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Quality Improvement in Services for Adults with Intellectual and Developmental Disabilities: Guiding Principles

Abstract

Services and supports for persons with intellectual and developmental disabilities (IDD) worldwide have transitioned – or currently are – towards a community-based approach that enhances social inclusion. This paper presents principles that could guide quality improvement monitoring in community services for adults with IDD. The principles were developed through a series of activities aiming to better understand relevant service outcomes, such as social inclusion and choice; consultations with various stakeholder groups including persons with IDD; and review of available data about the users of services and supports for Ontarians with IDD. The five guiding principles are: (1) activities are embedded within a continuous quality improvement cycle; (2) activities focus on personal outcomes that are important to persons with IDD; (3) activities capture the multidimensional nature of the outcomes being measured; (4) knowledge is developed from multiple perspectives; and (5) knowledge is meaningful, actionable, and informs policy and service improvements. The paper also presents a possible way forward in operationalizing a quality improvement monitoring system related to services for adults with IDD.

International, national and regional bodies have called for demonstrated effectiveness and for improved quality in the services and supports provided to persons with disabilities. The World Health Organization (World Health Organization, 2010) recommends a community-based approach to providing supports that enhance the social inclusion and overall quality of life of persons with disabilities. The United Nations Convention on the Rights of Persons with Disabilities (UN General Assembly, 2006) reaffirms their fundamental rights, including the rights to social inclusion and individual choice. The World Report on Disability (World Health Organization, 2011) identifies persons with intellectual and developmental disabilities (IDD) as particularly vulnerable to social exclusion and poor quality of life. For instance, compared to persons with other types of disabilities, persons with IDD may not have all their support needs met in community-based settings. Furthermore, the general population may not be sufficiently aware of their abilities, which limits opportunities for social connectedness and meaningful contributions.

In Ontario (the most populated Canadian province at more than 13 million inhabitants), the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* (SIPDDA) (2008) governs services and supports provided to adults with IDD. SIPDDA is part of a transformation agenda that involved the closure of the last three residential institutions in Ontario in 2009. It aims to build on the transition to community-based supports to further promote the social inclusion of adults with IDD, and demonstrates Ontario's commitment to modernizing and improving the quality of services provided to this population. Ontario's Ministry of Community and Social Services (MCSS, 2013) has developed an accompanying set of regulations and Quality Assurance Measures to help agencies plan for and provide high-quality services and supports. MCSS funds more than 300 community agencies that provide services to adults with IDD, referred to as "developmental services." Developmental services support adults with IDD to live, work and participate in a wide range of activities in their communities. In addition, MCSS helps adults with disabilities through its social assistance programs. For example, the Ontario Disability Support Program (ODSP) provides income and/or employment supports to adults with disabilities, including those with IDD. In 2013, the province's budget announced an additional investment of $42.5 million to enhance services provided to persons with IDD and their families – especially those with complex needs, as well as reduce service delivery wait times (MCSS, 2013). In 2013, the province spent a total of $1.7 billion on developmental services (MCSS, 2013). Given this significant investment, there is interest in ensuring that the supports and services provided are of high quality, and are meeting the needs of persons with IDD and their families.

Many service agencies are committed to evaluating the quality of their services through accreditation processes and consumer satisfaction surveys. However, many stakeholders expressed concerns about service gaps. Since 2009, provincial and national media have reported stories of families waiting for services, and families who can no longer cope with their situation. The Ontario Ombudsman, an independent watchdog who investigates complaints from the public about Ontario government services, has enquired on hundreds of complaints from families of adults with IDD (report forthcoming). In 2013, the legislature convened a select committee (elected provincial representative) to investigate concerns and make recommendations for future services across the province (Legislative Assembly of Ontario, 2014).

