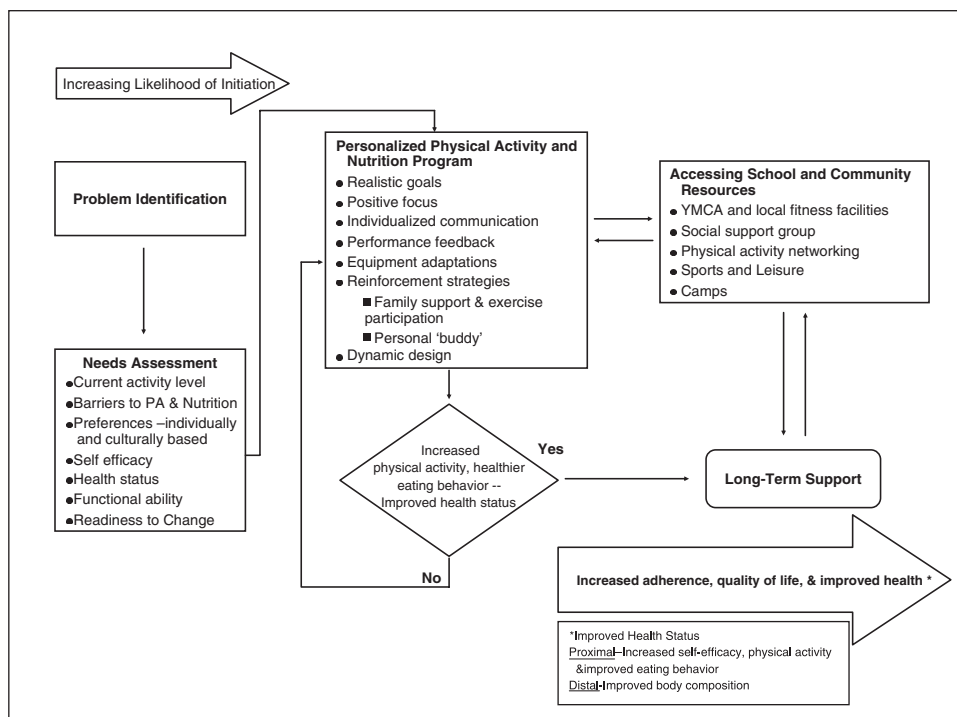


Figure 2. *PEP-for-Youth* physical activity intervention model.

National Center on Physical Activity (www.ncpad.org), which lists various types of accessible sports and recreational programmes in the US for youth and adults by state, city and zip code.

The *PEP-for-Youth* programme focuses on encouraging PEP wellness coaches to work with youth with disabilities and/or a family member to make positive changes in easily achieved increments of physical activity. Support activities are tailored to the specific needs and characteristics of each participant and include providing programme and activity adaptations as needed, performance monitoring and feedback and suggestions for simple but effective solutions for increasing physical activity. While maintaining the same physical activity goals (e.g. Increase physical activity to 40 minutes a day), the specific details of the programme can be revised at any time to accommodate changing needs, desires or conditions. Successful participants are linked to community resources to help establish natural supports for long-term maintenance of the behaviour. The key benefit of the *PEP-for-Youth* programme is that it can change frequently to accommodate lifestyle changes and growth and development of the participant (e.g. not enjoying a certain type of exercise, etc.).

Information technology is a promising approach to addressing the problem of physical inactivity among youth with disabilities. First, it allows paediatric rehabilitation and healthcare professionals to custom-fit a physical activity programme to specific requirements of the individual user and allows revision or modification of the programme to meet changing circumstances or participant interests. Secondly, it offers a framework for systematically tracking progress and maintaining or enhancing successful features of the programme while eliminating unsuccessful features in a timely and efficient manner. Thirdly, it makes it easier to work with a larger target audience from remote areas (i.e. rural) where access to sports and recreation may be limited and where it may be necessary to communicate with local sports and recreation programme providers regarding certain accommodations that are needed for increasing participation among youth with disabilities in that community. And, fourthly, it allows materials to be revised and updated on an as-needed basis to reflect new programmes, equipment or services offered in a particular community or for a certain disability group.

Conclusion

One of the most important responsibilities and challenges for paediatric rehabilitation and healthcare professionals is providing effective strategies

and resources for increasing physical activity among youth with disabilities who face enormous physical, programmatic and attitudinal barriers to participation in community-based sports and recreation programmes. An expert panel has recommended that school-age youth participate in 60 minutes a day or more of moderate-to-vigorous physical activity that is enjoyable and developmentally appropriate [60]. Unfortunately, the majority of youth with disabilities do not achieve this recommendation.

Increased participation in physical activity and improved fitness levels could have substantial health benefits by reducing the incidence of chronic diseases in adulthood (i.e. type 2 diabetes, heart disease), minimizing or eliminating secondary conditions (e.g. obesity, weakness, fatigue, mobility, social isolation) and reducing the need for personal assistance in performing activities of daily living (ADL) and instrumental activities of daily living (IADL). Information technology (IT) offers a promising approach to reaching a broader audience of youth with disabilities by allowing personalization and relevance of information to the end user (i.e. youth with physical, cognitive or sensory disabilities) that is difficult or impossible to achieve through pre-printed materials. Increasing physical activity among youth with disabilities is an important medical, rehabilitation and public health responsibility and will need greater attention by all parties in the future.

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