



Findings from 2014 Spring Stakeholder Engagement Process

Final Report

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Executive Summary

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.

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Any society, any nation, any province is judged on the basis of how it treats those who are most vulnerable.

1.0 Introduction

1.1 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. Much appears to have been accomplished during these years to extend the supports that thousands of adults depend on for their safety, well-being and quality of life.

Over this same period, the service system has also grown increasingly complex with more than 100 community-based agencies now delivering these essential services. The agencies operate under separate contracts negotiated with different government staff working in the seven service regions spanning the province.

This combination of rapid growth and increasing complexity has contributed to a number of the challenges currently facing the overall service system:

- There are substantial inequities in funding arrangements among agencies and across regions and even differences in funding available within the same agencies to provide similar services to different participants.
- Several of these agencies are under extreme financial stress and are struggling to remain solvent.
- Disability support workers among all agencies remain one of the lowest paid human services workforces in Manitoba making it difficult to recruit and retain qualified staff.
- There is no system-wide capacity for assessing the effectiveness of current services, nor the personal outcomes they provide for program participants.

There is also strong reason to believe that the demands placed on this service system will increase substantially in the coming years. These new demands will result from:

- The aging of both the population of adults with intellectual disabilities and the primary caregivers within their families.
- Improved understandings and availability of diagnostic assessments related to FASD and autism.
- Changing social expectations.

In late 2013, with so many issues needing to be addressed, community-based agencies 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 (a copy of the “action card” is included as Appendix A). Through the campaign, an estimated 10,000 Manitobans asked the Minister to take five specific measures.² The measures included:

- Ensuring that funding decisions made in the short term not diminish the quality, scope and viability of current services.³
- Establishing 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. The purpose of the engagement process was to consult those most directly affected by the adequacy of services for Manitoban adults with intellectual disabilities on:

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

² Concurrently, Abilities Manitoba tabled a request with Manitoba Family Services for specific information including:

- Assessments of spending increases over the past decade related to CLdS supported services, including the identification and assessment of cost drivers.
- Past departmental discussions and options papers on cost containment strategies related to CLdS services.
- Departmental research on service delivery and funding models for CLdS-like services in other jurisdictions.

Responses from Manitoba Family Services are still pending.

³ 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.

This report presents the summary findings from this stakeholder engagement process.

1.2 Structure of the Report

The information presented in this report is organized into the following sections.

Section 2: Approach – This section of the report provides a more detailed description of the methodologies used as part of the spring 2014 stakeholder engagement process.

Section 3: Overall Ratings of the CLdS System – This section presents the results from a question included in selected engagement activities that asked persons to rate the overall quality and availability of services and supports currently available through the CLdS system.

Section 4: What is Working Well? – This section presents and discusses features related to the CLdS system that were identified as working well and were seen to provide a basis to build on in the coming years.

Section 5: What is Not Working Well? – This section covers the major areas that were identified through the engagement activities as being weaknesses in the current CLdS system and that need to be addressed to both improve and ensure the long term sustainability of services.

Section 6: What Changes are Needed? – This section focuses on ideas and suggestions for specific improvements for strengthening the CLdS system.

Section 7: Suggestions for System Planning – This final section discusses suggestions that were shared on how best to approach an inclusive planning process related to the future of the CLdS system.

1.3 Qualifications

There are four important qualifications related to this report that merit attention at the outset. First, the report has been prepared to provide a summary of the views shared by the many hundreds of persons who participated in the engagement activities. The report is not designed, nor is it able, to include coverage of each and every view that was shared. Rather, the report focuses on the key themes that emerged.

Second, the methodologies used to gather information were not designed to secure feedback from a representative sample of individuals from different stakeholder groups. While the persons who did participate in the engagement activities comprised a broad cross-section, the findings presented in this report are only suggestive of the views that may be held among the much larger memberships of these stakeholder groups.

Third, this report has been prepared by The Project Group (TPG) Consulting Cooperative Ltd., the Winnipeg-based social policy consulting firm that played the major role in designing and implementing the stakeholder engagement process. The Project Group had previously been retained by Abilities Manitoba to provide strategic advice and consultative services. While The Project Group has made every effort to ensure the fidelity of this report based on the views shared, the firm has not served as an entirely independent third party in the engagement process.

Finally, the report attempts to accurately summarize, without effort to identify or correct any possible factual errors or omissions, what was shared by those who participated in engagement activities. In short, the findings are based on the self-reported opinions and experiences of those who participated in the engagement activities.

1.4 Acknowledgements

The spring 2014 stakeholder engagement process was a very ambitious initiative both in terms of scope and in the amount of work that needed to be done in a very short period of time.

The Project Group would like to acknowledge and thank the following for their extraordinary contributions to the engagement process.

- The Executive of Abilities Manitoba.

