

How can we help youth with cerebral palsy to be physically active? Perspectives from pediatric rehabilitation professionals on physical activity promotion

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Why did we do this survey?

Physical activity benefits health, function, and well-being. For youth with cerebral palsy (CP) these benefits can include reduced risk of secondary impairments and fatigue, improved independence in mobility and self-care activities, and optimal participation in social, educational, and community activities. Despite the importance of physical activity, youth with CP spend less time being physically active and more time in sedentary pursuits compared to their age matched typically developing peers; very few meet recommended physical activity guidelines (Carlton, Taylor, Dodd, & Shields, 2012). Structured and unstructured exercise interventions have been shown to increase physical activity levels, however gains are often not maintained upon program completion, thus potential long-term benefits are limited (Bania, Dodd, & Taylor, 2011).

The Stay-FIT program of research was created to investigate physical activity and sustainable active lifestyle programs for youth with CP. A series of three projects have examined the facilitators and barriers to participating in physical activity faced by youth with CP and explored strategies on how to promote sustainable participation. The findings will inform the development and evaluation of comprehensive, community-focused programs to promote and maintain a physically active lifestyle for youth with CP. The first project explored the circumstances that make it easy or hard for youth with CP to participate in physical activity (Shimmel, Gorter, Jackson, Wright, & Galuppi, 2013). Four major themes were identified through interviews with youth with CP and their caregivers from six Ontario communities:

1. Youth with CP experience personal and environmental factors that act as barriers and facilitators to participation in physical activity.
2. Impairments of body structures and functions can inhibit the ability or desire to be physically active.
3. Perceived health benefits alone do not motivate youth to be physically active; social and fun aspects are important.
4. A wide range of physical activity options and accommodations is necessary to meet the diverse preferences and needs of youth with CP.

The objectives of the second project were to confirm and expand on the findings of the first project by adding the perspectives of pediatric rehabilitation professionals and including a wider geographical area across the province of Ontario.

How was the information collected?

One hundred and nine pediatric rehabilitation professionals from the Ontario Association for Children's Rehabilitation Services centres responded to an online survey. The survey asked respondents to rate and comment on their perceptions of the knowledge and attitudes of stakeholders (youth, families, professionals in the health care and education systems, and community recreation staff) regarding the short- and long-term benefits, the youths' motivations, and various personal and environmental characteristics of participating in physical activity.

Participants were also asked to suggest strategies to promote participation in physical activity through an open-ended narrative question: “Imagine you have just received \$100,000 to spend on resources to promote physical activity in adolescents with CP in your community over the next year. Please provide a breakdown of how you would spend this money.”

What was found?

The following is a summary of the responses.

Knowledge translation is an important component

- Awareness of the short- and long-term health benefits of exercise can contribute to participation in physical activity. Many youth and their families may be unaware of the benefits. There was general agreement that youth recognize value in stretching and strengthening muscles, enhancing fitness and endurance, and maintaining or improving movement abilities, however, they may have less awareness of how exercise can mitigate fatigue and pain or help in maintaining a healthy weight.
- Knowledge on how to exercise safely and efficiently is also important.
- Marketing physical activity opportunities and resources through promotion and advertising of available programs is necessary, as many families are unaware of the resources available to them. Electronic communication and social media provide many options and opportunities.
- Knowledge translation is important for engaging the youth and their families, but also for teachers and community coaches, instructors, and volunteers, as they contribute to informed, encouraging, and supportive exercise environments through their relationships with youth.
- The responses suggest health promotion roles for pediatric rehabilitation professionals in their interactions with their client and family and in educational and community settings.

Knowledge alone may not be enough to motivate youth

- Knowledge of health benefits does not necessarily translate into healthy living behaviours. Socializing with peers and having fun were ranked highest as motivators for participation in physical activity. To achieve optimal participation in physical activity, strategies should take advantage of youth’s desire for participation in fun and social activities. Programs that achieve physical activity as a collateral benefit of social experiences should be explored. Conversely, participation in physical activities can provide youth with opportunities to socialize, participate in community activities, develop skills, and make new friends.

Welcoming communities and infrastructure where the physical, social, and attitudinal environments are conducive to sustained physical activity participation for youth with CP

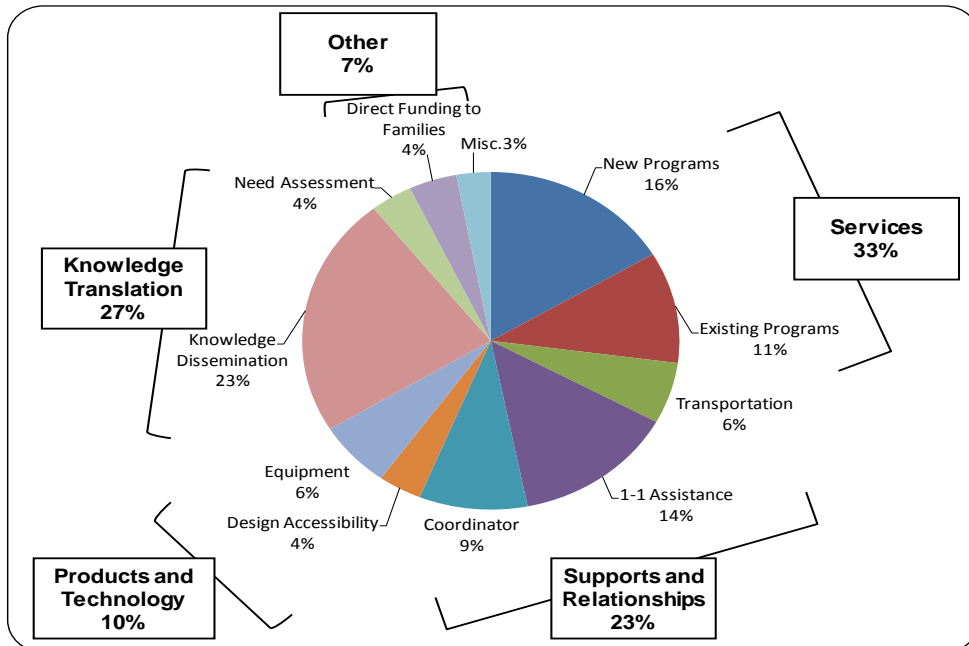
- The survey results suggested that a safe and accessible environment providing diverse and equal opportunities is needed to encourage physical activity for youth with CP of all levels and abilities. Suggestions were categorized using the following ICF-CY domains:
 - *Design and construction* – accessible and safe gyms, equipment, pools, parks, and transportation.

- *Supports and relationships* – Program coordinators who promote, communicate, schedule, and monitor programs; attendants for safety, personal care, or access to programs; specialized personal trainers to set up programs for individuals.
- *Services* – a wide variety of programs including some where youth can exercise with peers of similar abilities; opportunities for youth in their educational settings; partnerships between children’s treatment centres and community programs/facilities.

Other Thoughts

- Early intervention and sustainability were recurring themes. Programs, systems, and policies that focus on fostering positive attitudes and finding activities youth will enjoy across their lifespan will “keep awareness alive” into adulthood. Family education needs to start in the preschool years.
- Ongoing needs assessments and evaluations are necessary to determine which approaches are working or not working in respective communities so that appropriate adjustments in programs and services can be facilitated.
- Resources for youth with CP could also be useful for people in other age groups or with different diagnoses.

Figure 1. Figure displaying allocation of funding proposed by participants in response to the narrative question.



References

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