

BACKGROUND

Recently, there has been increasing awareness of the supports needed by individuals with intellectual and developmental disabilities (IDD) to participate in community activities. In particular, attention has focused on the needs of those with behavioural issues. Yet, it is known that individuals with IDD exhibit less community participation, fewer social relationships, and lower leisure and employment rates¹ than the general population. What is less clear is how individual and environmental factors interact to create such conditions and how best to support adults with IDD for full and meaningful participation in community life.

The transformation of the current developmental services sector in Ontario, Canada and beyond is in line with the principles of Occupational Justice, wherein the environment promotes access to adequate supports and resources that enable individuals to participate in meaningful occupations². While occupational therapists (OTs) "have the knowledge and skills to identify factors... to facilitate the removal of barriers to participation"³, only one parent explicitly requested OT in a recent study of over 200 parents seeking developmental services for their adult sons or daughters⁴. This suggests a general lack of awareness of the potential OT role with this population.

The current project stems from a larger research initiative entitled Multidimensional Assessment of Providers and Systems (MAPS), intended to identify quality indicators for the developmental services sector in Ontario. This study hoped to better define the role of OT in working with individuals with IDD by contributing knowledge on the community participation of this population.

OBJECTIVES

1. Identify the community participation profile of adults with IDD who also have behavioural support needs (BSN) and determine if their profile differs from those without BSN;
2. Examine individual and family demographic and environmental factors that may influence participation; and
3. Explore the perceived support needs identified by parents.

METHODS

Design: Cross-sectional, province-wide survey

Participants:

- N=118 parents of 120 adults with IDD
- Most (64.2%) adults with IDD were male
- 45% would have recently left school (age 18-22). The rest were between 26 -36 years old.
- Among those identified as having BSN (n=63), aggression was the most commonly reported concern

Measures:

- Participation Environment Measure-Children/Youth (PEM-CY)⁵ provided the participation frequency, level of involvement & environmental factors

Analysis:

- Quantitative analyses were used to compare community participation profiles, determine significant differences in frequency and involvement scores and reveal which demographic/environmental variables were associated with greater community participation
- Open-ended responses as to the perceived supports needed for individuals with IDD and BSN were analyzed qualitatively.

DISCUSSION

Despite ample literature that exists highlighting the support needs for individuals with IDD and behavioural issues^{6,7,8}, no difference was found between the rate of participation or involvement in community activities between those with and without behavioural issues.

Interestingly, the only variable significantly associated with community participation was an environmental variable pertaining to the physical demands of the activity. Whether this is due to individual capacities or the types of activities commonly available in communities is unknown. However, these findings indicate that participation is not determined by demographic variables such as age, diagnosis or household income.

Highlighting the role of the environment as a significant contributor to community participation emphasizes an important role for OTs to play in supporting this population. Moreover, qualitative analysis suggests that parents express a need for greater professional services in this area and as such may be receptive to OT services.

TAKE HOME MESSAGES

- The recent shift promoting social inclusion of individuals with IDD is well suited to the scope of OT.
- Although families identify a need for more professional supports, they are generally unaware of the potential relevance of OT services.
- This research provides evidence for a larger role for OTs to play in supporting adults with IDD and their families that fills a gap in the existing structure of developmental services.