- The staff of agencies that served as regional coordinators (listed in Appendix C).
- Officials from Manitoba Family Services who supported the process and provided valuable assistance.
- The hundreds of Manitobans who participated and shared honestly and thoughtfully based on their experience.

Many lessons were learned in these efforts to seek input and feedback from such a wide range of stakeholder groups with interests in CLdS-funded services. It is hoped that these lessons will help improve future efforts to engage stakeholders in the months and years ahead.

2.0 Approach

Abilities Manitoba's 2014 spring stakeholder engagement process relied on three different methodologies to invite and collect input and feedback:

- Focus groups
- Spring Gatherings
- An online survey for participants, families and agency staff who did not attend one of the focus groups or Spring Gatherings.

Brief descriptions of each of these three methodologies are provided below (see Appendix B for the schedule of engagement events).

2.1 Focus Groups

A total of 14 focus groups (two in each of Manitoba's seven service regions) were held as part of the stakeholder engagement activities. Five of the focus groups were held with collateral agencies (45 participants), seven were held with staff from Abilities Manitoba's member agencies (88 participants), and two were held with families of individuals who were seeking to access services or were experiencing difficulties in securing these (10 participants).

Each focus group explored similar themes, which included what was working well, what was not working well and what the next stages of the planning process might look like. Each of the focus sessions ran 90 minutes in length.

The focus group methodology was employed because it is well suited to exploring participants' perceptions and opinions of their experience. The method produces rich qualitative data by encouraging dialogue among participants and allows the facilitator to probe further at key points, both of which encourage in-depth and reflective feedback. The methodology, however, is limited in that it produces a one-time snapshot and engages a relatively small portion of the focus population.

All focus groups were facilitated and recorded by the same two-person team from The Project Group.

With the agreement of focus group participants, audio recordings were made of each of the sessions. The recordings were exclusively used to support the development of this report.

2.2 Spring Gatherings

Spring Gatherings (informal, two-hour, open house style events) were held during late afternoon/early evening hours in each region of the province, with

two held in Winnipeg. In total, an estimated 355 individuals attended one of these events.

The Spring Gatherings were designed to reach out to program participants and families in order to gain their perspective on the current system and services, and what they would like to see in the future. Attendees were invited to visit with other participants and families and staff, to enjoy the food provided, but most importantly to answer four questions:

1. What are up to three things you think are working best with current services and supports?
2. What are up to three things you think are working least well with current services and supports?
3. What's your overall rating of the quality and availability of current services and supports? (scale of 1=poor, 2=fair, 3=good, 4=very good and 5=excellent)
4. What is the most important change you would make to improve current services and supports and to enhance inclusion in the community?

For the first three questions, volunteers assisted participants and family members to understand what was being asked of them and to write their response on a card, which was posted onto the wall. For the fourth question, attendees were invited to videotape their response. Anyone who wished to respond to the question, but preferred not to make a video, was given the opportunity to write their answer on a card.

All responses posted by attendees, along with written notes based on the videos, were collected and analyzed to support the development of this report.

2.3 Online Survey

A survey was posted online that included the same basic questions that were used as part of the Spring Gatherings. The survey was designed to provide a way for participants and families who could not or preferred not to attend one of the Spring Gatherings to share their views. The survey also provided for input from the agency staff persons beyond those who had been invited to the focus groups.

One major difference with the survey was that respondents were invited to share the reasons for their respective ratings of the services and supports, as well as for their priorities identified for change. A second major difference was that respondents were asked to report their primary relationship to CLdS-funded services and supports (participants, family of participants, employee, other) at the start of the survey.

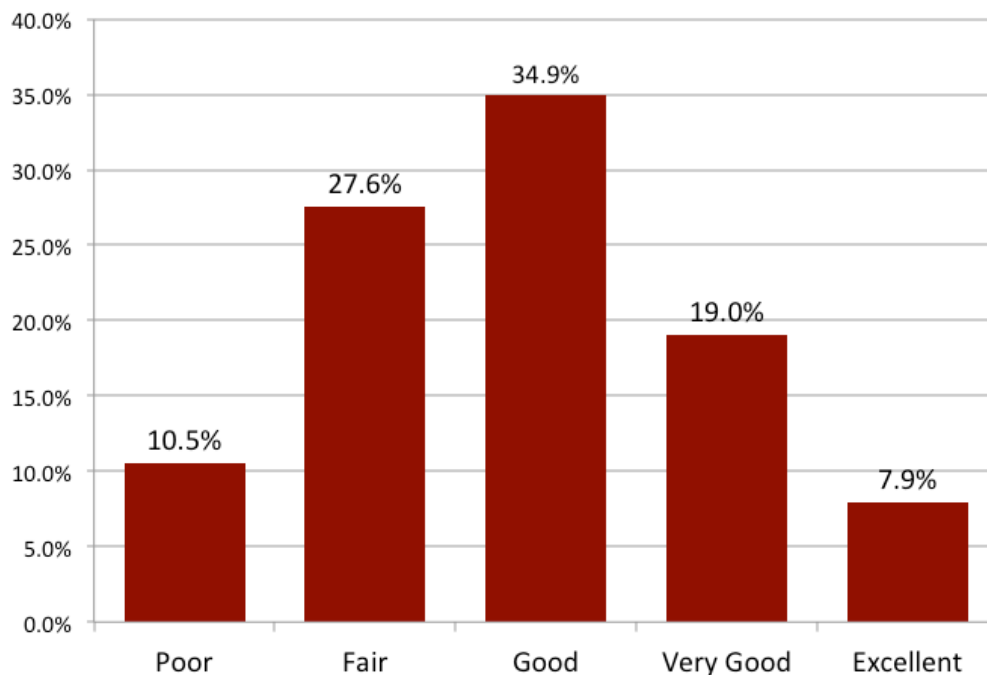
There were a total of 270 completed responses to the online survey that remained open from the morning of May 26 to midnight on June 26, 2014.

