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Exercise in Children with Disabilities

Sherilyn W. Driscoll[1] · Erin M. Conlee[1] · Joline E. Brandenburg[1] · Bradford W. Landry[1] · Amy E. Rabatin[1] · Cara C. Prideaux[2] · Edward R. Laskowski[2]

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Abstract

Purpose of Review The goal of this paper is to review the role and importance of exercise in the overall health and fitness of children with disabilities and to identify unique considerations in specific populations.

Recent Findings Exercise and activity are known to be of critical importance to the health and well-being of typically developing children and adolescents. Children with disabling conditions are not immune to the obesity epidemic and even less likely to participate in structured or recreational activities than their typically developing peers. Although barriers to participation exist, studies largely support the same physiologic benefits of exercise in children with medical conditions and disabilities as those without. Providers must be aware of exercise precautions and restrictions specific to children with certain diagnoses. Furthermore, children with disabilities may need additional supports, accommodations, and individualization to facilitate participation. Future research should address activity guidelines for children with specific diagnoses as well as means of engaging children and adolescents with disabilities to participate in exercise.

Summary Physical activity and exercise have been proven to be beneficial, safe, and effective for children and adolescents with disabilities, though some individuals will require special precautions for safety or adaptations to permit participation.

Keywords Exercise · Children · Disability · Adaptive sports · Precautions · Physical activity

Introduction

The USA is in the midst of a childhood obesity and sedentary lifestyle epidemic. While regular physical activity is essential in promoting health and fitness in children and associated with better health in adulthood [1–6], more than 80% of adolescents do not meet the guidelines for youth aerobic physical activity [7••]. Increased sedentary time is related to lower cardiorespiratory fitness and increased BMI [8]. In less than 30 years, the prevalence of overweight children ages 6–19 years tripled [9]. In addition, a report on childhood obesity from 1999 to 2016 showed increasing rates among youth, disproportionally affecting children ages 2–5 years and adolescents [10•]. The effects of childhood obesity can carry into adulthood, with 70 to 80% of overweight children becoming obese adults [11]. Associated with the current obesity epidemic is an increase in pediatric obesity-related health conditions previously only seen in adults, including hypertension, type 2 diabetes mellitus, and unhealthy lipid profiles [12••].

Children with disabling conditions are also susceptible to the obesity epidemic and even less likely to participate in structured or recreational physical activities than their typically developing peers [13–15]. Numerous personal and environmental barriers to physical activity in this population exist, including fear, participant motivation, perceived negative attitudes toward disability, lack of transportation, appropriate facilities or programs, and monetary cost, among others [16, 17].

High rates of sedentary behavior in individuals with neuromuscular conditions lead to earlier age-related changes in cardiovascular, metabolic, and musculoskeletal domains [18]. For example, adults with cerebral palsy (CP) have higher rates of chronic medical conditions including coronary artery disease, diabetes, joint pain, and hypertension than age-matched peers without CP, emphasizing the need for development of

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✉ Sherilyn W. Driscoll
Driscoll.sherilyn@mayo.edu

1 Mayo Clinic Children's Center, 200 First Street SW, Rochester, MN 55905, USA

2 Mayo Clinic, Rochester, MN, USA

healthy exercise behavior in childhood [19, 20]. As a group, individuals with childhood-onset disabilities have a greater need for maintaining a healthy weight and cardiovascular fitness into adulthood due to susceptibility to earlier age-related health changes and vulnerability to a sedentary lifestyle due to numerous barriers to exercise.

Exercise Recommendations for Children and Adolescents

Children and adolescents experience wide variation in functional abilities, medical concerns, motivation, and support. As a result, specific exercise and activity recommendations will vary and must be individualized. The following sections address considerations and precautions related to some of the most common conditions a prescriber of pediatric exercise might encounter.

Typical Development

The current Physical Activity Guidelines for Children and Adolescents, released by the U.S. Department of Health and Human Services, provides evidence-based guidelines for physical activity for children and adolescents ages 6 to 17 years [21••]. The guidelines focus on three types of activity: aerobic, muscle strengthening, and bone strengthening. Children and adolescents should obtain 60 min or more of moderate to vigorous physical activity every day, with vigorous activity at least 3 days a week. Muscle strengthening (with body weight, resistance band, or weight training) activities and bone strengthening activities (such as running, jumping, and play activities involving ground impact) should occur 3 days a week.