Outside of Ontario, some jurisdictions have already invested in monitoring and quality improvement systems. For example, in the United States, 25 states and four sub-state regions are contributing information on an annual basis to the National Core Indicators (NCI) (Human Services Research Institute & The National Association of State Directors of Developmental Disabilities Services, 2013). The program is a partnership between the Human Services Research Institute (HSRI) in Cambridge Massachusetts and the United States National Association of State Directors of Developmental Disabilities Services (NASDDDS). Multiple data sources are used including interviews with consumers, family self-administered surveys, and collated agency or government-held data. The valid and reliable consumer survey gathers about 50% of the annual data on 114 indicators across five domains: (1) individual outcomes, (2) health, welfare and rights, (3) system performance, (4) staff stability, and (5) family indicators.

In the Netherlands, the *Quality Qube®* approach was developed (Buntinx Training & Consultancy, 2012) to promote quality improvement measures rather than performance indicators. One of its fundamental assumptions is that the data collected are useful when they inform the achievement of expected outcomes from the service users' perspective. The approach recognizes that comparisons and rankings alone do not lead to actions that can have positive outcomes for service users; a quality improvement cycle has to be adopted. *Quality Qube®* indicators are categorized into five domains: (1) independence, (2) social participation, (3) well-being, (4) facilitators, and (5) relationships with the service.

Both the NCI and *Quality Qube®* include the perspectives of various stakeholders (services users, families and staff members) when assessing the quality of services. Both have the capacity to report developed knowledge at different levels (i.e., team, agency, jurisdiction) to inform actions. Comparisons with other agencies or other jurisdictions are also rendered possible through standardized data collection. The capacity to monitor the quality of developmental services allowing for comparisons across agencies or regions, and across stakeholder perspectives has yet to be developed in Ontario.

This paper presents five principles that should guide efforts to assess and monitor the quality of services for persons with IDD. These principles have been developed in consultation with various stakeholders, including persons with IDD. Although this knowledge has been developed for and with Ontarian stakeholders, it applies to many other jurisdictions.

Methods

This paper reports on the work completed by the Multidimensional Assessment of Providers and System (MAPS) research program that aimed to inform the Ontario developmental services system in its efforts to monitor the quality of supports and services provided to adults with IDD (Martin & Ouellette-Kuntz, 2014).

Several activities led to the identification of the principles of quality improvement presented in this paper. First, a better understanding of social inclusion and choice was developed through reviews of the literature and an international consultation process (see Cobigo & Stuart, 2010; Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012; Lysaght, Cobigo, & Hamilton, 2012; Mahar, Cobigo, & Stuart, 2013; Mahar, Cobigo, & Stuart, 2014; Martin & Cobigo, 2011; Webber & Cobigo, 2014). Reviewed literature was not specific to the social inclusion and choice of persons with IDD, but rather explored these concepts from the perspective of members of society with and without disabilities. The consultation process involved a survey of various stakeholders, as well as presentations and workshops at international scientific conferences, including the European and world congresses of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (Cobigo, Mahar, & Stuart, 2012; Cobigo & Webber, 2012), the world congress of the World Association for Social Psychiatry (Cobigo & Webber, 2012), and the congress of the Association internationale de recherche sur le handicap mental (Cobigo, Lysaght, & Ouellette-Kuntz, 2010).

Second, initiatives in Ontario and elsewhere evaluating or monitoring the quality of services provided to adults with IDD were reviewed. Initiatives from other jurisdictions included the National Core Indicators in the USA (Human Services Research Institute & the National Association of State Directors of Developmental Disabilities Services, 2013), as well as the *Quality Qube*® from the Netherlands (Buntinx Training & Consultancy, 2012). These strategies were chosen because they provide two examples of quality monitoring of IDD services, which both facilitate the use of standardized data collection and multi-level reporting leading to action. In addition, both are led by senior academics with long-standing reputations in the IDD field.

Third, data routinely collected by MCSS and developmental services agencies (in 2010–2013) were examined to determine whether they could be used to support quality improvement practices. These data included: service satisfaction surveys, information requested by accreditation bodies, information collected on persons with IDD who receive income supports from the Ontario Disability Support Program (ODSP), and information on persons requesting services at one of the province's nine Developmental Services Ontario (DSO) offices. We described what data were collected, as well as what processes were used at the time to analyse and report developed knowledge.

