

Barriers and Facilitators to Physical Activity for Youth with Cerebral Palsy

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Research Summary

Regular engagement in physical activity (PA) for children and adolescents has been found to have protective health benefits by strengthening the skeletal system through weight bearing activity, assisting with weight maintenance, and enhancing psychosocial and mental health, as well as decreasing one's risk for developing secondary health problems, particularly metabolic dysfunction and cardiovascular disease (Carlson, Taylor, Dodd, & Shields, 2013). Interestingly however, prolonged engagement in sedentary activity, despite the amount of weekly engagement in PA, can also negatively affect metabolic and cardiovascular systems in youth, as both systems have different cellular responses (Carlson et al., 2013). The amount of PA and sedentary time in youth with cerebral palsy (CP) is particularly concerning. A systematic review of the literature by Carlson et al. (2013) found that youth with CP participate in 30% less PA than non-disabled peers according to Dutch PA guidelines that recommend one hour of daily moderate to vigorous PA for people under age 18 (World Health Organization, 2016), which is the same as U.S. PA guidelines for children and adolescents (Office of Disease Prevention and Health Promotion, 2016). The researchers also found that youth with CP engage in an average of 28.6 hours of screen time per week (hours spent in front of a TV or computer), which is double the maximum recommendation of less than two hours a day for children age 5-17 years (Australian Government Department of Health, 2014). The U.S. does not currently have sedentary guidelines.

To better understand how to enhance participation in regular PA and reduce prolonged sedentary behavior in youth with CP, five qualitative studies on perceived barriers and facilitators to PA engagement for youth with CP were summarized (Conchar, Bantjes, Swartz, & Derman, 2016; Lauruschkus, Nordmark, & Hallstrom, 2015; Shimmell, Gorter, Jackson, Wright, & Galuppi, 2013; Verschuren, Wiart, Hermans, & Ketelaar, 2012; Verschuren, Wiart, & Ketelaar, 2013). Individuals who took part in the studies included youth with CP who were 7-17 years old (Verschuren et al., 2012; Verschuren et al., 2013), 8-11 years old (Lauruschkus et al., 2015), 9-21 years old (Shimmell et al., 2013), 12-18 years old (Conchar et al., 2016), and their parents (Shimmell et al., 2013; Verschuren et al., 2012; Verschuren et al., 2013). The youth in the studies had varying characteristics. Some were able to understand and respond to interview questions (Conchar et al., 2016; Shimmell et al., 2013; Verschuren et al., 2012; Verschuren et al., 2013), whereas others were not, and parents responded on the participants' behalf (Shimmell et al., 2013). The participants also varied in having mild to profound motor function limitations (Lauruschkus et al., 2015), mild to profound cognitive dysfunction (Lauruschkus et al., 2015), and ranged from I to V on the Gross Motor Function Classification System – Extended & Revised (GMFCS E&R) (Lauruschkus et al., 2015; Verschuren et al., 2012; Verschuren et al., 2013). Some of the participants were able to ambulate without assistance or without the use of an assistive device (Conchar et al., 2016; Verschuren et al., 2012; Verschuren et al., 2013), whereas others required the use of a wheelchair or assistive ambulatory device for mobility (Conchar et al., 2016; Lauruschkus et al., 2015). Some of the participants also utilized augmentative or alternative communication (Lauruschkus et al., 2015).

All five of the studies explored personal and environmental facilitators and barriers to engagement in PA for youth with CP (see Figure 1). The findings from each study were compiled into a table and category themes were identified. In total, 30 personal barriers and 20 personal facilitators were identified, falling into two subcategories of physiological and psychological factors. Additionally, 30 environmental barriers and 23 environmental facilitators were identified, falling into five subcategories of parental factors, opportunities for sport and PA, practical feasibility, social environment, and facility/program factors.

Figure 1: Personal & Environmental Barriers and Facilitators to PA Engagement for Youth with CP

PERSONAL BARRIERS	PERSONAL FACILITATORS
Physiological Factors	
Loss of physical strength and skill as a result of interruptions in training after surgery ¹ , lack of energy/fatigue ^{2,3,4,5} , physical limitations ¹ , feelings of pain ^{1,2,3,4,5} , needing more time than peers/not being able to keep up ^{1,2,3} , feeling sport of interest is too difficult ^{4,5} , competitive activities without a chance to win ² , being constrained by body ¹ , fear of increased risk of injury ^{3,4,5} , inability to perform certain tasks/lack of control over body ² , learning skill is too time consuming ^{4,5} , presence of secondary/cognitive impairment ^{3,4,5}	Good training ² , good feeling of tiredness ² , belief that being active is good for body ^{1,2,3,4,5} , relieved pain ² , relaxation ^{4,5} , desirable changes in body shape or function ¹ , reduced need for OT and PT ¹
Psychological Factors	
Dislike competition ³ , child does not accept extent of disability ^{4,5} , belief that activity is not good for body ^{3,4} , boredom/activity is not fun ^{2,3,4,5} , attitude/decreased motivation ^{4,5} , feeling insecure/ashamed ^{1,3,4,5} , being nervous/anxious ^{1,3} , being overestimated due to invisible handicap ⁵ , negative feelings about losing all the time ² , feeling like an outsider ^{4,5} , less interested in sport around puberty ⁵ , vulnerability ¹ , fear of teasing ³ , being afraid of having to explain disability over and over to peers ⁵ , embarrassment ³ , being separated from parents ⁵ , disappointed at being excluded ¹ , difficult to ask parents to take on additional responsibilities ⁵	Enjoys competition ³ , acceptance of disability ^{4,5} , positive emotions/feelings ^{1,2,3,4,5} , confidence ^{3,4,5} , self-growth/independence ^{1,3} , having perseverance ^{4,5} , new experiences ^{1,2} , belonging to group/being accepted ^{2,3,4,5} , enjoy sensation of speed ² , reach personal goals ³ , social interaction ^{2,3,4,5} , reach personal goals ³ , positive attitude towards being challenged ^{4,5}
ENVIRONMENTAL BARRIERS	ENVIRONMENTAL FACILITATORS
Parental Factors	
Challenges with managing day-to-day aspects of raising a child with CP ^{4,5} , investment of time/energy ¹ , opinion that PA is not important ^{4,5} , doesn't accept extent of disability ^{4,5} , prevents child from participating in sport of choice/risky sport ^{2,3} , dissatisfaction with environment ^{4,5} , fear of child not fitting in ^{4,5} , hesitant to ask for support ^{4,5} , challenges with observing child struggling ^{4,5}	Involvement in managing child's participation in sport program ³ , aware of the benefits of PA ^{4,5} , assertiveness/perseverance ^{4,5} , approval of family ¹ , positive attitude ^{4,5} , helping the child ⁵

