

Considerations for promoting healthy development and extracurricular activity involvement
among adolescents with disabilities

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Abstract

Adolescence is usually a time of good health for most people, characterized by specific physical, intellectual, emotional, and social developmental tasks that prepare a young person for a successful transition into adulthood. Nonetheless, a substantial proportion of children and adolescents have one or more disabilities that will uniquely impact that development and transition. It is therefore important for those working with young people to understand the developmental needs of youth with disabilities so that these young people can thrive. In this paper, we review the epidemiology of disability among youth, the developmental stages of adolescence and how they intersect with disability, and the promotion of resilience and healthy transitions to adulthood for youth and their families. We specifically discuss participation in extracurricular activities as a way to support health development and promote resilience among youth with disabilities, and we conclude by providing a specific example of how one school that serves students with visual impairments has modified sports and other activities so that these youth can experience the developmental benefits of participating in such activities.

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Currently in the United States, 42 million people (12%) are between the ages of 10 and 19, and this number is expected to grow to 45 million by 2050 (U.S. Department of Health & Human Services [USDHHS], 2016). As they grow in numbers, America's youth are also expected to become more racially and ethnically diverse (USDHHS, 2016). Although most of these young people are physically healthy, a substantial proportion of children and adolescents have one or more disabilities that uniquely impact their physical, cognitive, emotional, and social development. It is therefore important for health care providers, educators, social service providers, and others working with young people to understand the developmental needs of youth with disabilities so that these youth can be empowered to thrive during adolescence and into adulthood.

Epidemiology of Disability among Youth

There is no standard approach for defining or categorizing disabilities, which vary in type (e.g., physical, emotional/behavioral, intellectual), etiology (e.g., genetic and/or environmental), onset (e.g., congenital or acquired after birth), degree of severity, and impact on daily living (Pacer Center, 2004). Without a standard definition or approach, estimates of the prevalence of youth with disabilities also vary and are hard to assess (Suris, Michaud, & Viner, 2004). For example, about 15% of youth between the ages of 3 and 17 years have one or more developmental disabilities—chronic, severe disabilities that appear prior to age 22, can be congenital or acquired, and can be physical, cognitive, or both (American Association on Intellectual and Developmental Disabilities, 2013; Centers for Disease Control and Prevention [CDC], 2015; Pacer Center, 2004). This broad category includes disabilities such as ADHD, autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment (CDC, 2015). Yeo and Sawyer (2005) estimated that 10-13% of adolescents in Western countries have a chronic condition that significantly restricts their daily living. Worldwide, Gore et al. (2011) found that neuropsychiatric disorders (45%), unintentional injuries (12%), and parasitic and infectious diseases (10%) accounted for most of the years lost to disability.

Adolescents can acquire disabilities due to environmental, social, and behavioral factors. For example, common causes of traumatic spinal cord injuries among adolescents include road traffic accidents, falls, firearms, being struck by objects or other people, and sports (Selvarajah et al., 2014). And while accidents (e.g., car accidents, poisoning, drowning, unintentional discharge of firearm; 48%), homicide (13%), and suicide (11%) are the top three causes of death for youth 12-19 years old (Miniño, 2010), those who survive such events are at risk for disabilities stemming from spinal cord injuries, traumatic brain injuries, and other injuries.

Due to changes in health care, policy, and law—such as the Olmstead Act of 1999—most youth with disabilities now live at home. The percentage of those living in congregate care settings (e.g., skilled nursing facilities, intermediate care facilities, transitional facilities, specialty hospitals, residential schools) who are between 0 and 21 years old has decreased from 36% in 1977 to only 4% in 2010 (Friedman, Kalichman, & Council on Children with Disabilities, 2014). About two thirds of youth (nearly 16,000) living in congregate care settings in 2010 were between the ages of 14 and 21. Many youth in congregate care have both complicated medical conditions and severe intellectual and developmental disabilities; however, some may have a complicated medical condition along with normal cognitive skills (Friedman et al., 2014).

Developmental Stages of Adolescence: Intersection with Disability

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All adolescents progress through three main stages of development on their way to becoming autonomous adults: early (ages 11-14), middle (ages 15-17), and late (ages 18-21) (American Academy of Pediatrics [AAP], 2015). The specific developmental tasks of adolescence can be categorized as physical/biological (e.g., puberty), intellectual (e.g., progression from concrete thinking to abstract thinking), emotional (e.g., establishing independence and identity), and social (e.g., forming friendships and romantic relationships with peers, distancing from parents; AAP, 2015). Although the developmental tasks of adolescence are interrelated within each stage of adolescence, they can progress along their own timelines, as when a young person develops faster physically than intellectually, emotionally, or socially (AAP, 2015; Suris et al., 2004).