Fourth, findings from projects within the overall program of research (i.e., literature reviews, surveys, interviews, and case studies related to productivity options, staff practices, parents applying for services, and person-directed planning) informed the development of indicators and data collection methods that could be used to assess and monitor quality of supports and services and inform quality improvement efforts.[1] Some of these projects used data routinely collected in Ontario. Most of them included original data collection. These projects have informed data collection feasibility in the developmental services system in Ontario.

Finally, persons with IDD and their families, service providers, and government represent-

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[1] See Cobigo et al., 2013; Hickey, 2011; Lunsky, Tint, Robinson, Vickar, & Ouellette-Kuntz, 2012; Lunsky, Robinson, Tint, Vickar, & Ouellette-Kuntz, 2013; Lysaght, Ouellette-Kuntz, Cobigo, & Petner-Arrey, 2013; Lysaght, Cobigo, Petner-Arrey, & Ouellette-Kuntz, 2014; Martin, Ashworth, & Ouellette-Kuntz, 2012; Martin, Ouellette-Kuntz, Cobigo, & Ashworth, 2012a; Martin, Ouellette-Kuntz, Cobigo, & Ashworth, 2012b; Martin, Ouellette-Kuntz, & Cobigo, 2013; Martin, Ouellette-Kuntz, Petner-Arrey, & Walker, 2013; Martin & Ouellette-Kuntz, 2014; Ouellette-Kuntz et al., 2014; Ouellette-Kuntz et al., 2011; Ouellette-Kuntz et al., 2012; Ouellette-Kuntz et al., 2013; Ouellette-Kuntz, Lunsky, Blinkhorn, Robinson, & Tint, 2013a; Ouellette-Kuntz, Lunsky, Blinkhorn, Robinson, & Tint, 2013c; Ouellette-Kuntz, Lunsky, Blinkhorn, Robinson, & Tint, 2013d; Saaltink & Ouellette-Kuntz, 2014 (all reports available upon request)

atives were consulted on the best approach to monitor the quality of services for Ontarians with IDD. The consultation structure involved regular meetings with Consumer Consultations groups (i.e., about six persons with IDD in each group), and Local Advisory Committees that included at least one family member of individuals with IDD, service agency directors or delegates, and representatives of MCSS (about 10 individuals per group, most of whom were service agency representatives) (Martin & Ouellette-Kuntz, 2014). These structures and meetings were held in three locations across the province (i.e., Kingston, Toronto, and Thunder Bay). In addition, annual meetings took place with representatives of MCSS, including branch directors, managers, policy analysts at the corporate level, and representatives from regional offices. Consultation groups were asked to reflect on the following questions: What should we know to improve Ontario's Developmental Services system? What should we know to make sure we are doing the "best possible job"? These groups were invited to advise the research program on the interpretation of its findings and knowledge dissemination plan. Meeting minutes were recorded and shared with committee members.

This paper integrates knowledge learned from these activities and proposes guiding principles for quality improvement monitoring of services for adults with IDD in Ontario's developmental services system.

Results

In Ontario, extensive data are collected on the services and supports provided to adults with IDD. Nevertheless, consultations with representatives of service agencies and MCSS have emphasized the limitations of the data collected; although these data have potential, in their current form they cannot shed light on where and how to improve service quality.

Lessons Learned on Data Collection in the Developmental Services System

There are five areas in which data collection could be improved to maximize its ability to inform quality improvement efforts. First, the data currently collected by the developmental services system cannot always be aggregated. Agencies collect a broad range of information about the people receiving supports. Such information may be related to individual service plans, operational planning or compliance with Quality Assurance Measures. However, this information is not systematically aggregated because agencies lack capacity at the local level or because variances in indicators make broader aggregation at the regional or provincial level impossible. The capacity of the system to better understand what could be done for quality improvement would increase if standardized data collection existed across agencies. Similarly, some information collected by the application entities (DSOs) is collected in formats that make aggregation infeasible. For example, the application package Application for Developmental Services and Supports (ADSS) for developmental services is standardized across the province, but many of its questions are open-ended. The complexity and resource intensity of analysing open-ended questions has made the aggregation of data difficult (Ouellette-Kuntz et al., 2013c). This limitation could be easily overcome with a list of items within which to select those that best represent individuals' responses. However, because the ADSS is mainly used for personal service planning, it is important to maintain the capacity to record individuals' responses verbatim.

