



Findings from 2014 Spring Stakeholder Engagement Process

Executive Summary

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Background

The passage of *The Vulnerable Persons Act* in 1996 coincided with the start of an almost 20-year period of significant expansion of the services available to adults with intellectual disabilities in Manitoba. Over this same period, the service system has also grown increasingly complex with more than 100 community-based agencies now delivering these essential services under a complicated set of contract arrangements.

This combination of rapid expansion and increasing complexity has created a series of challenges that hamper the effectiveness and sustainability of this service system. Left unaddressed, the challenges will only intensify as the system deals with significant new demands that will emerge in the coming years.

In late 2013, the community-based agencies in this sector became profoundly concerned when they were advised that Manitoba Family Services was contemplating deep funding cuts to the Community Living disAbility Services (CLdS), the program that serves as the primary funder of these services and supports.

In response, Abilities Manitoba, the umbrella organization representing most of the community-based agencies delivering services, launched an ‘action card’ campaign addressed to the Minister of Family Services in February 2014. Through this campaign, Abilities Manitoba, along with the estimated 10,000 Manitobans who sent in cards, asked the Minister to:

- Ensure that funding decisions made in the short term not diminish the quality, scope and viability of current services.¹
- Establish an inclusive planning process (including the voices of persons with intellectual disabilities, their families, agency staff and the public) to ensure the long-term sustainability and quality of services upon which so many depend.

In the spring of 2014, Abilities Manitoba began an extensive series of stakeholder engagement activities to support the development of the inclusive planning process requested in the card campaign. Through the engagement activities, the stakeholders most directly affected by adequacy of services to Manitoba adults with intellectual disabilities were asked to help identify:

- Current strengths in services and in the overall CLdS system.

¹ Abilities Manitoba and its member agencies were pleased that the Province’s 2014 budget included an 8.2% increase in CLdS funding rather than the significant funding reduction that was being considered in late 2013.

- Limitations in services that result in unmet needs, diminished potential, constrained choice and limited community inclusion.
- Priorities for changes that will provide for strengthened services and a more sustainable CLdS service system.

Four stakeholder groups were consulted as part of the engagement process:

- Program participants, their families and other members of their support networks.
- Families of individuals eligible for and wanting to access CLdS services and supports.
- Staff employed by community-based agencies delivering services and supports.
- Collateral agencies that work with or complement the work of CLdS-funded agencies in support of adults with intellectual disabilities.

Focus groups and Spring Gatherings (informal, two-hour, open house style events) were held in each of the seven service regions in Manitoba to invite and secure feedback from stakeholders.

An online survey was also developed so that participants, families and agency staff who did not attend one of the focus groups or Spring Gatherings could share their thoughts.

This Executive Summary highlights key findings from this stakeholder engagement process. The full version of this report discusses the findings in much more detail and includes extensive quotations from the hundreds of persons who shared their views and opinions.

Ratings of the Current CLdS System

All persons who attended the Spring Gatherings and all those who completed the online survey were invited to rate the overall quality and availability of current services and supports. A total of 504 ratings were received.

The combined ratings from Spring Gatherings and the online survey indicate that respondents were decidedly split in their assessment of the quality and availability of current services and supports.

The most positive ratings came from the Spring Gatherings and suggest that most persons involved with CLdS-funded services would rate them as at least “good”, although almost one-third would rate services as “poor” or “fair”.

The most critical ratings came from the online survey and would suggest that more than one-half of the participants and families being served would rate the services they receive as only “poor” or “fair”.

Factors that account for these marked differences in ratings are not clear.

What is Working Well?

The first question in the engagement activities asked stakeholders to identify what they felt was working well with CLdS-funded services or within the CLdS service sector.

Stakeholders identified seven major areas of strength.

Staff

The staff who provide the services and supports were one of the strengths most frequently identified by stakeholders. Many participants and family members thought highly of the staff. Staff also offered very positive comments about their colleagues.

Inclusion

Stakeholders felt strongly that individuals with intellectual disabilities were now more visible and accepted within the community and that a definite shift in attitudes had taken place over the last decade.

