Disability policy in Canada and new funding initiatives: Innovative or opportunistic?

ONE-SIZE-FITS-ALL

Since the 1800s, people with intellectual disabilities in Canada have had minimal opportunity to experience true freedom and self-determination in their own lives. This struggle persists as a result of limitations in the equitable assessments used to establish funding for many Canadians with intellectual disabilities. Currently in Canada, most people with intellectual disabilities rely on provincial government funding for all aspects of their lives. Government departments across Canada are increasingly seeking measures to develop and implement standardized funding models. These models are outcome-based and create a one-size-fits-all approach to the funding provided to people with intellectual disabilities. Provincial governments are also moving toward the exclusive use of quantitative methodologies, excluding qualitative measures, to assess and determine funding for adults with intellectual disabilities. This is done to produce outcome-based data, which are viewed as objective and concrete, rather than qualitative data, which are viewed as subjective and non-tangible.

Of note is the Supports Intensity Scale (SIS) assessment tool, which is currently being used in Manitoba and Ontario as the sole tool to assess and measure the level of funding each qualifying adult receives from the province. The SIS quantitatively "measure[s] the level of supports that a person with an intellectual disability needs in order to successfully participate in areas such as home living, community living, lifelong learning, employment, health and safety, and social activities" (Government of Manitoba, 2017).

QUESTIONS ABOUT THE SIS TOOL

There remains much skepticism about whether the SIS is a valid and reliable

BY ANGIE CONRAD

Angie Conrad is a completing a master's degree in public administration at the University of Manitoba. Her research focuses on disability policy, and state–civil society relations. She is currently a manager at a non-profit social services organization in Winnipeg.

tool to measure and determine funding levels, which ultimately shape services for people. Much of the criticism is levelled at the administration of the assessment, which produces biased data that often reflect only the opinions of others, not the opinions of those receiving support. Another criticism is that the SIS has been manipulated by government departments for use as a tool for reducing funding, rather than for its intended purpose as an assessment tool to measure a person's support needs. Currently, SIS assessments to determine funding are being used by provincial governments as a move toward an "increasing emphasis on outcomes and performance assessments" (Jenaro et al., 2013, p. 497). Provincial governments stress that "it is important to examine support needs at the population level, to ensure that public services meet the requirements of clients in the community and to improve resource capacity and allocation" (Weiss et al., 2009, p. 933). Indeed, in recent years, "the SIS has become the measure of choice among state and provincial governments who aim to understand and analyze the service needs of their citizens with intellectual disability" (Weiss et al., 2009, p. 934). The issue with implementing the SIS is that it removes any autonomy, individual rights, and choice that persons should receive in order to exercise their freedom and self-determination. In 2010, Developmental Services Ontario, within the Ministry of Community and Social Services, adopted the use of the

SIS as the criterion for receiving services. "The SIS is intended to be used in conjunction with person-centred planning processes to assist planning teams to develop individualized support plans that are responsive to the needs and choices of persons with disabilities" (CSCN, 2010, p. 3). However, the SIS is being used by Manitoba and Ontario as the only tool for determining the support needs of individuals. As a result, the tool becomes invalid because it not being used with person-centred planning, which also includes factors such as quality of life.

MISSING MEASURES: QUALITY OF LIFE

Proponents of the SIS argue for the validity of the SIS as a proven, reliable tool to determine the funding needs for people with intellectual disabilities. They argue that the "SIS has potential, if used insightfully, to document the support required to make a good life a reality for the people we serve" (Swanton et al., 2010, p. 26). Further, "the SIS scores provide valid information regarding the intensity of support needs of individuals with intellectual disability currently receiving services" (Weiss et al., 2009, p. 939). While the SIS does quantitatively measure a person's functional areas, it excludes any qualitative areas such as quality of life.

The major flaw with this approach is that the administration of the SIS needs to be more holistic. It is important to include "both objective measures (e.g. functional assessment characteristics) and subjective measures (e.g. Life Satisfaction) in order to get a better understanding of the [quality of life] of people with [intellectual disabilities]" (Schwartz & Rabinovitz, 2003, p. 83). The main issue with using the SIS as the sole assessment tool in assessing funding is

that it leaves out other proven and valid ways of determining the funding needs of people, particularly in the measurement of the quality-of-life indicators. For example, the Personal Outcomes Measures tool could be a good complement to the SIS assessment. It measures 21 indicators that are used to "understand the presence, importance and achievement of outcomes, involving choice, health, safety, social capital, relationships, rights, goals, dreams, [and] employment" (Council on Quality and Leadership, 2017) as determined by the person and his or her support network.