Central Nervous System and Neuromuscular Disorders

Cerebral Palsy

Exercise recommendations have been proposed for children and adults with CP [22••]. Some children with CP, especially those at Gross Motor Function Classification System levels IV and V, have minimal baseline physical activity, in which case a starting point may be reducing sedentary behavior [22••]. For example, a child with CP could start with active play on the floor with siblings for 10 min daily and increase play by 5 min every other week. Alternatively, a program of standing twice a day for 15 min could be initiated, gradually increasing in time thereafter. For those who do have a baseline level of physical activity, a combination of aerobic and strengthening exercises is suggested. Children should perform an aerobic exercise program of at least 20 min two to three times per week [22••]. Achieving 60–95% of peak heart rate, 40–80% of heart rate reserve (heart rate reserve is the difference between maximum heart rate and resting heart rate) or 50–60% of VO2 max would indicate the proper level of exercise intensity [22••]. Maximum heart rate differs based on age, but in general can be calculated by subtracting the child's age in years from 220. A multi-joint strengthening program with one to four sets of 6–15 repetitions two to three times per week on nonconsecutive days is recommended. However, single joint strengthening may be beneficial for individuals with lower baseline strength or those who use muscle substitution or compensation when performing multi-joint exercises [22••]. When initiating a strengthening program, individuals should start with lower weights, greater number of repetitions, and avoid exercising to maximal fatigue. By using a conservative approach to starting a strengthening program, individuals may be at lower risk of injury and reduce severity of delayed onset muscle soreness. It is important to remember that gains made with strength training will regress quickly if the activity is discontinued.

Traumatic Brain Injury

For children and adolescents with mild traumatic brain injury (TBI) or concussion, a brief period of physical and cognitive rest followed by a gradual return to activity as symptoms permit is recommended [23, 24]. For children with moderate to severe TBI, there are no agreed upon exercise recommendations following acute rehabilitation. In adults with history of moderate to severe TBI, deconditioning was more pronounced than in aged-matched uninjured sedentary controls [25]. Furthermore, aerobic exercise should be encouraged in subacute and chronic TBI as it may promote recovery with neuroprotective effects on locomotion, cognition, learning, and memory. These effects are thought to be related to increased production of growth factors, including brain derived neurotrophic factor, with increased angiogenesis and neurogenesis [26]. In adults, aerobic exercise of 30 min three times per week has been shown to improve cognitive function, cardiorespiratory fitness, and fatigue [27, 28]. In addition, exercise of at least 90 min per week can reduce depressive symptoms [29]. For those with a TBI who underwent craniotomy, return to sports should be delayed until demonstration of complete healing of the bone flap, which generally occurs within a year [30]. There are no clear guidelines for return to sport for individuals with persistent neurologic or cognitive impairment. In rare cases, some young adults have returned to high-level amateur and professional sports including hockey, boxing, soccer, and football after craniotomy, although return to contact or collision sports after a parenchymal injury that required a craniotomy should be discouraged [31].

Ventriculoperitoneal Shunts

No specific exercise recommendations have been generated for children with ventriculoperitoneal (VP) shunts. However, as many children with shunts have physical impairments similar to children with CP, CP exercise guidelines may serve as a reasonable starting point [22••]. Historically, about two-thirds of pediatric neurosurgeons recommend some restrictions for sports participation for children with shunts and one-third of neurosurgeons restrict all contact sports [32]. The incidence of sports-related shunt adverse events is low and is estimated between 0.0003 and 0.001 per shunted child participating in sports [32]. Subsequently, in 2004, the Hydrocephalus Association recommended that activities of children and adults with shunts should not be restricted [33]. Prior to engaging in sports, the patient and family should discuss potential risks, benefits, and current guidelines with their medical providers.