Although the developmental stages and tasks of adolescence are common to most young people regardless of the presence or type of disability (Suris et al., 2004), adolescents with disabilities and their families may face unique developmental challenges that those without disabilities do not (Yeo & Sawyer, 2005; Suris et al., 2004). Thus young people with disabilities constitute a marginalized population; they often experience social exclusion, discrimination, and violations of their rights (United Nations Children's Fund, 2013). Despite advances in U.S. law such as the Americans with Disabilities Act, youth with disabilities still face barriers to living a healthy lifestyle, including inaccessible facilities, poverty, and discriminatory attitudes and false assumptions on the part of others (Association of University Centers on Disabilities [AUCD], 2016). Family functioning is also impacted by extra responsibilities such as finding and financing appropriate health care, education, and other social services for the young person with a disability; facing stigmatization and isolation from the community; and balancing other relationships and professional obligations (Patterson & Blum, 1996).

For youth who live in congregate care, contact with parents and siblings may be minimal. Interaction with peers who are developing normally is often limited, which can be a negative or a positive influence depending on the youth's personal and familial factors. The developmental needs of those with complicated medical conditions and normal cognitive skills differ from those of youth with severe intellectual disabilities. Studies have shown, however, that families report advantages of placing youth with intellectual and developmental disabilities in congregate care, that it may have no negative impact on siblings, and that youths in congregate care continue to influence the functioning of their families (Baker & Blacher, 2002; Eisenberg, Baker, & Blacher, 1998; Friedman et al., 2014; Hostyn & Maes, 2007).

Depending on the type of disability, adolescents may face delayed puberty and short stature (Yeo & Sawyer, 2005). If the condition limits the young person's ability to be physically active, obesity may become an issue (Yeo & Sawyer, 2005). As a result, adolescents may experience negative body image and lower self-esteem. In addition, adolescents may face other challenges to their emotional and social development including feeling socially isolated and alienated from their peers, frustrated by navigating the healthcare system and managing their condition, poor school performance and/or chronic absenteeism, and challenges due to transitioning from adolescence to adulthood (e.g., finding a job and establishing financial independence; Yeo & Sawyer, 2005). These consequences can reach beyond adolescence into adulthood. For example, youth with learning disabilities and emotional and behavioral disorders face lower postsecondary education attainment, lower employment rates, lower earnings, and—in the case of those with emotional and behavioral disorders—higher rates of incarceration

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(Murray, 2003). Therefore, the need for opportunities to participate in activities that nurture the developmental processes of adolescence is especially critical for those with disabilities.

Resilience and Transitions among Youth with Disabilities

Despite the unique challenges that adolescents with disabilities may face while progressing through the developmental stages and tasks of adolescence, many are able to cope well and transition into adulthood successfully (Yeo & Sawyer, 2005). The ability to successfully cope with adversity and to experience better-than-expected outcomes is known as *resilience*, a central concept in understanding how to empower all youth—including those with disabilities—to thrive during adolescence and into adulthood (Resnick, 2000). Risk factors (i.e., those that increase a young person's vulnerability for a negative outcome) and protective factors (i.e., those that increase a young person's likelihood of a positive outcome or decrease the likelihood of a negative outcome) are keys to understanding the concept of resilience, as practitioners seek to mitigate risk factors and promote protective factors for young people (Bernat & Resnick, 2006; Resnick, 2000).

Although little research has been done to understand how resilience operates in adolescents with disabilities as they transition into adulthood, Mannino (2015) has found crucial individual and environmental attributes that promote resilience in emerging adults, including having a sense of purpose in life, equanimity (i.e., the ability to stay level-headed in stressful situations), and social support from family, friends, school, healthcare providers, religious institutions, community, and work. This maps on to conceptualizations of resilience in general adolescent populations, which identify protective factors at both the intrinsic (i.e., within the individual) and extrinsic (i.e., external to the individual, including social and environmental) levels (Resnick, 2000). Service providers must not forget to work to promote the health and resilience of the entire family unit too. Families with youth who have disabilities also display resilience; the traits of resilient families have been outlined elsewhere and should be considered when promoting resilience among adolescents with disabilities (Patterson & Blum, 1996).

The AUCD provides helpful guidelines for supporting youth and families during adolescents' transition into adulthood (Antosh et al., 2013). First, everyone must understand the importance of allowing the adolescent to have a sense of self-determination in making decisions about his or her life, including educational and work plans, living situations, and transitioning from pediatric to adult health care providers. Teachers and providers should work together with other organizations involved in the care of the adolescent to incorporate the perspectives of everyone involved and the culture of the adolescent and family into the transition process. Having the adolescent fill out the worksheets provided by the AUCD and having discussions about them can help foster resilience and facilitate a successful transition.

Supporting healthy development during adolescence: the case for leisure activities

Participation in leisure and extracurricular activities during adolescence such as sports, after-school clubs, and community and religious organizations, which is widespread, provides crucial opportunities to foster individual and environmental factors that promote resilience among adolescents. Youth who participate in such activities generally have better health, social, and educational outcomes than those who do not participate (Babiss & Gangwisch, 2009; Fredricks & Eccles, 2006). Engaging youth with disabilities in leisure and extracurricular activities can provide them with important experiences that can foster healthy development and

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resilience while combating the social isolations, stigmatization, and other obstacles they may face as adolescents.