Independence and Empowerment

Many stakeholders spoke of empowerment as having become an essential element in the current system, explaining that participants now have a voice, they have choices and can make decisions.

Options and Opportunities

Many stakeholders remarked that there were more options and opportunities available to people with intellectual disabilities. During the Spring Gatherings, participants discussed many aspects of the programs that they appreciated, including learning life skills, pursuing hobbies, enjoying social outings, engaging in recreational activities, and participating in the community through volunteering or employment.

Agencies

Stakeholders identified community-based agencies as important strengths within the CLdS system. A number of family members praised agencies for doing a great job, often with mention of limited funds. There was also an appreciation expressed by both family members and staff for the commitment and support shown by many of the agencies, and praise for the programs they have created.

Rewarding Work

Direct support workers at all the focus group sessions discussed appreciating the rewarding nature of this line of work.

Housing

The move to smaller group homes and more mainstream living arrangements within communities was seen as having been very beneficial to participants.

Several participants reported their homes as being a safe and nurturing environments and other stakeholders remarked that they had more of a home-like feel to them. Stakeholders were also pleased that there was now a greater effort being made to make appropriate roommate matches.

What is Not Working Well?

Stakeholders were also asked to share their views on what was not working well with current services and supports and/or within the broader CLdS service system. The most frequently identified concerns and limitations related to one of the five following major themes.

- Human Resources
- System Operations and Management
- Cross System Collaboration
- Community Constraints
- Limited Choice

Human Resources

Human resource issues were, by a wide margin, the predominant concern identified by stakeholders.

Wages

The most frequently identified weakness of current services and supports was low staff wages, in particular those of direct support workers. The negative impacts of low wages on overall services were seen to be significant and of great concern to all stakeholders.

Turnover

The high rate of staff turnover, a direct consequence of low wages, was of great concern to stakeholders, owing to the diminished quality of service received by participants that resulted from the constant churn in primary care providers.

Training

The lack of adequate staff training currently being provided to many direct support workers, most of whom have little to no relevant skills coming into the job, was a considerable concern for many stakeholders.

Staff Shortages

Limited financial resources and, to a lesser extent, staff turnover were also reported to contribute to staff shortages. Staff shortages were seen to create a stressful work environment for staff, resulting in overtime, low morale, lack of motivation, and burnout. Not having enough staff also compromises the quality of care provided to program participants.

System Operations and Management

Stakeholders identified several features of overall system operations and management as being serious weaknesses.

Community Service Workers

Most family members reported that while they liked their Community Social Worker (CSW) as individuals, they were continually receiving new workers and their calls were usually not acknowledged in a timely way. In fact, some family members reported that calls to their CSWs were frequently not returned at all.

Crisis-Driven

Many family members expressed frustration, and in some cases despair and tears, as they shared their experiences over the long waiting lists to get services for their adult children. Several family members expressed anger that the system was “reactionary and crisis driven” and that the only way to receive services was to be in calamitous or near calamitous circumstances.

Lack of Lifespan Planning

Another significant concern was the lack of adequate planning throughout the lifespan of participants. Focus group participants identified two specific life stages they felt were not being properly addressed – the transition to the adulthood and the seniors years.

System Disparities

System disparities and an overall lack of transparency were discussed by stakeholders in a number of the focus groups. They highlighted the inconsistent application of the funding model as being the primary source of the inequalities between regions, within regions, and even within agencies.

Assessments and Eligibility Criteria

Significant concerns were expressed over delays in, and the limited access to, diagnostic assessments for both children and adults. The current eligibility criteria that a person must meet to qualify for CLdS-funded services were a source of frustration.

Cross System Collaboration

The need for better coordination and communication between major service systems (e.g., mental health, home care, health care providers, police/corrections, and addictions services) was a common theme in discussions of current weaknesses. The current lack of coordination was reported to result in people with intellectual disabilities being “bounced” around between different government agencies and service providers, as well as in persons falling through the cracks.