Opportunities for Sport & PA	
Limited choices of activity ¹ , activities of interest in are not offered or are too far away ^{2,4,5} , lack of awareness of possibilities ^{4,5} , not knowing what suits the child ^{4,5}	Awareness of opportunities for sport and PA ^{4,5} , school encourages PA ^{4,5}
Practical Feasibility	
Finding time to participate ^{1,3,4,5} , financial restrictions ^{4,5} , lack of access to transportation ^{1,3,4,5} , time of activity is inconvenient ^{4,5}	Access to PA/sports in community ^{4,5} , use of adaptive/mobility equipment ³
Social Environment Factors	
Not being accepted by peers or parents ^{4,5} , being bullied ^{4,5}	Allows child to establish peer relationships/interpersonal support ¹ , provides opportunities for social interaction ¹ , participates with assistance ² , sense of belonging/being a part of a team ¹ , being accepted by peers or parents ^{1,4,5} , presence of supportive/knowledgeable staff ³
Facility/Program Factors	
Availability of adaptive/mobility equipment ^{1,2,3} , lack of stimulating activities/equipment ² , teams are too big ⁴ , cost of programing ³ , child singled out from group ² , trainer not aware of complexity of child/needs not met ^{1,2,3,4,5} , not "open" for children with disabilities/no team suits child ^{1,4,5} , poor condition of facilities ² , child is not allowed to play in competitive games ^{4,5} , long waiting lists ^{3,4,5} , child is underestimated ^{4,5}	Systems that allow for spontaneity ³ , good trainer/good communication between trainers ^{3,4,5} , availability of funding ³ , stimulating equipment ² , making/achieving progress ¹ , activities in small groups ^{4,5} , accessibility of facilities/programs ³

Key= Conchar et al. (2016), 2 = Lauruschkus et al., (2016), 3 = Shimmell et al. (2013), 4 = Verschuren et al., (2012), 5 = Verschuren et al. (2013)

Despite the extensive findings, study limitations were identified. All five studies identified self-report, inability to generalize findings to other countries, and inability to generalize findings to youth with CP with varying abilities as study limitations (Conchar et al., 2016; Lauruschkus et al., 2015; Shimmell et al., 2013; Verschuren et al., 2012; Verschuren et al., 2013). Additional limitations included the inability to determine which facilitators and barriers had the greatest impact on PA engagement (Conchar et al., 2016; Shimmell et al., 2013; Verschuren et al., 2012; Verschuren et al., 2013), the participant's perceived level of interest in PA, which affected if the participant was invited to participate in the study (Lauruschkus et al., 2015; Verschuren et al., 2012; Verschuren et al., 2013), differences among participants in cases where a facilitator for one was a barrier for another (Shimmell et al., 2013), young participants possibly saying what they thought the researchers wanted to hear (Lauruschkus et al., 2015), and challenges associated with using interpreters (Lauruschkus et al., 2015).

Knowledge Translation Plan

Understanding the factors that influence participation in PA for youth with CP provides useful information to healthcare professionals and service providers, as this information can be used to enhance participation and aid in designing PA opportunities for this population (Verschuren et al., 2012). As depicted in Figure 2, specific recommendations in the literature include: 1) designing PA interventions that focus on strengthening facilitators and minimizing barriers to engagement (Lauruschkus et al., 2015), 2) helping youth with CP overcome PA barriers by understanding and influencing the youth's person-environment interaction (Shimmell et al., 2013), 3) being cognizant that some barriers are fixed, challenging, and impossible to change (Verschuren et al., 2013), 4) exploring the youth's PA preferences and interests when planning specific PA (Lauruschkus et al., 2015; Shimmell et al., 2013), and 5) communicating regularly with service providers and youth about the youth's PA interests and preferences because these may change over time, especially near puberty (Shimmell et al., 2013).

Figure 2: Knowledge Translation Plan

Youth with CP	PA Concerns: Participates in 30% less PA than non-disabled peers; participates in double the maximum recommended screen time
	Benefits of PA: Strengthens skeletal system, weight maintenance, enhances psychosocial/mental health, decreases risk of secondary health problems
	Recommendations: Design PA interventions that strengthen facilitators and minimize barriers, understand/influence person-environment interaction, be cognizant of barriers that can't be changed, explore youth's PA preferences and interests, communicate regularly with service providers

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