Second, the data collected is not currently linked between social assistance programs and service agencies, which limits the capacity to estimate the number of persons supported by the developmental services system and only provides fragmented information on their support needs. Agreements between data holders could be negotiated to facilitate data sharing and still respect the protection of personal information (Lunsky, Klein-Geltink, & Yates, 2013). Examples of such agreements exist, and often require the involvement of a third party that has the knowledge and capacity to link datasets (e.g., the Manitoba Centre for Health Policy holds and links data from multiple sectors in the province of Manitoba; the Institute for Clinical Evaluative Sciences is a data repository for provincial health administrative data in Ontario; and the Canadian Institute of Health Information acts as a nation-wide repository for linked administrative and clinical health data).

Third, no comprehensive baseline information is available on the impact of services in order to monitor change over time. Support needs assessments are conducted for individuals requesting services. Although informative for service planning purposes at the individual level, this information is not currently used to monitor service impact at an agency, regional or provincial level. This information gap makes difficult any evaluation of the effectiveness of services and supports. The projects conducted within this program of research (and reported elsewhere) provide some baseline information to this end.

Fourth, most data collection activities do not focus on issues persons with IDD and their families consider most relevant. Data collection focuses mostly on compliance to processes. Information on many key personal outcomes – i.e., the impact of services and supports on the lives of persons with IDD and their families, as well as on critical service needs – is missing or cannot be aggregated. For example, the sense of burden and perceived distress of caregivers are critical indicators of the system's capacity to care for persons with IDD that are currently only assessed by some agencies (Ouellette-Kuntz, Lunsky, Blinkhorn, Robinson, & Tint, 2013b).

Last, and arguably most importantly, current data collection efforts often miss the perspective of persons with IDD, since many of the questionnaires and surveys used rely on parents and caregivers as proxy respondents. The perspective of family members and significant others in the lives of persons with IDD is important to inform quality improvement efforts, but their opinions should not substitute those of persons with IDD, since discrepancies between their opinions are not unusual (Foxx, Faw, Taylor, Davis, & Fulia, 1993; Golubovic & Skrbic, 2013; Reid, Everson, & Green, 1999; Stancliffe, 1995). Techniques exist to support the participation of persons with IDD in interviews and questionnaires (Finlay & Lyons, 2001; Finlay & Lyons, 2002; Lloyd, Gatherer, & Kalsy, 2006) and should be considered when planning data collection. Among others, the following tips apply: (1) Avoid using complex multiple-choice questions; (2) Minimize acquiescence and be sensitive to the tendency to please interviewers or carers; (3) Abstract concepts should be avoided, as well as negative questions; and (4) The level of literacy should be consistent with the cognitive abilities of interviewees.

Therefore, in spite of the wealth of data that currently exists within the developmental services system, much work is needed to ensure that these data are relevant to persons with IDD and include their perspectives; are collected in a consistent way across agencies; and are collected in a way that easily permits data linking, aggregation, and analysis. To do this, stakeholders reinforced the need for clear partnerships between researchers, service providers, database holders, and service users. They expressed a desire to focus on data collection efforts that could inform service improvements needed to promote social inclusion, and would represent more than a "checklist" approach to measurement. Stakeholders also discussed the importance of focussing data collection efforts on elements that are meaningful and actionable by the agencies collecting them, and that go beyond measuring issues related to compliance to process standards. To support stakeholders in their efforts to improve service quality monitoring, we propose the following five guiding principles.

Guiding Principles to Quality Improvement Monitoring

Research and consultation with Ontarian stakeholders have permitted the identification of five principles that should guide the assessment and monitoring of supports and services to inform quality improvement efforts in IDD services.

Principle 1: Activities Are Embedded Within a Continuous Quality Improvement Cycle

In the context of IDD services, continuous quality improvement requires that stakeholders engage in a cycle of ongoing data collection and analysis to develop knowledge about actions needed to improve the quality of services with regards to desired outcomes for service users (van Loon et al., 2013). The cycle leads to the translation of knowledge into actions, and monitoring of their impact on outcomes for service users. From the lessons learned through the research program, a graphic representation of this cycle has been developed and is represented in Figure 1.

