

BACKGROUND

- The International Classification of Functioning, Disability and Health (ICF) defines **participation** as "ones involvement in all areas of life".¹
- Despite recent **policy in Ontario** promoting social inclusion—*Services and Supports to Promote Social Inclusion of Persons with Developmental Disabilities Act (2008)*, individuals with intellectual and developmental disabilities (IDD) exhibit **less community participation**, have fewer social relationships, and lower leisure and employment rates than the general population.²
- Ample research exists highlighting the support needs of individuals with IDD who also have **behavioural support needs (BSN)**,^{3,4,5} yet none identifies their participation profile and related support needs in Ontario.
- CAOT states that "Occupational therapists [OTs] have the knowledge and skills to identify factors that allow people to engage in daily activities and to facilitate the removal of barriers to participation",⁶ which suggests a broader role for OTs to play in supporting adults with IDD.
- In a recent survey of over 200 parents seeking Developmental Services Ontario (DSO) supports for their adult son or daughter with IDD, only 1 explicitly requested OT,⁷ suggesting a **lack of awareness of the role for OT** among those who often seek formal services.
- The present study stems from a larger project examining the experiences of parents seeking supports from DSO for their adult child living at home at the time of request.

OBJECTIVES

- Examine the types of behaviour for which individuals require support and determine if this changes over time;
- Describe the community participation profile of adults with IDD who also have BSN;
- Explore what parents perceive would improve the family situation in relation to the behavioural issues of their son or daughter.

METHODS

- Design:** Cross-sectional, Ontario-wide, Mixed methods
- Participants:** 120 parents of adults with IDD seeking services and supports from DSO completed a baseline and 24 month follow-up telephone interview and mailed survey.
- Individuals with IDD were mostly male (64.2%) and ranged in age from 18-51 years, with 45% between 18-22 years old.
- Measures:** Parents were asked if their child required behavioural support needs (BSN) defined as behavioural issues that were diagnosed or required ongoing professional support. The Participation Environment Measure-Children/Youth (PEM-CY)⁸ provided the participation frequency at the 24-month follow-up. Open-ended questions were asked at this time to identify if BSN had changed and what would improve their family situation.
- Analysis:** Quantitative analyses were used to determine community participation profiles. Qualitative analyses were used to establish the behaviours of adults with IDD and perceived support needs as reported by their parents.

RESULTS

- In a sample of 120 parents, the proportion of individuals with IDD reported to have BSN increased from 46.7% to 52.5% over a period of 24 months while waiting for DSO services
- Aggressive behaviours** were most frequently reported.
- Common themes parents discussed surrounding behavioural support needs were related to: **TRANSITIONS** **SAFETY** & **COGNITION**

