

Quality Improvement in Ontario's Developmental Services System

In Ontario, the Ministry of Community and Social Services (MCSS) funds over 300 community-based agencies that provide services to adults with intellectual and developmental disabilities (IDD) to support them in living, working and participating in a wide range of activities in their communities. Over the last few years, MCSS has undertaken efforts to transform the developmental services sector. The closure of all institutions and the creation of Developmental Services Ontario organizations to help adults with IDD connect to supports in their communities are two such efforts. Arguably one of the most important transformation initiative has been the adoption of the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (SIPDDA, 2008)*, which replaced the *Developmental Services Act*, repealed in 2011. The SIPDDA aims to build on a successful transition to community-based supports to further promote the social inclusion of adults with IDD, and governs the services and supports provided to adults with IDD. This Act is in keeping with international efforts to respect and protect the rights of persons with disabilities.

Through these initiatives, Ontario has furthered its commitment to improve the services provided, and has taken steps toward monitoring the implementation and impact of these efforts. In particular, MCSS has developed a set of quality assurance measures and regulations to support agencies in planning and providing high-quality services. Among these measures, one specifically targets the promotion of social inclusion. Therefore, there is also a need to assess and monitor the extent to which the developmental services sector is successfully promoting and facilitating social inclusion.

This special issue on Quality Improvement in Ontario's Developmental Services System focusses on findings from the Multidimensional Assessment of Providers and Systems (MAPS) program (www.mapsresearch.ca), a 3-year program of research funded by MCSS (2010–2013), on the best approach for assessing and monitoring the quality of the services provided to adults with IDD in Ontario.

MAPS is comprised of a provincial transdisciplinary team of researchers, led by H el ene Ouellette-Kuntz (Department of Public Health Sciences, Queen's University) and including Virginie Cobigo (School of Psychology, University of Ottawa), Robert Hickey (School of Policy Studies, Queen's University), Rosemary Lysaght (School of Rehabilitation Therapy, Queen's University), Yona Lunsky (Department of Psychiatry, University of Toronto, and Dual Diagnosis Program, Centre for Addiction and Mental Health), and Lynn Martin (Department of Health Sciences, Lakehead University). Over the years,

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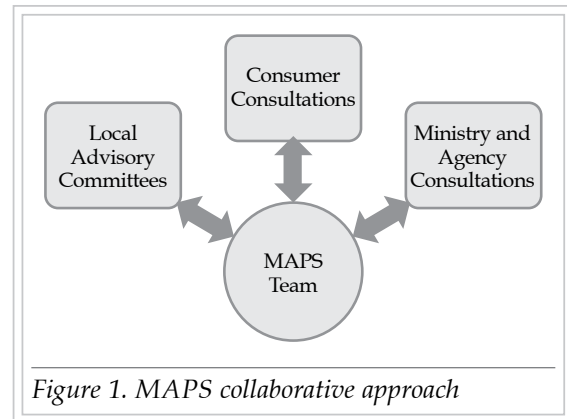
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many students from the respective institutions have been engaged. As such, MAPS researchers brought expertise in a variety of areas including epidemiology, nursing, psychology, rehabilitation, public health, social policy studies, geography, sociology, information systems, and program evaluation.

Building on the team's strengths and responding to concerns from MCSS and service agencies, MAPS studied a variety of issues, including the meaning and measurement of important concepts such as social inclusion, choice, and belonging; person-directed planning approaches; participation of adults with IDD in productive activities; the roles and practices of staff in promoting social inclusion; and the experiences of parents seeking services for adults with IDD. A variety of approaches were used to study these areas – for example, summaries of scientific knowledge; surveys, interviews and case studies; as well as examination of the data routinely collected by MCSS or service agencies that could support quality improvement practices in developmental services.

Throughout the program, the MAPS team employed a collaborative approach (Figure 1). Three times a year, the MAPS team met with local (i.e., in Kingston, Toronto, and Thunder Bay) stakeholder groups: consumer consultations and local advisory committees. Through the consumer consultations infrastructure, adults with IDD from four communities across the province contributed to the MAPS program: Central Region (Toronto), Southeast Region (Kingston and Kemptville), and North Region (Thunder Bay). The local advisory committees included family members of adults with IDD, service agency directors or delegates, and representatives of MCSS. Once a year, the MAPS team also met with representatives of MCSS, including branch directors, managers, policy analysts at the corporate level, and representatives from the regional offices.

During these consultations, the MAPS team engaged stakeholders by presenting interim research findings and asking for feedback on their relevance to Ontario with regard to the life experience of adults with IDD and their families, as well as policy and service delivery. The goal of these many consultations was also to better



understand stakeholders' perspectives on social inclusion, quality, and quality improvement.

This special issue of the *Journal on Developmental Disabilities* highlights the knowledge gained through various MAPS projects. While the papers cover a variety of topics explored through a variety of methodologies, each reports on how findings can be used to inform quality improvement in developmental services.