A continuous quality improvement approach is distinct from Quality Assurance Measures

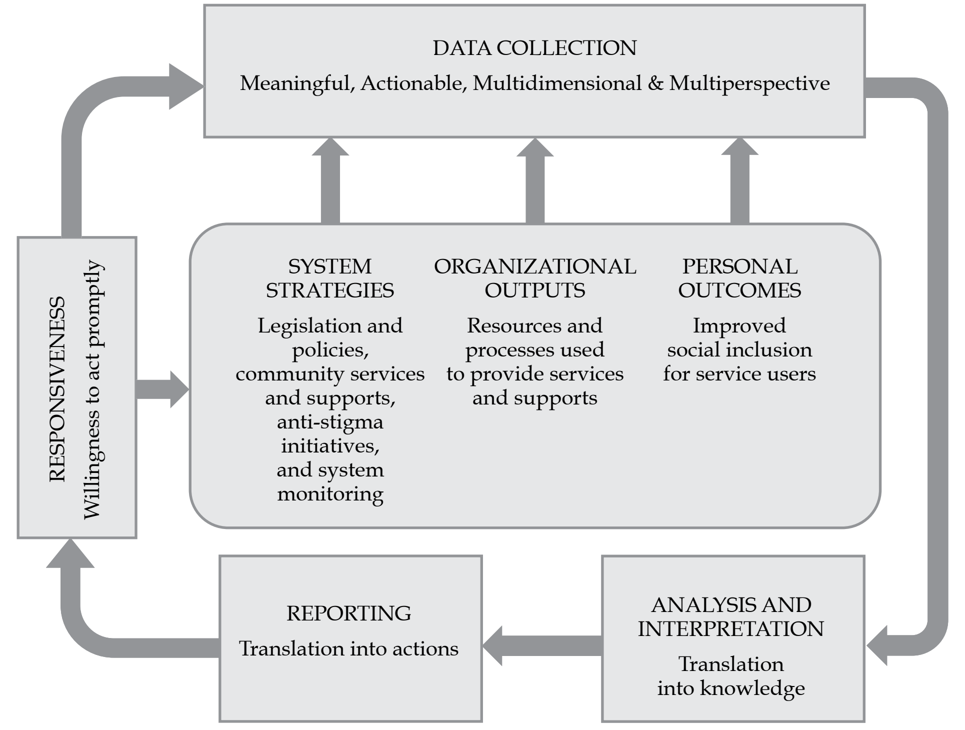

Figure 1. Continuous quality improvement in the developmental services system

which focus on compliance to process standards (Schalock & Verdugo, 2012). The latter, while important to ensure safeguards against harm and abuse, lacks a collaborative approach that could lead to quality improvement, and does not focus on outcomes for the service users. Stakeholders engaged in continuous quality improvement take ownership of the process, identify improvements in their own field of action, and are committed to respond (Bryson & Patton, 2010; Cousins & Whitmore, 1998; O'Sullivan, 2012). A collaborative approach is recommended to enhance multidirectional communication between service providers, service users, policy makers, data analysts and researchers, and to ensure their meaningful contribution (O'Sullivan, 2012). Contrasting stakeholders' perspectives and identifying common priorities for action should be central to quality improvement practices. In a continuous quality improvement cycle, all stakeholders should be responsive to the knowledge developed and put it into action. Actions include service and support improvements, as well as improvements to data collection and analysis processes.

Principle 2: Activities Focus on Personal Outcomes That Are Important to Persons with IDD

Decision-making should ideally be done based on empirical evidence of the effectiveness and efficacy of services and programs. However, empirical knowledge of best practices for supporting adults with IDD and improving their social inclusion remains scarce. In the absence of such supporting evidence, there is a need for quality improvement activities to focus on the outcomes that are important to service users, rather than solely on those relevant to the needs of policy makers and service providers (Schalock & Verdugo, 2012; van Loon et al., 2013).