3.0 Overall Rating of the 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 provided.⁴

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 (see Table 1).

Figure 1
Percent Distribution of Ratings of Current CLdS-Funded Services and Supports

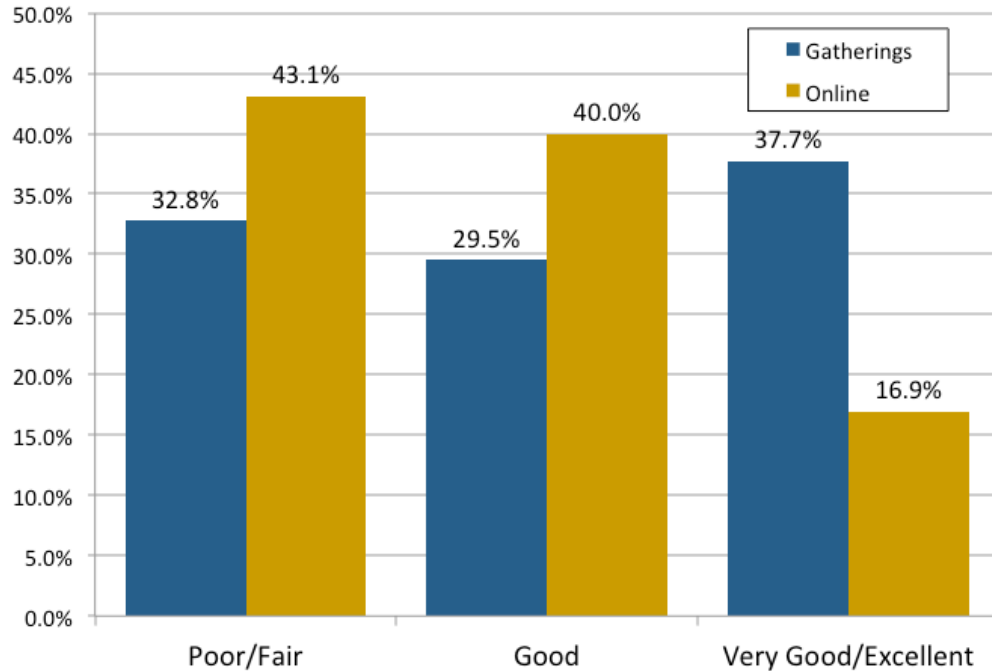


Just over one-third (35%) provided a rating of “good”, while just over one-quarter (27%) provided ratings of “very good” or “excellent”. The remainder, almost 40%, provided ratings of “poor” or “fair”.

Significant differences in ratings exist between those who provided them as part of the Spring Gatherings (T= 244) and those who provided them online (T= 260). Those who attended at Spring Gatherings were, by far, more positive with 38% rating the quality and availability of services as either “very good” or “excellent” (see Table 2). This compares to 33% who rated services as “poor” or “fair”.

⁴ Appendix D provides additional information on ratings and how these were processed.

Figure 2
Comparison of Ratings of Current CLdS-Funded Services
and Supports from the Spring Gatherings and the Online Survey