Community Constraints

Stakeholders believed inaccessibility was a significant barrier to meeting the needs of participants. These barriers limited individuals' choices, potentially restricting their participation in certain day programs, volunteer/employment opportunities, outings, and activities, as well as narrowing their housing options.

Also, although many noted that there have been improvements in the area of employment, most stakeholders believed that there was still a lack of opportunities for individuals with disabilities.

Limited Choice

As noted above, a strength of the existing system is that people with intellectual disabilities have greater choice. However, many focus group members pointed out that real choice for program participants continued to be significantly limited primarily due to inadequate and inflexible funding.

What Changes are Needed?

Eleven key changes were identified by different stakeholders as being required to strengthen services funded through CLdS and ensure the sustainability of the overall service system.

- 1. Increased Wages:** Increasing the wages of direct service workers was seen to be foundational to any significant improvements of services and supports.
- 2. Improved Government Resources:** Manitoba Family Services must significantly improve its capacity to help participants and their families make informed decisions regarding their futures and to enhance their capacity to provide timely and equitable access to services.
- 3. Improved Service and Systems Coordination:** Community-based agencies, service systems and government departments must develop better strategies to maximize the effectiveness and responsiveness of resources that are now divided between separate organizational mandates and silos.
- 4. Standardized Training:** As part of professionalizing the field, all direct service workers should receive standardized, mandatory training.
- 5. Policy Changes:** Current policies related to eligibility criteria, per diems and individualized funding, and service flexibility need to be reviewed and revised.
- 6. Increase Front End Investments, Reduce Downstream Costs:** Greater investments in early intervention and in the CLdS sector are needed to reduce high downstream costs now incurred by the justice and health care systems.

- 7. Service Quality Assurance:** New quality assurance measures are needed to promote the delivery of consistently high quality services among CLdS-funded agencies.
- 8. Better Planning throughout the Lifespan:** More effective planning and coordination are required to ensure effective transitions for youth with intellectual disabilities as they reach adulthood and then for adults as they age.
- 9. Expanded Employment Opportunities:** A significant expansion is required in the employment opportunities available to adults with intellectual disabilities.
- 10. Increased Political Will:** Expanded lobbying and more effective communication is required so that politicians better understand the challenges faced by adults with intellectual disabilities and their families.
- 11. Enhanced Programs:** Enhancements are needed in many programming areas, including:
 - Increased one-on-one care
 - More life skills training
 - Greater access to experts (e.g., OTs, physiotherapists, dieticians, behavioural therapists, psychiatrists)
 - Tailored day programs (i.e., different programs for lower needs individuals, higher needs individuals, and seniors)
 - Improved recreational activities/exercise programs
 - More funding for community participation.

Suggestions for Inclusive Planning

These preliminary stakeholder activities were organized by Abilities Manitoba in support of the request made to the Minister of Manitoba Family Services for an inclusive planning process. The major focus of these activities was to ask those most directly affected by the adequacy of these services to help identify the major issues that this inclusive planning process would need to address.

As part of the focus group sessions, stakeholders were also asked to discuss how this inclusive planning process might best be structured to provide practical and lasting benefits.

All stakeholder groups expressed a strong interest in having a meaningful involvement in the planning process. Each stakeholder group also suggested various options to provide for their respective participation.

The importance of having the planning process incorporate a regional lens was strongly supported in the focus group sessions outside Winnipeg. Many stakeholders suggested that past Winnipeg-led planning processes have failed to effectively take

into account the unique challenges and opportunities that exist in regions outside the 'perimeter'. This opinion was most strongly, though far from exclusively, expressed by collateral agencies. Many of these agencies (e.g., health authorities and school divisions) are organized on local or regional levels and can best contribute to planning on that basis.

Finally, many stakeholders expressed the concern that the Manitoba Family Services' and the overall provincial government's commitment to an inclusive planning process had to be genuine. Many focus group members emphasized that effective planning will need to move well beyond setting a vision for a better future. The focus group members felt that it was essential that planning establish change objectives, adequately resourced strategies required to achieve the objectives, and clearly identified and time-bound deliverables.