Without knowledge of the outcomes deemed important by service users, it is difficult to determine what services and policies are needed, and how to prioritize what actions are required to improve social inclusion (van Loon et al., 2013). Social inclusion outcomes include experiencing valued and meaningful social roles, as well as feelings of trust, reciprocity and belonging shared among members of a community (Cobigo, 2012; Cobigo et al., 2012; Lemay, 2006; Sherwin, 2010). Monitoring the quality of services for Ontarians with IDD, therefore, should appraise the extent to which services improve these outcomes (see Table 1 for a list of relevant personal outcomes).

Principle 3: Activities Capture the Complexity and Multidimensional Nature of the Outcomes Being Measured

A conceptual framework is important in transforming data into meaningful knowledge (Buntinx & Schalock, 2010; Schalock & Verdugo, 2012; van Loon et al., 2013). It provides an understanding of the complex interactions between input, processes and outcomes, and therefore goes beyond the "checklist" approach of quality assurance measures and accreditation bodies. From the MAPS research program, a theoretical framework of social inclusion, developed in consultation with persons with IDD and their families, providers of developmental services, policy makers and researchers, has emerged (Cobigo, 2012; Cobigo et al., 2012). Therefore, the information to be collected should relate to the various dimensions of social inclusion, if quality improvement efforts are to be successful in promoting social inclusion.

In addition, gathered information should focus on areas where the developmental services system can act (i.e., organizational outputs and system-level strategies). Organizational outputs include efficiency measures, staff-related measures, and program and service options available to service users. A focus on the quality of outputs from the perspective of users is suggested (Schalock & Verdugo, 2012; Zeithaml, Parasuraman, & Berry, 1990) (see Table 1 for a list of the characteristics of outputs appraised positively by users). System-level strategies to improve the social inclusion of adults with IDD include: legislation and policy enactment; community-based and person-centred services and supports; anti-stigma and anti-discrimination initiatives, and system monitoring (Cobigo & Stuart, 2010).

Principle 4: Knowledge is Developed from Multiple Perspectives

Because of the diverse systems in which they belong, stakeholders' perspectives on the quality of services and the priorities for action are likely to differ. It is important that all points of view are considered to support decision-making when planning service quality improvement (Buntinx & Benjamins, 2010; Buntinx, 2008). The perspective of service users and their families is crucial, and they are the best respondents when measuring service users' outcomes. The perspective of service agencies and their staff, as well as the perspective of the funding entity (i.e., the entity funding services, which is the MCSS in Ontario), must also be considered.

Social inclusion is the outcome of complex interactions between personal and environmental factors (Cobigo, 2012; Cobigo et al., 2012; Cummins & Lau, 2003). A linear relationship between services or policies and improve social inclusion is difficult to draw; factors independent of the service system will influence observed outcomes. An ecological approach is thus more appropriate, where the individual is at the centre of a microsystem (i.e., family and friends), a mesosystem (i.e., connections between elements of the microsystem), an exosystem (i.e., services and benefits), and a macrosystem (i.e., values, attitudes and laws) (Buntinx & Schalock, 2010).

Principle 5: Knowledge Is Meaningful, Actionable, and Informs Policy and Service Improvements

Continuous quality improvement means that the information collected should lead to knowledge and actions on how to improve outcomes for the individuals supported (Schalock & Verdugo, 2012). To do so, stakeholders must develop a management information system that allows for the collection, analysis and reporting of meaningful, timely and useful data from various perspectives (Poister, 2010). Stakeholders must also be responsive to the knowledge developed so that it leads to action. Ongoing exchange among policy makers, service providers, service users and researchers is essential if one is to collect relevant data, devel-

Table 1. Quality Improvement in IDD Services: Domains Proposed by the Multidimensional Assessment of Providers and System.