Spinal Cord Dysfunction

Individuals with spinal cord dysfunction due to spina bifida or spinal cord injury (SCI) demonstrate lower levels of activity and worse aerobic fitness than those with other disabling conditions [34, 35]. Initiating an exercise program early in life or shortly after injury may ameliorate some of the risk of sedentary behaviors although evidence is scant in the pediatric population [36, 37]. Individuals with paraplegia or paraparesis are more likely to rely on upper extremity activities for exercise while individuals with tetraplegia are even less likely to engage in physical activity than those with paraplegia [38]. Medical assessment and oversight of exercise programs for individuals with SCI are necessary because of serious risks during exercise including autonomic dysreflexia, orthostatic and exertional hypotension, bone fragility, thermoregulatory dysfunction, and sensory impairment leading to pressure sores or wounds [39]. Obesity, short stature, scoliosis, and contractures pose challenges to equipment fit and activity participation. Bowel and bladder continence is a significant concern for children and their caregivers, thus necessitating adequate assistance, appropriate equipment, and privacy during exercise [40]. Awareness about the potential impact on exercise of common medications used for people with SCI is critical, including oxybutynin (light sensitivity and reduced sweating) and baclofen (hyperhidrosis and hypotension) [39].

While no guidelines exist for exercise in children with spinal cord dysfunction, there are exercise recommendations for adults with SCI. The American Congress of Rehabilitation Medicine recommends greater than 20 min of moderate to vigorous intensity aerobic exercise twice a week [41•]. In contrast, the Exercise and Sports Science Australia organization recommendations include greater than 30 min of moderate aerobic exercise at least 5 days per week or greater than 20 min of vigorous aerobic exercise 3 or more days per week [39]. Both suggest strength training on 2 or more days per week. Nightingale et al. [42] suggest that both the American and Australian recommendations are insufficient to prevent cardiometabolic disease, and they propose high-intensity interval training as an alternative exercise strategy.

Neuromuscular Disorders

Providers have long held concerns about the potential of exercise to accelerate disease progression in patients with neuromuscular disorders; however, numerous studies suggest that submaximal exercise programs (i.e., exercising shy of the point of fatigue) are safe and efficacious for individuals with a wide variety of neuromuscular diseases with appropriate precautions [43•, 44]. Boys with Duchenne muscular dystrophy (DMD), for example, should avoid eccentric muscle activity and high resistance strength training [44]. Increased fracture risk due to osteoporosis must be considered in high-risk groups such as those with spinal muscular atrophy (SMA) and boys with DMD on steroid treatment. Children with myasthenia gravis should exercise during cooler parts of the day, avoid prolonged endurance-based exercise, and exercise only after adequate rest [43•]. Fatigue in neuromuscular disease is problematic in terms of motivating participation, but exercise may also exacerbate fatigue and result in temporary impairments in strength, postural control, and gait [45]. However, with appropriate precautions in place, evidence demonstrates that children with neuromuscular disease benefit from both strengthening and aerobic activities [43•, 46–48].

Specific, widely accepted exercise or activity recommendations do not exist for the various subcategories of children with neuromuscular disease although aquatic exercise is promoted for individuals with DMD and SMA as a safe and enjoyable option [43•]. Adapting activities for individuals with limited muscle strength can be challenging and best guided by a physical therapist rather than a non-medical community exercise specialist [48]. Because most of these conditions progress, activity methods and support requirements change over time. Encouraging exercise at a younger age may ultimately have more clinical and functional benefit than starting later in life when muscle mass has already been lost due to disease progression and disuse [43•, 44].

Bone, Joint, and Connective Tissue Disorders

Amputation and Limb Deficiency

Children with amputation or limb deficiency, whether acquired or congenital, may participate in exercise or sports with or without adaptive equipment. If using a prosthesis or orthosis, proper fit with appropriate adjustments is necessary to help maintain skin health and proper overall biomechanics.

For children who use a prosthesis, abrasions, blisters, skin rash, and bursitis can result from a poor fitting socket or socket irritation. Residual limb overgrowth may occur in skeletally immature athletes and be discovered based on increased bony prominences and local erythema. Pain in and injury to an intact lower limb, including stress fractures and muscle strains, are possible given the increased work and biomechanical stress experienced by the intact limb during training and activity [49]. Back pain can occur in these athletes, due to compensatory lateral flexion and extension of the lumbar spine during activity. Core strength and overall flexibility as well as skill development related to balance and agility can be helpful for overall physical performance [50, 51].

Juvenile Idiopathic Arthritis

Exercise and participation in sports are not contraindicated in children with juvenile idiopathic arthritis. However, joint involvement, such as atlantoaxial pathology, must be considered given the risk of subluxation or dislocation during contact sports as well as activities such as gymnastics. Aquatic exercise may be preferred to help preserve joint integrity and avoid disease flares. Physical activity, even in times of disease flare, may be helpful for pain management, mood, and quality of life. Exercise for weight management should also be encouraged, as increased weight and obesity may increase joint pain [52, 53].