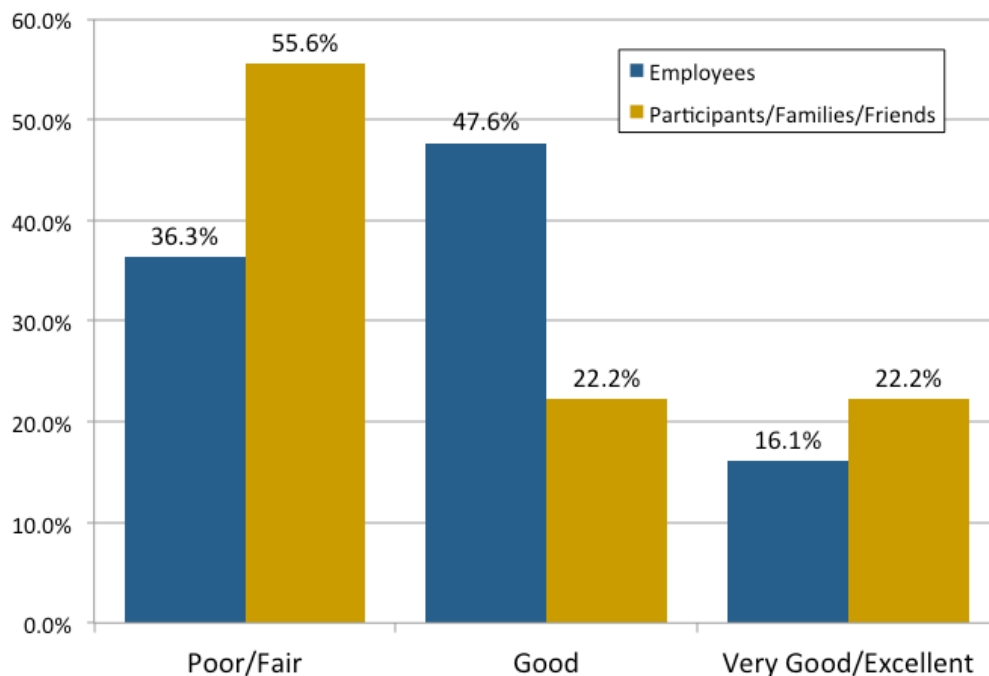
In sharp contrast, 43% of online respondents rated current services as “poor” or “fair”. Only 17% of the online respondents rated current services as “very good” or “excellent”.

Even sharper differences are evident in the online ratings based on the self-identification of the respondents. Table 3 compares the ratings given by persons who identified themselves as agency staff (T= 168) with those who identified themselves as either a program participant or a family member or friend of a program participant (T= 72).

Program participants and family members and friends of program participants were particularly critical of current services. The majority (57%) of participants, family members and friends rated current services as “poor” or “fair”, with the others equally split between “good” (22%), on the one hand, and “very good” or “excellent” (22%), on the other.

The employees of community-based agencies that deliver the services and supports were less critical. Just over one-third of these respondents rated services as “poor” or “fair”. However, only 16% of employees rated current services as “very good” or “excellent”.

Figure 3
Comparison of Ratings of Current CLdS-Funded Services
and Supports from the Employees and Participants, Families and Friends



In summary, the most positive interpretation of the 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 are 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.

The reasons for the ratings provided by those who completed the online survey have been incorporated into the other sections of the report.

4.0 What is Working Well?

The initial question in virtually all the engagement activities⁵ asked stakeholders to identify what they felt was working well with CLdS-funded services or within the CLdS service sector. Focus group participants were also often asked to identify what they saw as the greatest strengths in services and the overall system that provided a base upon which to build.

This section of the report presents the major themes that emerged from individual responses, as well as from group discussions.

4.1 Staff

The staff who provide the services and supports were one of strengths that was most frequently identified by stakeholders. Many participants and family members thought highly of the staff. Examples included:

"I appreciate the care and concern the staff have for supported individuals."

"Staff try to engage at different levels, using all the tools at their disposal."

"There are those who take time to understand the client."

"My first impression has been of the many people striving to provide excellence for other people, which enables those people to grow and blossom."

"The staff has been so supportive and informative."

Strong and positive comments were also offered by staff about their colleagues. For example:

"Many caring staff that are not working for "the Money". They are working because they enjoy the people."

"Staff always go the extra mile to make up for any possible deficiencies."

"We have a great team."

4.2 Inclusion

Stakeholders also 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. One stakeholder shared that:

⁵ This was even true for the Spring Gatherings where the station most proximate to entrance asked attendees to identify up to three things they felt were best with current services and supports.

“I think people that we support are making a contribution to society more. They are working in paid jobs in the community, giving back, volunteering at their churches, involved in clubs, and all those kinds of things ... we’re seeing a lot more of that reciprocal relationship with community. “

Program participants themselves discussed enjoying being a part of their community, meeting new people, and helping their neighbors. Similarly, community members were reportedly more open, friendly and accepting.

Family members and agency staff indicated that there are more opportunities for employment in the community and, within those workplaces, there is a greater acceptance of those with disabilities. It was also noted that organizations (e.g., sports teams) and employers are becoming a lot more accommodating in creating and operating single, inclusive programs as opposed to separate or special ones. For example:

“I have worked in the field since the mid-eighties and there have been many improvements since then in terms of inclusion in the larger community and more work opportunities instead of sheltered workshops.”

Many attributed this overall change in attitude and organizational behavior to mainstreaming and inclusion in the schools, resulting in a younger generation who is accepting and supportive of people with intellectual disabilities.