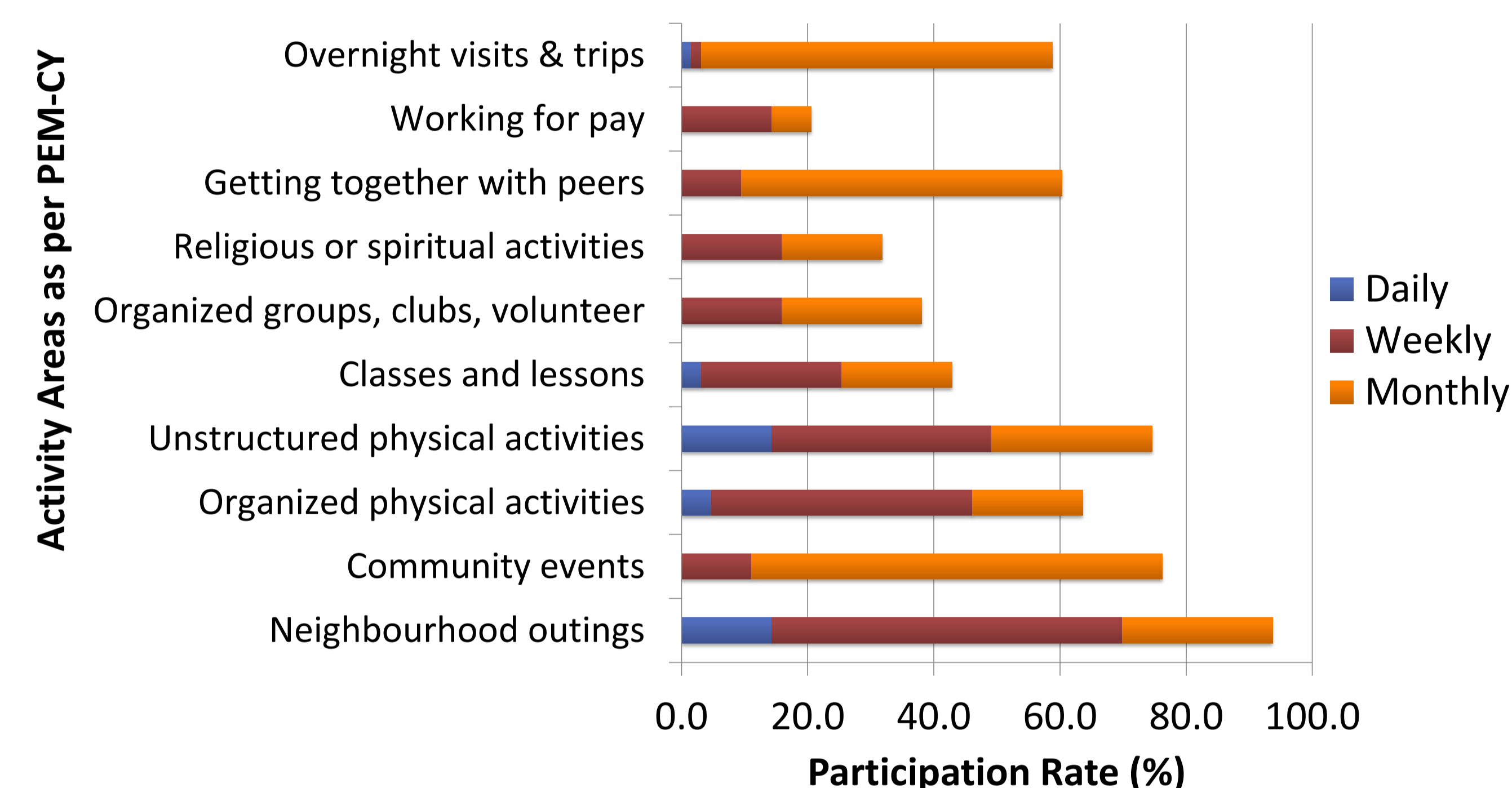
RESULTS CONTINUED

COMMONLY REPORTED BEHAVIOURS

- "When he gets angry he goes around slamming and punching...I worry about my own safety."
- "Because she's very friendly [she] doesn't know about strangers, traffic, etc."
"He'll jump out of my car when I'm driving...any time he's unsupervised I worry".
- "[His] outbursts are getting better. We needed to help him find better ways for him to communicate... he was teasing another client in his program...[who] had hit him"

COMMUNITY PARTICIPATION PROFILE

Figure 1. Proportion of adults with IDD and BSN who participated in activities at 24 months follow-up (n=63)



- 20.6% of this group **work for pay** compared to 61.3% of Ontarians⁹
- Between **38.1% and 61%** of this group participate in some form of **social activity** compared with 62% of Ontarians¹⁰
- 50.8%** of this group does not meet Canadian Physical Activity Guidelines for adults (18-64 years)¹¹