FOCUS	*DOMAIN*	*DEFINITION*
PERSONAL OUTCOMES Benefits for service users	Valued social roles	Being socially included means experiencing a range of social roles within a variety of contexts. Social roles are valued when they respect the individual and the community's expectations, choices and needs.
	Competency	To perform a given social role, the person has to have acquired the required skills to be competent in that role.
	Reciprocity	Complementary social roles; social roles only exist when reciprocated by others.
	Belonging	A sense of belonging is a subjective feeling of value and respect that is built from reciprocal relationships and shared experiences.
	Choice	Social roles are the result of an individual's choices.
	Satisfaction	Social inclusion relies on the satisfaction of all members of the community that their social roles are valued, meaningful and respectful of choices.
ORGANIZATIONAL OUTPUTS Resources and processes used by agencies to provide services	Tangibles	Quality of physical facilities, equipment and people.
	Reliability	Ability to perform the promised service dependably and effectively.
	Responsiveness	Willingness to help consumers and provide prompt services.
	Assurance	Knowledge and courtesy of employees and their ability to convey trust and confidence.
	Empathy	Caring and individualized attention provided to consumers.
	Availability	Presence of needed services and supports.
	Affordability	Ability to procure the services and supports.
	Awareness	Degree to which the service user is aware of potential services or supports.
	Accessibility	Ability to access the services and supports (e.g., barrier-free environment).
	Extensiveness	Variety of services and supports.
	Appropriateness	Degree of correspondence between needs of the consumer and availability of relevant services or supports.
SYSTEM STRATEGIES Ways in which agencies and MCSS enhance personal outcomes and organizational outputs	Legislation and policy	Human rights discourse and legislation that protect the rights and freedoms of persons with IDD.
	Supports and services	Community-based and person-centered supports and services.
	Anti-stigma Initiatives	Efforts to eliminate social barriers and promote adequate and equitable access to public goods and services.
	System monitoring	Developing evidence of the effectiveness of actions.

op knowledge of where improvement is needed, and transform this knowledge into action.

Social inclusion outcomes are complex, and causal links between actions from the developmental services system and improved social inclusion cannot be ascertained. Activities are intended to gather evidence that the developmental services system is moving towards targeted actions, and the social inclusion of persons with IDD is improving over time. However, it is unlikely that a specific action will be the unique cause of observed changes. In addition, factors external to the developmental services system have an impact on the social inclusion of adults with IDD (Hartley, Finkenflugel, Kuipers, & Thomas, 2009). For example, well executed supported employment programs are likely to improve access to productivity options for adults with IDD, although these also increase as a result of support from family and friends, as well as changes in the attitudes of employers. It is thus important to observe trends in both service users' outcomes and organisational outputs when monitoring the quality of the services. Trend analysis and interpretation require multiple data points (i.e., repeated measures at the population/system level), an understanding of random variability in population/system level measures, and consideration of external factors contributing to observed changes (Poister, 2010). Most importantly, trend data are informative if analyzed and understood in light of program and policy changes (Rosenberg, 1997).

Discussion

Movement toward a continuous quality improvement approach to the assessment and monitoring of developmental services and supports demands a culture that is supportive of knowledge-informed policy and practice. To create that culture in Ontario, it is suggested that three goals be pursued concurrently: (1) building capacity; (2) improving data collection and interpretation; and (3) exchanging knowledge.

Building Capacity for a Province-Wide Quality Improvement System

An important factor that emerged from our review of evidence-based practices is the critical role of organizational readiness (Hodges & Hernandez, 1999) to manage data collection, analyse results, and translate findings into action. Key to building capacity is the development of partnerships between all stakeholders who play an important role in quality improvement including persons with IDD and their families, services agencies, funding entities, responsible ministries, and researchers (see Table 1). These partnerships will open discussions relative to obtaining legal agreements for data sharing and linkages; understanding technical issues for data sharing and linkages; and developing the infrastructure for an efficient information management system, including data collection, analysis, interpretation, and reporting of meaningful and actionable information.

In addition to having common goals and objectives, these partnerships must be based on mutual trust and a commitment to improving the quality of services. Differences in perspectives, interests and power must be acknowledged. Persons with IDD and their families must believe that their views and contributions are valued, and trust that the information they provide will be used to improve the quality of services. Further, there needs to be a clear commitment among all stakeholders to act based on the knowledge gained through quality improvement activities, which means making relevant changes to services and policies.

