



CIHR Team in Optimal Environments for Severely Disabled Youth:

PHASE 1 REPORT

“It’s just fun to be around somebody as opposed to being in your room by yourself on a computer.”

“On the outside, I know that people know that I’m in a wheelchair because it’s visible. I’m used to people watching me wherever I go, but I don’t really care. This is what makes me me. On the inside I’m a helpful, caring, sweet person.”

“I love Facebook because this is the one area that I have control over how I express myself. I feel like I’m more independent and can really be me there.”

~ Quotations from study participants

What are Activity Settings?

- Activity settings are places in the home and community in which people ‘do things’. Examples are going to a concert, watching a video at home, or going shopping with friends (King, Rigby, & Batorowicz, 2013).
- Optimal activity settings are those that provide positive experiences, such as enjoyment, self-development, challenge, choice and control, self-understanding, or a sense of belonging.

Why is it Important to Understand Optimal Activity Settings for Youth?

Little is known about how youth—either with or without disabilities—view their home and community activity settings (Holloway & Valentine, 2000). It is important to know the qualities of activity settings that make youth feel happy, involved, and fulfilled, and those that have the opposite effects. There are implications for services and the community opportunities available to youth, especially those with physical disabilities.

What was Done?

This summary reports findings from the first phase of a two-part project investigating optimal activity settings for youth. In this first phase, we developed

a series of tools to capture youth’s experiences. Our next aim is to determine the qualities of settings associated with specific types of experiences.

The three parts to the project were:

- A. Self-Reported Experiences of Activity Settings (SEAS)** – In Study A, youth completed a questionnaire that measures 5 types of experiences, including Personal Growth, Psychological Engagement, Social Belonging, Meaningful Interactions, and Choice & Control (King, Batorowicz et al., 2013). The SEAS was found to have good psychometric properties.
- B. Photo Elicitation** – In Study B, youth took photos and videos. These were then used in qualitative interviews in which they discussed their experiences (Gibson et al., 2012).
- C. Heart ECG Acceleration Respiration Transdermal (HEART) Measure** – In Study C, youth wore sensors to capture physiological signals in activity settings. The aim was to develop a language-free measure using physiological sensors to help us understand youth experiences when they are unable to verbally tell others how they feel (Kushki et al., 2012).

We also developed an observational Measure of Environmental Qualities of Activity Settings (MEQAS) (King et al., 2012). This measure captures the pleasantness of the physical environment; opportunities for social and physical activities; and opportunities for choice, personal growth, and to interact with adults.

We then used these measures to better understand how youth experience every-day activity settings of a voluntary nature.

Who Participated?

Fifty youth took part in one of three parts to the project. The youth with disabilities who took part had complex continuing care needs, used augmentative and alternative communication systems, and/or had cerebral palsy.

	Self-Report Measure	Photo Elicitation	HEART Measure
Number	10 youth with disabilities 35 without disabilities	10 youth with disabilities	11 youth with disabilities
Age	13 to 22 years	14 to 22 years	14 to 22 years
Gender	28 females 17 males	7 females 3 males	8 females 3 males

What was Found?

Four major themes emerged from the three parts in Phase 1. These indicated that taking part in activities with others is important to them, but also could present challenges. The themes also indicated the types of activities that youth took part in, and their experiences.

1. Tradeoffs in making choices

For youth with disabilities, there are tradeoffs in the choices they make with respect to participating in activity settings. Time to travel, effort, and physical accessibility affected their selection of recreation and leisure activities (Study B).

2. Assemblages

Specialized networks of technologies, personal assistance, and accessible places were needed for engagement in preferred activities (Study B). For example, participants used video game

controllers in a variety of new ways in partnership with others to enable play.

3. Involvement in a variety of activity settings

Youth took part in the following types of activity settings (Study A):

Type of Activity Setting	Examples	Percent of Youth Taking Part	
		Youth with disabilities	Youth without disabilities
Active physical	playing sports working out running	11%	33%
Recreational	watching TV/movies playing video/board games	49%	24%
Social	hanging out listening to music	19%	14%
Skill-based	taking music lessons sports team practice	5%	14%
Self-improvement	homework work volunteering	16%	16%

The most common activities for youth without disabilities were: sports/physical activities, chores, hanging out, and doing arts activities. The most common activities for youth with disabilities were: chores, hanging out, computer/Internet activities, and playing board games.

4. Nature of experiences

Youth reported having a variety of social, psychological, and physical experiences (Studies A and B). Good experiences included having fun, feeling calm and relaxed or energized, learning something new, enjoying oneself, feeling good/excited/ happy/proud, and being around friendly and positive people. Bad experiences included not having the time to express oneself, being in an environment that is over-crowded, not experiencing anything new, feeling tired, feeling uncomfortable, being ignored/not included/unappreciated, and being overwhelmed.

The SEAS indicated that youth's most common types of experiences in their chosen activity settings were psychological engagement

(having fun, being in a good mood, interested), social belonging, and a sense of control or choice.

What Does this Mean?

Implications for Youth

- The most common type of leisure activity setting was recreational activities and the least common was skill-based activities. Youth with disabilities were less likely to engage in active physical activities, which we know from previous research.

Implications for Service Providers

- This study developed a range of tools that can be used to understand how youth experience activity settings, including life skills programs offered by rehabilitation centres.

Implications for Families

- The findings suggest the importance of providing children with choices from an early age, and encouraging/enabling social interaction.

Conclusion

This study provided insights into what youth do on their leisure time and the types of experiences they typically have in these activity settings. Youth with and without disabilities reported similar experiences but youth with disabilities were less likely to take part in sports or physical activities and had limited opportunities to socialize.

What are our Next Steps?

We are presently completing a study to explore the experiences of youth with disabilities within different activity settings. A total of 21 youth with severe disabilities have participated. We will report on their activity settings and experiences, with the goal of identifying the qualities of activity settings that are most highly associated with optimal experiences.

Thanks

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References

- Gibson, B., King, G., Teachman, G., Mistry, B., & Hamdani, Y. (2012). *Activity/assemblages: Enabling connectivities for disabled youth*. Paper presented at the Qualitative Health Research Conference, Montreal, QC.
- Holloway, S., & Valentine, G. (Eds.). (2000). *Children's geographies: Playing, living, learning*. London: Routledge.
- King, G., Batorowicz, B., Rigby, P., McMain-Klein, M., Petrenchik, T., Thompson, L. et al. (2013). *Development of a measure to assess youth Self-reported Experiences of Activity Settings (SEAS)*. Manuscript submitted for publication.
- King, G., Rigby, P., & Batorowicz, B. (2013). Conceptualizing participation in context for children and youth with disabilities: An activity setting perspective. *Disability and Rehabilitation*. Retrieved from doi: 10.3109/09638288.2012.748836.
- King, G., Rigby, P., Batorowicz, B., McMain-Klein, M., Thompson, L., & Petrenchik, T. (2012). A direct observation measure of environmental qualities of activity settings (MEQAS). *Developmental Medicine and Child Neurology Abstracts*, 54(Suppl. 6), 30.
- Kushki, A., Andrews, A. J., Power, S. D., King, G., & Chau, T. (2012). Classification of activity engagement in individuals with severe physical disabilities using signals of the peripheral nervous system. *PLoS ONE*, 7(2), e30373. doi:10.1371/journal.pone.0030373.