ACKNOWLEDGEMENTS

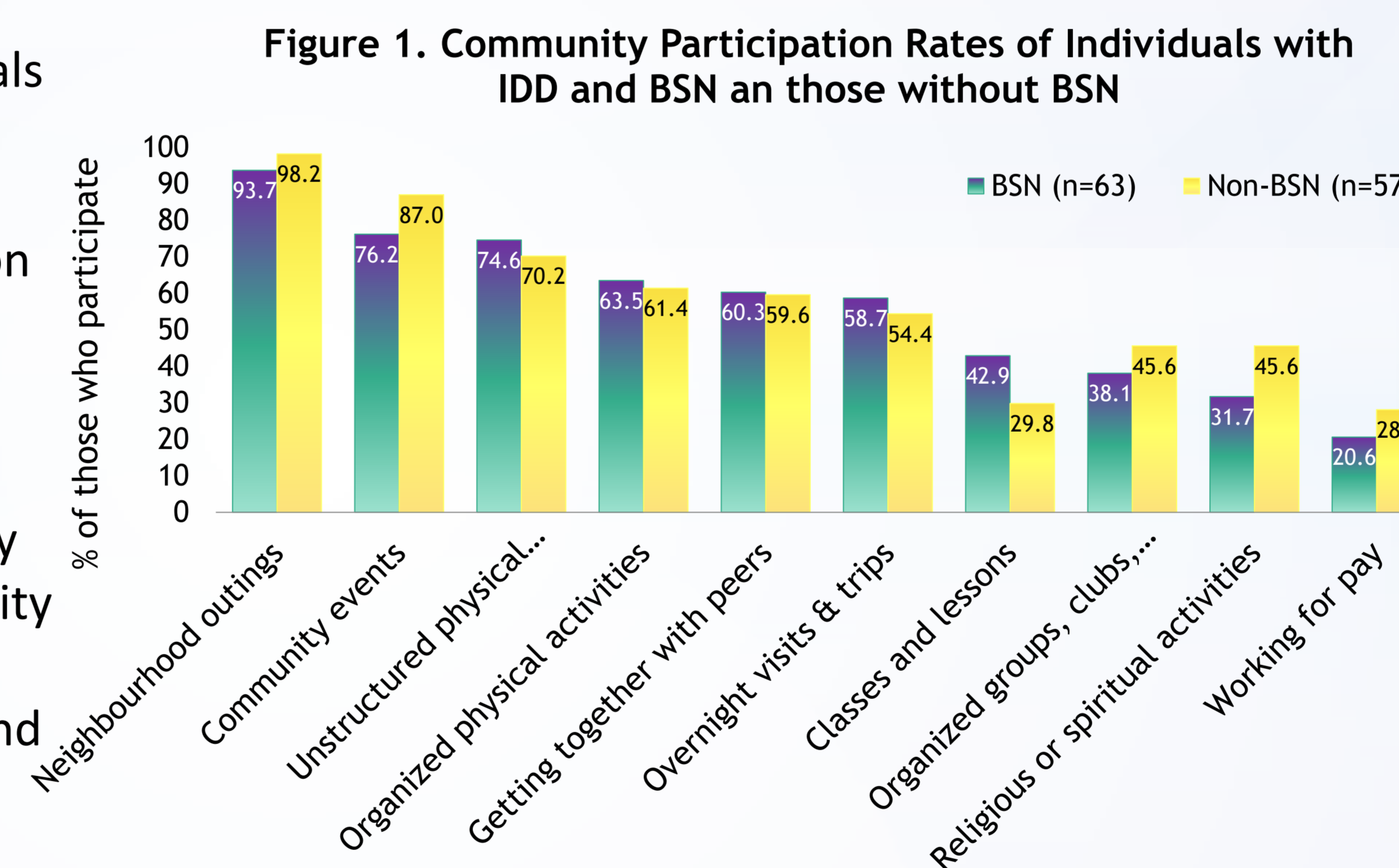
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The views expressed are not necessarily the views of all MAPS partners.

RESULTS

1. What does the community participation profile look like and how does it compare?

- The proportion of individuals participating in activities at least once in the last 4 months varies depending on the type of activity (see Figure 1)
- No significant difference between average frequency or involvement in community participation was found between those with BSN and non-BSN.



2. What factors influence community participation?

- Of the total sample (n=120), no demographic factors were significantly associated with participation
- Of the environmental factors measured (i.e. the sensory, physical, cognitive & social demands of the activity, relationships, attitudes, weather, access to transportation, services, information, equipment, time & money), only one (1) was significantly associated with participation: *the physical demands of the activity*.

3. Parents of individuals with IDD and BSN said that **enhanced professional and medical supports would improve their family's situation**

REFERENCES

1. 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.
2. Townsend, E. & Wilcock, A.A. (2004). Occupational justice and client-centred practice: a dialogue in progress. *Canadian Journal of Occupational Therapy*, 71(2), 75-87.
3. Canadian Association of Occupational Therapists: ACE. (2014). Occupational therapy and social inclusion [fact sheet]. Retrieved from http://www.caot.ca/otmonth/OTandSI_FS.pdf
4. 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).
5. 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.
6. Soenen, S., Van Vercckelaer-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.
7. 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.
8. 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.