Comments included:

“When I went to school, people with disabilities were not integrated and they were in the back part of the school and you never really saw people. Now people are in class with my kids. They have friends, they have relationships.”

“I think that inclusion, from an educational perspective, has really started to change and grow. I think that the way our young people look at people with disabilities has changed. They see persons with disabilities as an integral part of their community and that they are capable individuals. They also see where there needs to be support and help, and they are willing to do those things because they have built relationships with those individuals. The change in our young people is starting to force and push society well beyond the school system.”

The move from larger group homes to smaller ones, as well as to independent living settings and shared housing, was also believed to be a contributing factor. As shared by one collateral agency representative, “what is wonderful too, is having those community homes with a smaller number of individuals. They become more centred in a community, more like a family unit”. Staff and collateral agencies further identified *The Vulnerable Persons Act* (VPA) as having had a dramatic impact on attitude shifts.

4.3 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. One said participants now had “freedom to explore goals and live their lives.” Others expressed similar sentiments:

“It’s more individualized. It’s about each person having the opportunity to plan their own lives and their own day. Whereas, when I first started it was about personal care; that was the focus of my job ... now I support them in their lives, moving them into the community and helping them get to know people.”

“Having their own home and no longer having to rely on family has improved self-esteem.”

“I enjoy seeing the independence being gained.”

4.4 Options and Opportunities

Many stakeholders also remarked that there were more options and opportunities available to people with intellectual disabilities. Participants can join day programs, get involved in recreational and social activities, take part in group outings, work or volunteer, and go on trips.

During the Spring Gatherings, participants discussed many aspects of the programs that they appreciated, including learning life skills (e.g., cooking), pursuing hobbies, enjoying social outings (e.g., supper with other houses), engaging in recreational activities (e.g., swimming and soccer), and participating in the community through volunteering or employment. Comments included:

“I love the day trips. I like daily exercise.”

“I enjoy my job. I like going to bingo on Sundays. I like seeing other participants and my friends and staff.”

“I like the cooking classes and the special events.”

“I like helping with chores at home – laundry, cooking, cleaning.”

4.5 Agencies

Stakeholders also 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. Comments included:

“The agency is very caring, competent and focused on the needs of the client.”

“The agency works hard to meet the demands and goals of support on very tight budget and high staff turnover”

“For the amount of funding received, they do the best they can.”

Participants noted that the friendships, interactions with other participants, and social opportunities provided for by the agencies were aspects that made their lives better.

A further positive identified by both participants and family members was that there were now more agencies available for them to choose from, and in some regions, these agencies were working well together and collectively were able to provide services tailored to individuals’ needs.

4.6 Rewarding Work

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

“It is a rewarding job. I enjoy doing it.”

“It’s a career in which you can always learn something new.”

“I like the change. Every day I do something different.”

Similar comments were also offered by staff in the online survey. The following are only a few examples:

“Watching people grow and become as independent as possible.”

“Giving individuals’ lives meaning.”

“We help people work towards and achieve their dreams.”

4.7 Housing

As noted earlier, the move to smaller group homes and more mainstream living arrangements within communities was seen as having been very beneficial to participants. Several reported their homes as being a safe environment and other stakeholders remarked that they had more of a home-like feel to them. One family member identified that what was working well was the “homey environment – my sister loves her ‘home’”.

Many stakeholders also commented that there seemed to be a more conscious effort to ensure the best fit amongst residents, looking for things they may have in common, more so than looking for someone to fill a vacancy. Having roommates they consider friends was highly desirable for participants, as was shared by one participant, “I like where I live. I live with my friends.”

5.0 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 Collaborations
- Community Constraints
- Limited Choice

Each of these themes is discussed below.

5.1 Human Resource

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

5.1.1 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. They discussed how challenging it was to recruit workers and how the low wages tended to attract workers with little to no knowledge of intellectual disabilities, few relevant skills and an overall lack of commitment⁶.

One family member commented, “they hire anyone”. This view was shared by many staff. One staff commented:

“Anyone gets hired and the industry has that reputation so as long as you pass criminal/abuse checks you're hired. Yet you are dealing with the most vulnerable in society.”

⁶ It must be noted that these comments do not reflect all direct service workers. As discussed above under what was “working well”, there are many dedicated and caring workers, providing high quality care to participants, who have gained the respect and admiration of family members, other staff, management, and program participants.

Moreover, once these workers gained valuable job experience, many left for higher paying jobs, resulting in very high turnover rates. One family member stated:

“There is a huge turnover of staff, both for residential and day programming. As a parent of an adult son with an intellectual disability, it is horrifying to know that at some time in our son's future, he will be left in the care of someone who is working in this profession not because they chose to but because they have no other options.”