Osteogenesis Imperfecta

Children with severe types of osteogenesis imperfecta (OI) endorse lower sports and exercise participation than children with mild or moderate OI. Because of the risk of fracture, children with OI may be reluctant to participate in exercise intense enough to provide sufficient benefit. However, in children with mild to moderate OI, supervised and individually tailored physical training has been shown to be safe and effective in increasing aerobic capacity and muscle strength, if activity is maintained [54, 55].

Hypermobility, Ehlers–Danlos Syndrome, and Marfan Syndrome

Hypermobility in and of itself is not a contraindication to exercise, and many children with hypermobile joints do not have any other associated medical diagnoses or activity restrictions. However, the diagnosis of Ehlers–Danlos syndrome (EDS) is important to consider in a hypermobile child, though distinction needs to be made between etiologic entities. A preparticipation evaluation should include a musculoskeletal, cardiovascular, and neurologic medical history and examination and family history, since the type of EDS influences the ability to participate in contact or collision activities and sports. Cervical hypermobility should be considered given the possible risk for serious consequences if a neck injury is sustained. A thorough cardiovascular evaluation in children with vascular type EDS is important because, similar to Marfan syndrome, cardiac issues such as valvular pathology are possible. The Bethesda Guidelines provide recommendations for sports participation in patients with vascular type EDS and Marfan syndrome as well as other cardiovascular conditions [56, 57].

Higher levels of pain are reported in some individuals with hypermobility, though exercise is still encouraged. In fact, many of these children may also gravitate to non-contact sports such as gymnastics and dance based on their natural flexibility. Joint pain, tissue fragility, and joint dislocations are among a variety of other commonly described symptoms in patients with hypermobility, but there is no conclusive association with any of these and hypermobility by itself. If concerns of pain or injury do arise, long-term dedication to a formal physical therapy and home exercise program are paramount. A focus on strength and proprioception to avoid end range joint positions can help to make exercise and sport participation safer and more enjoyable.

Given articular hypermobility, multidirectional joint instability can result in shoulder subluxation or dislocation or symptoms of perceived hip dislocation, typically secondary to iliotibial band snapping over the greater trochanter. Orthotics for foot deformities such as pes planovalgus can be helpful. Bracing of other joints should likely be reserved for high-risk activities or recurrent dislocations, as prophylactic braces may not improve pain or endurance [58].

Other

Chronic Pain Syndromes

For patients with a primary pain disorder such as fibromyalgia, a general aerobic-based approach to rehabilitation is recommended. An aerobic exercise program can prevent deconditioning, improve cardiac function, and mitigate bone demineralization associated with prolonged immobility. Pain control is also directly impacted through the release of endorphins, activation of pain inhibitory mechanisms, and improvement in mood and global well-being [59].

Chronic pain is prevalent in the general population [60–63], but an understanding of the incidence, prevalence, functional impact, and costs of chronic pain in children with physical disabilities is limited [64]. Two recent studies noted correlations between function, pain intensity, and distribution of pain in addition to a nearly twofold increased incidence of chronic pain in adolescents with physical disabilities versus able-bodied controls [65, 66]. Chronic pain disorders, such as chronic regional pain syndrome (CRPS), in children with disabilities can be difficult to identify but no less symptomatically problematic than in typically developing children. Risk factors such as female gender, prolonged immobility, or heightened levels of stress and anxiety should not be overlooked [67, 68]. In a child with impaired communication, pain symptoms may manifest as grimacing, emerging self-injurious behavior, disordered sleep, abnormal positioning, or avoidance of usual activities [69–71]. Despite differences in communicative, physical, and cognitive abilities between children with disabilities and able-bodied children, chronic pain symptoms in these populations require similar treatments [72].

Any child with chronic pain should be guided through a gradually progressive aerobic exercise plan that focuses on consistency of activity rather than intensity. Exercise should begin with a tolerable level of activity that can be performed regularly regardless of pain symptomology. The exercise activities should not cause a significant increase or rebound in symptoms. Despite the increased difficulty identifying pain in children with disabilities, the recommendations for exercise and method of implementation should differ only in the manner in which each individual is able to reach similar their own individual exercise goals.