Figure 2. WHAT PARENTS SAY WOULD IMPROVE THE FAMILY SITUATION

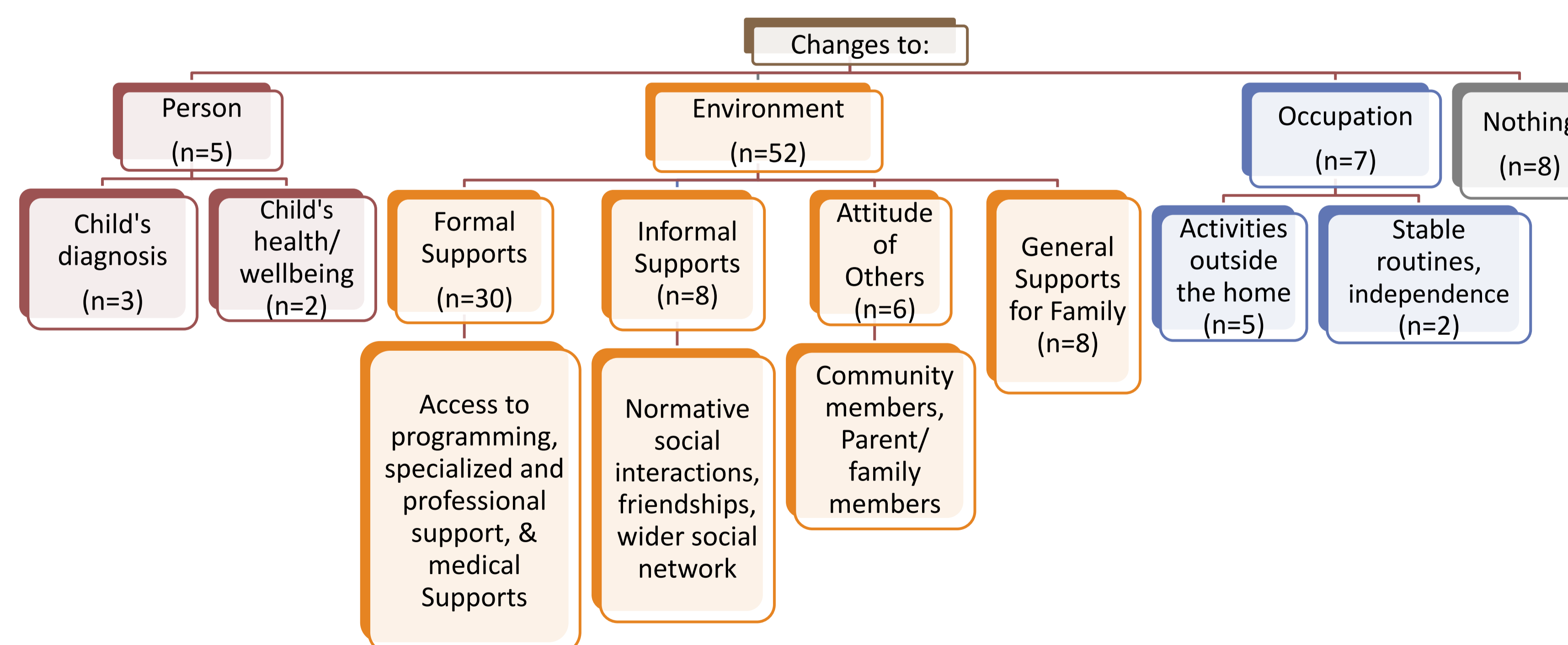


Table 1. Frequency of behaviours at baseline and 24 months follow-up (n=120)

Type of Behaviours	Baseline n (%)	24 Month n (%)
Any behavioural support need (BSN)	56 (46.7)	63 (52.5)
Aggressive (e.g. Self-injurious, injury to others, anger, frustration, threatening)	29 (24.2)	27 (22.5)
Risky (e.g. running away, lack safety re: strangers, traffic, money, health)	18 (15.0)	14 (22.2)
Disruptive (e.g. Non-violent tantrums, yelling, disturbances in sleep, socially inappropriate)	13 (10.8)	14 (11.7)
General* (non-specific, not clearly described)	18 (15.0)	19 (15.8)

*mutually exclusive from other categories

DISCUSSION

- The community participation profile of adults with IDD and BSN supports existing research around the low frequency of participation, providing evidence of several areas where the proportion of this population is below that of the general Ontario population^{9,10,11}.
- Challenging behaviours are recognized as an area of concern for families of adults with IDD^{3,4,5}. The types of behaviours reported by the present sample echo those identified in the research (i.e. injurious, destructive, and restrictive behaviours)⁵.
- Although the proportion of aggressive behaviours appears to decrease over time, overall more parents reported BSN at the 24 month follow-up.
- Parents overwhelmingly indicated that changes to their environment, especially access to formal supports such as professional and medical supports, would improve their family situation regarding their son or daughter's behavioural issues. Yet, parents are generally unaware of the role of OT when seeking services.

TAKE HOME MESSAGES

- Increased awareness** of a broader OT role is needed as OTs are well suited to work with adults with IDD and their families to address person, occupation and in particular, **environmental barriers** to participation.
- There is a **need for supports** to address behavioural issues that: a) arise in periods of transition, b) may be related to cognitive deficits, and c) address safety considerations for the individual with IDD.

ACKNOWLEDGEMENTS

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REFERENCES

- World Health Organization. (2001). International Classification of Functioning, Disability and Health (ICF). Retrieved from <http://www.who.int/classifications/icf/en/>
- Verdonschot, M., deWitte, L., Reichrath, W., Buntinx, W., & Curfs, L. (2009). Community Participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research*, 53(4), 303-318.
- Soenen, S., Van Verckelaer-Onnes, I., & Scholte, E. (2009). Patterns of intellectual, adaptive and behavioral functioning in individuals with mild mental retardation. *Research in Developmental Disabilities*, 30(3), 433-444.
- Daunhauer, L.A. & Fidler, D.J. (2011). The down syndrome behavioral phenotype: implications for practice and research in occupational therapy. *Occupational Therapy Health Care*, 25(1), 7-25.
- Perez, M., Carlson, G., Ziviani, J., & Cuskelly, M. (2011). Contribution of occupational therapists in positive behaviour support. *Australian Occupational Therapy Journal*, 59(6), 428-436.
- Canadian Association of Occupational Therapists: ACE. (2014). Occupational therapy and social inclusion [fact sheet]. Retrieved from http://www.caot.ca/otmonth/OTandSI_FS.pdf
- Ouellette-Kuntz, H., Lunskey, Y., Blinkhorn, A., Robinson, S., & Tint, A. (2013). Parents Seeking Adult Developmental Services for their Children: A Provincial Study [Phase II] Report on Six Months of Follow-up. [Kingston, Ontario, Canada] (see www.mapsresearch.ca).
- Coster, W., Law, M., Bedell, G., Khetani, M.A., Cousins, M., & Teplicky, R. (2012). Development of the Participation and Environment Measure for Children and Youth: Conceptual basis. *Disability and Rehabilitation*, 34(3), 238-46.
- Employment and Social Development Canada. (n.d.) Work-employment rate. Retrieved from http://well-being.esdc.gc.ca/misme-iowb/.3ndic.1t.4r@-eng.jsp?iid=13#M_1
- Employment and Social Development Canada. (n.d.) Participation in social activities. Retrieved from http://well-being.esdc.gc.ca/misme-iowb/.3ndic.1t.4r@-eng.jsp?iid=70#M_4
- Participation. (n.d.) Canadian physical activity guidelines for adults 18-64 years. Retrieved from <http://www.participation.com/get-started/physical-activity-guidelines/guidelines-for-adults/guidelines-for-adults-18-64-years/>