For many staff, the job is viewed as a “stepping stone” on the way to another career, simply a “means to an end”, or a second, less consequential, job. As a result, the job is not always treated respectfully, staff do not always act professionally, and many staff lack enthusiasm and dedication. One manager provided an example of how this may occur:

“I am a person who receives care and every Tuesday night I go swimming. But when I have this revolving door of staff, invariably they come on a Tuesday and “oh, you go swimming? I don’t have a swimsuit”, “oh, you go swimming? I’m afraid of water”, “oh, you go swimming? I don’t like swimming”. It’s just easier to turn on the television.”

The impacts that low wages have on the staff themselves were clearly identified and included stress, job dissatisfaction, personal financial struggles and burnout. Wages also often affected morale, which in turn adversely affected both the overall staff complement and program participants. The following example of this was shared by a manager:

“I had one staff in the home unhappy with the salary, unhappy with the expectations of her – I could see her unhappiness manifest in my clients ... and it was taken out on my staff. I almost lost everybody. My clients wouldn’t even come down for breakfast. That was the impact in the home of someone dissatisfied because of what they were earning or how they were respected, because some people relate the wage to the respect or value they get. And the staff are just not feeling valued.”

Many staff were also frustrated with providing the breadth of services expected of them without adequate compensation or the necessary training, with one saying, “we have too much responsibility for what we earn”.

Staff discussed having to clean, plan nutritious meals, cook, administer medical care (e.g., distributing medication, dressing wounds, catheter insertion/removal), provide personal care (e.g., bathing, changing briefs), plan and manage activities, and act as counsellors. Instead of receiving recognition for the wide range of activities they perform, they are often viewed as “glorified

babysitters”. Thus, for many this job was simply viewed as a “stepping stone” or simply a “way to pay the bills”, not as a career. Comments included:

“Group home staff have the responsibility of caring for our residents twenty-four hours a day. They are responsible for giving medications, doing personal care, wiping bums and doing laundry. They cook meals and clean houses. They are responsible for providing activities for the residents’ evenings and weekends and in other cases, seven days a week. They accompany our residents to medical appointments. They earn the same wage as a fast food server and less than a homecare worker and have far more responsibility. It is time to think of these workers as professional caregivers. It is time to increase their salaries so that they can think of their jobs in the long term rather than feel it is work until something better comes along.”

“Some of them come in with good intentions and say, ‘I don’t mind that wage. I can do it’. Then the good intentions run short at 6 months to a year and that’s when they realize – ‘I can’t pay the rent. I have to give up that and that’ and then their life becomes a struggle just by being in this sector.”

In the end, although many direct support workers felt that this was a rewarding line of work, many were unable to stay in the field.

5.1.2 Turnover

The high rate of staff turnover, a direct consequence of low wages, was also of great concern to stakeholders, owing to the detrimental impact it was having on the quality of care being received by participants. The instability associated with this “revolving door” of staff places a tremendous strain on program participants. One staff member explained:

“Some people can get very anxious around new people, and when you are constantly having new people coming in, they are constantly living in a state of anxiety ... it’s hard to make their home feel like a home. It feels like they are just staying there, because the people are not familiar.”

Some staff spoke of the impact this constant turnover had on participants’ self-esteem and feelings of vulnerability. For example, one person discussed how workers often provide very personal care to participants, and how it can be uncomfortable and distressing to have so many different people performing these duties.

Another discussed the impact on an individual when a worker with whom they had formed a strong bond leaves, in particular if they don’t understand why they left. Comments included:

“How does a person develop competency and confidence when nobody seems to really care? They might care in the moment they are there and the time they are there, but then the next person comes in ... it increases vulnerability”.

“They feel like they’re not good enough, nobody wants to work with them ... a lot of them have no family contact and if they constantly get new staff, it makes them feel like what’s wrong with me, why doesn’t anyone want to work with me?”

“Is the government really going to care whether these people are getting the best quality of life? If you have your longevity employees, the people have worked with them forever, they know that person. They know their allergies, they know their likes and dislikes, and who they get along with and who they don’t get along with – are they going to care about that? We could be running a far better system if we could keep the good employees.”

It was stressed that staff turnover did not just lead to disruption in participants’ routines, it could lead to substantial changes in all aspects of their lives.

Disheartening observations included:

“You get to restart your life whenever there is a new staff ... their whole story changes when there is a new staff.”

“I know when there is a new manager or someone new in someone’s house because their diets change, their lunches change, the way that they dress changes, everything about them changes.”

While person-centred planning was regarded as an important and valued aspect of the current system, the continual turnover in staff made some question the degree to which it is being done and the success of its implementation. One agency member commented, “You have this vision and it’s hard to put that vision into practice when someone is always leaving and you are starting again”.

Finally, it was stated that “low staff wages are putting people at risk”. This statement refers to the fact that high turnover and lack of training too often result in errors in the administration of medication.

Several members in both the staff and collateral agency focus groups pointed out that paying lower wages might not actually be saving money. Beyond the high costs associated with negative service outcomes for participants, it was noted that the costs associated with training, recruitment, human resource administration and overtime hours may well exceed any savings resulting from paying low wages.