ETHICAL QUESTIONS

There are also ethical questions around the use of SIS as a tool to measure needs and establish funding for a person with an intellectual disability. The criticism is that the tool is considered inhumane, because its implementation subjects people to invasive questions over a period of hours or days. "Many individuals and families have complained about the humiliating experience of being subject to the hours long interrogation of a SIS assessment that has little to offer in advancing their hopes and dreams" (Inclusion Alberta, 2016). In 2016, Alberta repealed its use of the SIS for this reason. The Alberta minister for human services stated that the government is "committed to reviewing the SIS and bringing in a policy that is more respectful in gauging the supports that people with developmental disabilities need" (Inclusion Alberta, 2016). Abilities Manitoba, a coalition of community-based organizations offering services for people with intellectual disabilities in Manitoba, believes that "the system needs a quality assurance framework to ensure value for money. The framework needs to be value-based and person-centered with measurable goals and tools for improvements" (Abilities Manitoba, 2017). This further strengthens the argument that a holistic approach, which includes an individual's assessment of what quality of life entails for

Scholarly literature that scrutinizes and questions the validity and reliability of the SIS as an assessment tool for determining funding and services for people with intellectual disabilities remains non-existent.

them, needs to be in place. As long as the SIS assessment remains the sole criterion for funding, the quality of services that people receive is at risk.

To date, there is little research into the validity and reliability of the SIS or its implementation in determining funding and ultimately the lives of people with intellectual disabilities. The scholarly literature on the SIS is unbalanced because it only promotes the validity and positive value that the tool brings to the field of intellectual disability. Scholarly literature that scrutinizes and questions the validity and reliability of the SIS as an assessment tool for determining funding and services for people with intellectual disabilities remains non-existent. This provides an exciting opportunity for more research and the development of practical applications in these areas in order to provide a balanced approach to the topic and to offer people with intellectual disabilities a future with greater freedom and self-determination.

REFERENCES

Abilities Manitoba. (2017). Our first (of three) priority goals! Retrieved from http://www.abilitiesmanitoba.org/our-first-priority-goal/

Community Services Coordination Network (CSCN). (2010). 2009-2010 annual report. Retrieved from http://cscn.on.ca/site/application/files/4314/3698/4958/2009-2010-annual-report.pdf

Council on Quality and Leadership. (2017). Personal outcomes measures. Retrieved from https://www.c-q-l.org/the-cql-difference/personal-outcome-measures

Government of Manitoba. (2017, June). Supports Intensity Scale (SIS). Retrieved from http://www.gov.mb.ca/fs/pwd/sis_fact_sheet.html

Inclusion Alberta. (2016). Inclusion Alberta applauds minister's commitment to end the use of "SIS." Retrieved from http://inclusionalberta.org/news/2016/06/02/feature-story/inclusion-alberta-applauds-minister-s-commitment-to-end-the-use-of-sis/

Jenaro, C., Vega, V., Flores, N., & Cruz, M. (2013). Quality of services and quality of life from service providers' perspectives: Analysis with focus groups. *Journal of Intellectual Disability Research*, *57*(6), 489-499.

Schwartz, C., & Rabinovitz, S. (2003). Life satisfaction of people with intellectual disability living in community residences: Perceptions of the residents, their parents and staff members. *Journal of Intellectual Disability Research*, *47*(2), 75-84.

Swanton, Sandra, Walsh, Siobhan, O'Murchu, Ronan, & O'Flynn, Pat. (2010). A tool to determine support needs for community life. *Learning Disability Practice*, *13*(8), 24-26.

Weiss, Jonathan A., Lunsky, Yona, Tasse, Marc J., & Durbin, Janet. (2009). Support for the construct validity of the supports intensity scale based on clinician rankings of need. *Research in Developmental Disabilities: A Multidisciplinary Journal*, *30*(5), 933-941.