Over the three years of this program of research, active and effective collaborations have been developed and fostered with persons with IDD (through Consumer Consultations), families and developmental services agencies (through Local Advisory Committees and individual research projects), as well as with representatives from various levels of MCSS (through Local Advisory Committees, consultations, and individual research projects). This type of partnership model and stakeholder involvement is strongly suggested for advancing quality improvement activities.

Improving Data Collection and Interpretation

The quality of the data on which decisions to create or change policy and practice is key. Moving forward, several steps are recommended to improve data collection and interpretation. The first step is to better understand how data currently collected could be interpreted and used for quality improvement. As previously mentioned, the system collects a range of data that could be integrated into a meaningful framework, and would provide additional information if linked and aggregated. Modifications to current data collection and management is also required. Adopting new data collection processes would be an important step to allow agencies and their funders to capture indicators of outcomes for service users. Finally, developing efficient systems for generating reports meaningful to stakeholder groups is a crucial next step for data to be used in a timely and relevant manner.

Consultations with stakeholders, exploration of current data collection, as well as scientific knowledge has led to the development of a set of 150 indicators (available upon request; Table 1 presents the list of domains and sub domains within which indicators are organized) related to personal outcomes, organizational outputs, and system-level strategies used to improve the social inclusion of Ontarians with IDD. Indicators appear to have face validity (i.e., deemed relevant by stakeholder groups, including persons with IDD) and to be conceptually sound (i.e., supported by a review of the scientific knowledge). A necessary next step is to appraise their validity and reliability through pilot testing among service agencies, and relevant data holders. The proposed list of indicators is not meant to be a rigid set of indicators that must be used in its entirety. Rather, it is intended to serve as a flexible framework guiding a phased approach to quality improvement activities. Implementation should reflect a partnership including service users, service providers, policy makers, data analysts, and researchers.

Exchanging Knowledge

While key stakeholder groups have been engaged throughout the program of research, there is a need for further collaboration and exchange to build a consensus on how to improve the quality of supports provided to adults with IDD in Ontario and, more widely, to promote a culture of knowledge-informed policy and practice. In particular, electronic forms of dissemination (e.g., websites, newsletters); presentations, webinars, videoconferences; as well as workshops with stakeholders interested in more detailed information about how to assess and monitor the quality of their services are needed.

To some extent, this has already started with the MAPS team leading a variety of activities to engage with multiple stakeholder groups. For example, over 60 participants attended a webinar from about 30 sites across the province in February 2014, a panel presentation was held at the Ontario Association for Developmental Disabilities (OADD) annual conference in April 2014, and persons with IDD, service providers and representatives of MCSS participated in workshops in June 2014. These activities help support the sharing of knowledge, ideas, and experiences related to improving the quality of services and supports, as well as to (1) build capacity within the developmental services system through connection and exchange; (2) build on existing relationships with persons with IDD, their families, agencies, and the representatives from the entity funding services; (3) promote the involvement of new stakeholders; and (4) foster interest in promoting the social inclusion of persons with IDD.

Conclusion

Over the past five years, Ontario has demonstrated leadership in the field of IDD through the adoption of the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*, 2008 and its related transformation agenda. The commitment to social inclusion is evident by a desire to understand fully what social inclusion means and how it should be measured. As services and supports are transformed, the system's processes for data collection, use, and interpretation must be adapted. Having already invested in the MAPS program of research, MCSS has taken an important first step towards knowledge-informed policy and practice. Next steps require a collaborative approach whereby all stakeholder groups – i.e., policy-makers, service providers, service users and their families, as well as researchers – engage in developing a quality improvement monitoring system, and become responsive to the developed knowledge.

Key Messages From This Article

Persons with disabilities: It is important to know how your services and supports help you to have the life you want.

Professionals: Agencies collect a lot of information on the supports they provide, but a standardized way of collecting this data across all agencies is needed to maximize its use and inform quality improvement. It is also important to involve persons with IDD and their families in order to obtain meaningful information on how to improve services and supports.

Policymakers: To improve the quality of the services and supports provided to adults with IDD, it is crucial to collect data on their impact in a consistent and useable manner.

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