Down Syndrome

Down syndrome (trisomy 21) is a genetic syndrome characterized by intellectual disability, increased risk of congenital heart disease, hearing loss, vision problems, seizures, and various musculoskeletal conditions including scoliosis, joint instability, and atlantoaxial instability. While specific exercise recommendations for children with Down syndrome do not exist, these children often enjoy participation in physical activities. In fact, aerobic training programs are effective for improving cardiovascular fitness and resistance training is safe and beneficial for improving muscle strength in individuals with Down syndrome [73].

A child with Down syndrome should have a preparticipation evaluation. Cervical spine x-rays with flexion and extension views should be obtained to evaluate for atlantoaxial instability, especially if the child will participate in a high-risk activity that involves neck flexion and extension (e.g., diving, swimming with flip turns, butterfly stroke, soccer, gymnastics, power lifting, and high jump) [74]. High-risk activities are contraindicated if atlantoaxial instability exists, but the child would still be allowed to participate in low-risk, noncontact activities. Further evaluation and specialist referral may be needed for specific medical conditions, such as neurology for uncontrolled seizures or cardiology for congenital heart defects.

Mitochondrial Syndromes

Mitochondrial syndromes manifest with a wide range of clinical presentations. Skeletal muscle is commonly affected, with symptoms including exercise intolerance, fatigue, muscle weakness, and myalgia. Both endurance and resistance exercise have been shown safe and beneficial in those with mitochondrial disorders. Specific recommendations for exercise should be determined on an individual basis, and cardiac screening is recommended prior to beginning an exercise program. Training should be supervised and begin at a low intensity and duration with slow progression [75].

Cancer

The overall childhood cancer cure rate is now about 80% in the USA [76]. Survivors of childhood cancer have higher rates of sedentary behavior, obesity, and risk for metabolic syndrome [76–78]. Frequently cited barriers to exercise during and after oncology treatment include physical complaints, such as fatigue, and safety or fear of injury [79]. However, a systematic review in 2013 found no adverse effects from exercise in individuals with a childhood malignancy both during and after medical treatment, affirming the feasibility and safety of exercise in this population [80]. Improvements in fatigue, body composition, muscle strength, and immune function as well as overall quality of life are reported. However, no one exercise regimen has been found to be statistically superior [81]. Recommendations for children and adolescents with malignant blood disorders, such as leukemia, and those with solid tumors are similar. The American Cancer Society and Children's Oncology Group encourage at least 5 days per week of moderate to vigorous physical activity lasting 60 min [82, 83]. Alterations to this regimen are largely based on medications received [83]. For example, in children exposed to cardio-toxic drug therapy (e.g., anthracyclines), cardiac function, cumulative medication dose, and radiation stratify children into three risk groups. Exercise is recommended for all risk groups, with modified strength training in those with moderate risk, and exercise only under the supervision of a cardiologist for the group with known cardiomyopathy [84]. Historically, cancer survivors with one functional kidney were restricted from sport, but the 2016 recommendations from the Children's Oncology Group no longer prevent sports participation for mononephric survivors [85].

Hemophilia

With proper supervision, protective equipment, and precautions, evidence supports the safety of participation of patients with a bleeding disorder in a wide range of exercise and athletic activities. Long-term, regular administration of recombinant factor for prophylaxis can prevent traumatic and spontaneous bleeding episodes, including hemarthrosis [86]. Numerous studies have shown that children with hemophilia receiving regular prophylaxis have no increased risk of injury or bleeding complications while participating in physical exercise or sports activities. Furthermore, Ross et al. [79]

showed no difference between high-impact versus low-impact sport groups.

Sickle Cell Disease

A child with sickle cell disease has abnormal hemoglobin that sickles with deoxygenation and is at high risk of dehydration, exertional heat illness, painful crises, and osteonecrosis. However, mild to moderate exercise in appropriate environmental conditions and with adequate hydration is safe in the sickle cell disease population [87]. High-level exertional activity or extreme environmental conditions can lead to serious complications including rhabdomyolysis, exertional heat stroke, and sudden death. Recommendations to reduce exercise and sport-related risks for children and adolescents with sickle cell disease or sickle cell trait include gradual acclimatization to stressful environments (e.g., extreme heat, humidity, or high altitude) and avoidance of overexertion with gradual progression in workout intensity with longer rest and recovery periods. Adequate hydration, avoidance of exercise during illness (especially febrile illness), and adequate control of any comorbid asthma are important for safety while exercising [88].