5.1.3 Staff Training

The lack of adequate staff training currently being provided to direct support workers, most of whom have little to no relevant skills coming into the job, was a considerable concern for many stakeholders.⁷ Increasing staff's understanding of the various intellectual disabilities, physical disabilities, and nutrition were recommended, as well as some medical training.

Further, a number of people commented that some recent immigrants⁸ working in the field lacked adequate cultural knowledge and language skills to work with people with intellectual disabilities, in particular those with communication disorders. Such communication challenges added additional stress for many program participants.

As mentioned above, staff discussed, at times with frustration, the array and complexity of tasks they were responsible for, much of which they were not properly compensated for or trained to do. These were said to involve duties usually performed by other professionals and para-professionals making higher wages (e.g., social workers, nurses, dieticians and home care workers).

5.1.4 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 stressful work environments leading to the need to pay overtime, a decline in morale, low motivation and burnout. Not having enough staff also significantly compromised the quality of care provided to program participants

The resulting higher staff-participant ratio has meant that workers have less time to spend with each individual, there is less community participation, there has been a need to cancel medical appointments (e.g., not an extra staff member to take them to appointment), and there is an increased potential for both increased risk (e.g., no one there to diffuse risky situation) and unsafe conditions (e.g., not enough workers to evacuate the house if need be). The following are some of the concerns shared:

“You are constantly short staffed. Staff are miserable and unhappy because they are constantly having to work overtime. For instance, we were in a crisis situation last September where no one had a choice, they

⁷ Notably, a number of staff in some of the focus groups indicated that the training opportunities had increased over the last few years. Views on training seemed to vary considerably depending on region and the agencies for which staff worked.

⁸ Newcomers to Canada have become the pool from which large numbers of employees are being recruited.

had to work extra hours because we had no staff. We had 10 people leave our agency within a two-week period. The participants really suffered - they couldn't go on any of their holidays."

"I have two clients that are in briefs – they may sit in their brief for a couple of extra hours because I only have two staff on the floor."

"... risks can escalate, residents can hurt each other because one staff is in the washroom helping someone with their personal hygiene and one is downstairs doing laundry or cooking."

5.2 System Operations and Management

Stakeholders identified several features of overall system operations and management as being serious weaknesses. The overall system was criticized for both a lack of transparency and responsiveness and many called for significant change.

5.2.1 Community Service Workers

Most family members reported that while they liked their Community Social Worker (CSW) as individuals,⁹ 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.

The quality of the services and support CSWs are able to provide was also questioned – with one family member describing the assistance as “pretty useless” and another stating that “for someone to meet with you for a half hour in a year and think they know your situation – that’s not fair”.

Many parents felt they were not receiving the information that they needed from Manitoba Family Services to make proper decisions or to provide the best care possible for their family member. One parent stated:

"I'd like to see information about what's available in all the communities. I'd like to see communication with all families from the time they are very small up until they are adults, because a lot of the time people do not

⁹ A CSW is a caseworker employed by Manitoba Family Services who is responsible for ensuring people with intellectual disabilities receive access to services consistent with the values of the VPA (protection, access to support services, supportive or substitute decision making). Under the direction of the individual and their support network, the CSW is responsible for confirming eligibility, assisting with transition planning, assessing needs, coordinating or facilitating planning, and overseeing service coordination and aspects of quality assurance, as well as for some duties shared with licensing.

know what supports are out there or where to get them. Without good communication you may not end up finding out what's available until it is long past due."

Described as the gatekeepers of the services, it was stated that the CSWs often held back information. When one mother asked for a brochure outlining the services and programs available, she was told, "if I gave that to every parent, they'd want every service. I will let you know what I think you need". The mother concluded that, "from that point on I figured we were on our own".

All the family members in the focus groups agreed with this sentiment and discussed the need to be self-advocates. They described feeling isolated and often uncertain as to what to do. Some of their comments included:

"I want good things for my son. I don't want him to be left in a vulnerable situation. We have to keep fighting for everything."

"You have to push for everything. You have to be the advocate, nobody comes to you."

"You have to be persistent and this takes a lot of time – to be the coordinator, the advocate, to be everything."

"Any ounce of care and dignity my sister has received has only happened because we have advocated for it. There is not enough interest by government to take care of our vulnerable people. It makes me so sad to think of individuals who have no family to advocate for them and how sad their lives must be."