Evidence, however, suggests that young people with disabilities participate in leisure and extracurricular activities less often and face more barriers to participating than do those without disabilities (Bult, Verschuren, Jongmans, Lindeman, & Ketelaar, 2011; Law, Petrenchik, King, & Hurley, 2007). This disparity in participation means that youth with disabilities are largely cut off from the developmental benefits of taking part in extracurricular activities, such as emotional well-being, school success, skill-building, and social and physical development (Bult et al., 2011; Law et al., 2007). Law et al. found that barriers to participation increased with age—a finding that was supported by Bult et al.'s systematic review. Low socioeconomic status is also an important barrier to participation for adolescents with disabilities (Bult et al., 2011).

Health professionals, educators, and others working with youth are uniquely positioned to advocate for youth with disabilities and their families to have opportunities for healthy living, social inclusion, equal treatment, and equal opportunity to engage in activities that promote their physical, cognitive, emotional, and social development. Creating and promoting opportunities for youth with disabilities to participate in leisure and extracurricular activities is one important way in which professionals and communities can help these young people thrive during adolescence and into adulthood. Next, we provide an example of how one school in Texas has created such opportunities for its students.

Example: Extracurricular activities at Texas School for the Blind. The Texas School for the Blind and Visually Impaired (TSBVI) is a public school that serves students from across Texas who are between the ages of 6 and 21 and are blind, deaf-blind, and visually impaired. These students may have other disabilities as well. TSBVI is also a statewide resource for parents and professionals who serve these young people from their birth through their transition from school (<http://www.tsbvi.edu/about-tsbvi>). Most students who attend TSBVI during the school year live in dorms on campus regardless of where in the state their home is located; however, those who live close enough for their home district bus to bring them to school are encouraged to be day students so that they can be with their families as much as possible. The dorms' staff help care for the students and teach them how to perform activities of daily living. TSBVI believes in the importance of the students to stay connected with their families and home communities. Therefore, most students go home on the weekends by either airplane or TSBVI buses. Parents meet the buses at various stops near their homes. Students are encouraged to go home on most weekends, and they are required to go home at least once a month, when the school is closed for the whole weekend, and during holidays.

TSBVI professionals encourage students to participate in extracurricular activities both on and off campus. TSBVI collaborates with other schools and organizations that serve children with similar disabilities to provide opportunities for the students to engage in various social activities with their peers. When an event is off campus, a registered nurse, a licensed vocational nurse, or a staff member who has been trained to give medications attends the event. This allows students with varying health conditions to attend off-campus events.

Sporting activities are favored by the adolescents at TSBVI. Many sports, including impact and nonimpact sports, are offered to the students. Students are required to have physicals, and they must be healthy enough to play their desired sport. Students who are on retinal precautions or have shunts cannot participate in contact sports, but they can participate

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in noncontact sports. Like most schools, TSBVI employs coaches dedicated to enriching the lives of young people. These coaches are trained and certified to help visually impaired students compete in various sports. Many students choose to participate in track and field activities, for example. Competitors can choose to have an individual who is not visually impaired act as a guide. A short rope is held at one end by the guide, and the other end is held by the runner. This helps the runner stay in his or her lane. Tactile markers are placed around the field events, and sound commands help the participants orient themselves. Medals and ribbons are awarded, and the children are proud of their accomplishments. They are required to have good sportsmanship, and they often cheer for their peers. Family members and friends are invited, and many attend the events.

Another very popular sport is goalball, which was invented specifically for individuals with visual impairment. In goalball, all participants wear blackout masks. The game is played indoors on a hard floor and is timed. The game's objective is to score points by rolling a ball with bells inside it into the other team's goal. The players work as a team by communicating and encouraging each other. This incredibly social sport is very important to the students who play it.

Other sports include tennis, played with shortened rackets, bell balls, and a lowered net, and the option of participating in an annual triathlon. For the triathlon, the students must be excellent swimmers and dedicated to a training program. A two-person bike with a sighted steering guide is used for the cycling stage. The students can have a sighted guide for the running and swimming portions as well. Indeed almost any sport can be adapted to allow visually impaired students the opportunity to participate. Physical education classes include multiple adapted sports using bell balls, tactile markers, and sound.

Students participate in other types of recreational activities as well. Many enjoy theater and perform in plays, which require that they rehearse and become oriented to the stage. They prepare for many weeks, spending hours working with the theater arts instructor and other cast members. Performances are held for staff, the community, family, friends, and fellow students. Dances and proms are also held. These are especially fun for the students when paired with events that include other schools. The TSBVI staff also encourages the students to advocate for themselves by attending awareness events, such as the nationally recognized White Cane Safety Day in Austin, TX:

The President of the United States annually recognizes White Cane Day by the Blind Americans Equality Day Proclamation on October 15th to acknowledge the abilities of people who are blind and to promote equal opportunities as any other American. The mission of White Cane Day is to educate the world about blindness and how the blind and visually impaired can live and work independently while giving back to their communities, to celebrate the abilities and successes achieved by blind people in a sighted world and to honor the many contributions being made by the blind and visually impaired (<http://www.whitecanneday.org/>).

The TSBVI staff recognizes adolescent participation in social and extracurricular activities as an important part of child development. TSBVI's professionals want the students to be empowered, independent, and proud contributors to society.

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