The issue begins with two articles that explore key concepts related to social inclusion – choice and belonging. Colleen Webber and Virginie Cobigo conducted a scoping review of the literature on choice to better appreciate how this concept is understood. In the literature, four key elements of choice emerged, including opportunities, options, actions, and support – each of which are needed for choice to occur. These themes were then explored through consultations with adults with IDD, family members, and representatives from service agencies. The challenges related to the practical implementation of the concept of choice are discussed, as are those related to its measurement in the context of service provision.

Alyson Mahar, Virginie Cobigo, and Heather Stuart provide information on the need to assess and monitor another important component of social inclusion: sense of belonging. Their literature review focused on available measures, and they identified 18 papers that presented unique methods or tools to measure sense of belonging. They note that the majority of these measures come from the field of education, with no measures having been specifically developed in the field of IDD. In measuring

belonging, the authors highlight the importance of ensuring that the information generated is both appropriate to the needs of the organization and actionable, and that different aspects of belonging are considered to ensure that the information can be used to improve service provision, and consequently, improve the sense of belonging of persons with IDD.

The next five articles focus on the experiences of adults with IDD, families, planning teams, and staff. In their paper, Rosemary Lysaght, Jami Petner-Arrey, Virginie Cobigo, and H el ene Ouellette-Kuntz studied productivity among adults with IDD receiving disability supports. They conducted a survey of work training, transition, and productivity activities among persons in the Greater Toronto, Northern, and Eastern regions of the province. These authors found regional differences in terms of productivity experiences, and provide direction for quality improvement in the area of work preparation and participation.

Two articles focus on the experiences of families. Robyn Saaltink and H el ene Ouellette-Kuntz examined the experiences of families seeking developmental services for their adult children. While it is known that parents expend a considerable amount of time to access services and are often placed on wait lists for several years, less is known about the types of efforts made by families to secure services and supports, and the extent to which these are successful. Transcripts of in-depth interviews with eight families seeking services in Ontario were reviewed. The analysis showed that parents often engaged in administrative, information gathering, relationship building and advocacy efforts when seeking services. Success in obtaining services was more likely when families had both parents living in the same household, and when the mother did not work outside of the home or have additional dependents. The authors discuss the implications of findings in terms of the amount of effort that can and should be expected of parents, and in particular mothers, seeking services.

A second paper concerning families was led by H el ene Ouellette-Kuntz. The authors studied the relationship between resilience in families of adults with IDD at the time they made a new service request for their child and their

perception of crisis six months later. Based on self-reported data from 154 parents, they found that family resilience was negatively associated with crisis. The authors conclude that family resilience is an important construct to assess when parents request adult developmental services for their child, that it can be quickly measured at the time of the initial service request, and that it is a good indicator of system responsiveness – a useful indicator of quality. Ouellette-Kuntz and colleagues also point to the need for further work examining the impact of earlier provision of supports to less resilient families, and to identify ways of fostering resilience in families of individuals with IDD so they are better able to cope when services are not readily available.

The SPIDDA legislates the use of person-directed planning (PDP) as a service to help individuals with IDD identify goals, as well as the supports and services needed to meet those goals. In their paper, Lynn Martin and H el ene Ouellette-Kuntz report on the lived experiences of planning team members to determine the extent to which their views on “good” planning fit with the framework for understanding quality PDP developed by the research team. A total of 48 individuals (including persons with IDD, families, staff, and planners/facilitators) from eight planning teams were interviewed. Team members discussed issues related to the person, the team, and the plan in a way that both aligned with, and expanded on, the conceptual framework. Confirmation of previously identified core elements of planning serves to reinforce these as areas that should be part of the approach to measuring the quality of planning.

Robert Hickey surveyed direct support professionals in Ontario’s developmental services sector to examine the complex nature of worker stress. While previous research has focused on employment practices and challenging behaviours as sources of worker stress, he found that prosocial motivation was a significant mediating variable in stress – through its interaction with positive affect or perceived organizational support, prosocial motivation was associated with higher feelings of emotional exhaustion, even when controlling for other factors. Implications for the use of quality indicators related to worker stress are discussed in light of the findings.

The issue ends with a recommended set of principles to guide the development of an approach to continuous quality improvement in Ontario's developmental services sector (Cobigo, Martin, Lysaght, Lunskey, Hickey, & Ouellette-Kuntz). The principles were developed over the three-year program of research, and through a series of activities that aimed to develop a better understanding of relevant service outcomes, namely social inclusion and choice. The MAPS program proposes that quality improvement efforts be guided by the following five principles: (1) assessment and monitoring activities are embedded within a continuous quality improvement cycle; (2) personal outcomes measured are the ones that are important to persons with IDD; (3) assessment activities represent the multidimensional nature of the desired outcomes; (4) knowledge is developed from multiple perspectives; and (5) knowledge gained is meaningful, actionable and informs policy and service improvements. Based on these principles, a possible way forward to implement a quality improvement assessment and monitoring system related to services for adults with IDD is presented. It is clear that multi-stakeholder involvement, such as has been exemplified by the MAPS program, will be required.