Transplant

Exercise following organ transplantation is vital given high levels of premorbid and post-transplant sedentary behavior, progressive obesity associated with steroid treatment, and increasing rates of metabolic syndrome, such as in liver transplant [89–93]. Although exercise-related adverse events or effects on graft survival have not been substantially studied in children or adults following organ transplantation, the benefits of exercise are promising [94]. Following cardiac transplant, denervation of the allograft results in altered response to exercise due to dependence of catecholamine concentration, rather than direct nerve stimulation. Therefore, slower times to reach peak heart rate and return to baseline heart rate occur. While autonomic re-innervation can occur, subjective exercise measurements for exercise intensity, such as the Borg Exertion Scale rather than heart rate, are recommended post-cardiac transplant [95–97]. Subjective patient measures are also used for dyspnea after lung transplant. For pediatric renal transplant recipients, participation in exercise should not be restricted as kidney injuries are rare during physical activity [93].

Educating and Supporting Children and Their Families to Be Active

Patients and their families should be informed regarding the importance of exercise for all children and encouraged to engage the child, regardless of physical ability, to participate in physical activity. All medical providers play an important role in educating and motivating patients and families. A pledge from providers to discuss exercise with their patients and provide a pediatric "Rx for Exercise" has been requested from the Americans with Disabilities Fund [98••]. Exploring interests and practical access to activities should be a part of the encounter with youth with disabilities, just as it is in those without disabilities. Despite the beneficial effects of exercise, many physicians do not participate in physical activities themselves and do not counsel their patients on exercise or the need to limit sedentary behavior. Approximately 40% of primary care physicians and medical students do not meet the Centers for Disease Control and Prevention physical activity guidelines [99, 100]. In addition, physically inactive doctors are less likely to provide exercise counseling to their patients. It is crucial that all healthcare professionals prescribe this basic and essential treatment for our patients. We must make a concerted effort to model healthy physical activity in our own lives.

Examples of exercise within an array of both informal and organized activities include track and field, wheelchair sports (racing or hand cycling, basketball), sled hockey, swimming, archery, cycling, tennis, rock climbing, bowling, skiing, table games such as bullet ball, Tai Chi, yoga, Pilates, and dance. As with all children, a pre-participation exam should be performed. Physical development, growth spurts, and overuse should be monitored, with training and equipment adjusted as needed. A variety of structured programs have been studied across home, school and community environments including the use of virtual monitoring [14, 18, 101•, 102•, 103]. Virtual exercise environments can be more visually stimulating than traditional exercise environments (such as a gym) and allow for different modes and intensities of exercise to be enjoyed simultaneously by parties with and without disability in a socially interactive environment [18].

School-based resources should include an adapted physical education program and an inclusive environment for all physical activities. Legal mandates through Section 504 of the Rehabilitation Act of 1973, IDEA, and ADA support participation in education as well as sports. The American Association of Adapted Sports Programs advocates for the development of a standardized structure for school-based athletic competition to improve the well-being of students with physical disabilities. Disabled Sports USA, the Special Olympics, and the National Center for Physical Activity focus on exercise inclusion for all. Other resources include local parks and recreation departments. Furthermore, healthcare providers and families can advocate for accessible playgrounds, pools, programs, and gyms in their communities. Many of these resources have developed and incorporated strategies to address some of the barriers that may prevent a child with a physical activity from participating, such as transportation, cost, adaptive equipment, and optimal time scheduling.

Conclusion

For children as well as adults, if the benefits of exercise could be distilled into one medication and bottled, it likely would be the best selling and most prescribed medication in history. Physically active youths have higher levels of cardiovascular fitness, which is associated with better health in adulthood. Physical activity has special importance for children with disability, and the health risks associated with sedentary behavior in the disabled population are significant. Physical activity and exercise have been proven to be safe and effective for children and adolescents with disabilities, though some individuals will require special precautions for safety or adaptations to permit participation. Providers should include discussions of activity and exercise as an essential component of their evaluation of children with disabilities as exercise is truly "good for every body."

Compliance with Ethical Standards

Conflict of Interest Sherilyn Driscoll, Erin Conlee, Joline Brandenburg, Bradford Landry, Amy Rabatin, Cara Prideaux and Edward Laskowski declare no conflicts of interest relevant to this manuscript.

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