5.2.2 Crisis-Driven

Many family members expressed frustration, and in some cases despair and tears, as they shared their experiences with the long waiting lists to get services for their adult children.¹⁰ Residential services were reported to be extremely limited and respite was seen to be difficult to secure and arrange, especially in

¹⁰ While the engagement process and this report focus on services to adults with intellectual disabilities, family members of children with developmental disabilities attended the Spring Gatherings and offered comment on the lack of resources and waiting lists for services needed by their children. Parents of children diagnosed with autism expressed the greatest frustrations. Early interventions with these children have proven to provide long term benefits, both in terms of increased personal capacity and in terms of decreased reliance on government funded services in their youth and adult years. Therefore, the multi-year waiting lists to access these interventions are understandably seen to rob their children of their potential and contribute to much higher costs in services over future decades.

the rural areas. Several mentioned being told that it would be up to 10 years to find a home. Parents currently without services find themselves struggling to get by. One shared her fight to get supports:

“I feel like I am being put through the grinder and I don’t think it is right ... this is what we need in our lives to continue to have a good life. I’ve been my daughter’s caregiver for 21 years and I can’t do it anymore.”

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 a dire situation. As was noted by one staff member, “you have to set your child up for failure in order to get services. You’re penalized if you set your child up for success”. Another comment was:

“I was on the backburner because [my son] is higher functioning and in a home where he was not being beat up or killed or stabbed or thrown out in the street – so it’s like, ‘you’re okay’”.

Family members and participants were not the only ones negatively affected by this “reactive” orientation. Staff reported that agencies are expected to address the needs of individuals who had been previously unable to access services, but who are in crisis situations on a high priority basis. Some staff reported that agencies do not feel as though they are in a position to say ‘no’ to Family Services even if they doubt their capacities to provide the needed services. One said, “if you have the space, you have to take them. We said ‘no’ a couple of times and we were slapped on the hand”.

Current homes were said to not be set up to deal with such crises that can greatly disrupt the lives of the other residents. “A crisis rings your doorbell and you’re throwing a wrench into three other people’s lives. To me there needs to be a separate home specific to crisis”.

Additionally, these individuals in crisis often need a great deal of support (e.g., behavioral psychologists, mental health workers, and police). Although, CSWs and Manitoba Family Services staff may promise help to the agency to manage the situation, it was said that the department rarely follows through on providing this assistance. Speaking of these needed supports, one agency staff member vented, “[We are told] all of that will be available, but it never is. It never, ever, ever is. And that is probably one of the biggest frustrations. Everyone just flies by the seat of their pants”.

5.2.3 Lack of Lifelong Planning

Another significant concern was the lack of adequate planning throughout the lifespan of participants. Family members felt that the CLdS system needs to be much more proactive in terms of planning for participants’ futures. Focus group

participants identified two specific life stages they felt were not being properly addressed – the transition into adulthood and then into the aging years.

Transition to Adulthood

“God help you when you turn 18 because you are on your own” and “you are thrown to the wolves” were comments parents used to describe this phase in the life of an individual with disabilities. For example, there were challenges with helping students fulfill their post-high school goals and apprehension that some students may become isolated following graduation.

However, the primary concern expressed by stakeholders was that upon turning 21 individuals “lose everything”. The information, communication and wide range of services that were provided to participants while in the school system (e.g., OTs, behavioural psychologists) are no longer easily accessible (if accessible at all) in the adult system.

Families and participants seemed ill prepared to enter the adult world. They especially expressed frustration over no longer knowing what their son or daughter was eligible for, what options were available, or even where to find such information. As discussed above, it is the role of the CSW to provide such information and ease this transition, but it would seem that this is not being done effectively.

Another concern for parents and educators was the fact that students were deemed adults by the child welfare system at 18 and graduated with their peers at 18, yet they were expected to stay in school until they were 21 as there are no funds for them to enter day programs. Following graduation, they no longer attended mainstream classes, but were sent to a life skills program. Being separated from their peers had a negative effect on the students’ self-confidence and parents reported it led to a regression in their social skills.

Aging Population

When it came to planning for the aging population, it was felt by most that the sector was not yet ready to cope with managing their specialized needs. Two different perspectives were offered on how best to accommodate aging individuals. The first approach involves people with intellectual disabilities entering the mainstream system, and just as many others their age, residing in personal care homes. However, it was felt by one group of care workers that those working in the care homes did not understand the social needs of people with intellectual disabilities, and did not have the established relationships and ability to properly care for these individuals.

The second approach entails individuals “aging in place” or aging in their homes, and receiving palliative care when necessary. Regarding the latter, staff stated they were not adequately trained for the additional duties that would

accompany seniors and palliative care and felt it was unfair to expect them to take on additional responsibilities without increasing their wages. It was also mentioned that the costly equipment and renovations required to properly care for these individuals was not always covered by government.

Another issue raised by stakeholders related to the appropriateness of many day programs for aging program participants. Successful stand-alone day programs specifically for seniors have been developed by some agencies in some regions. However, due to system inequities (e.g., funding, information sharing), not all areas in the province have programs to serve the unique needs of those 65 years and older. This greatly concerned some of the stakeholders. One worker explained:

“I have someone who is going to be 65 in September and she doesn’t want to work anymore, but that is not possible because she is able to walk, she is able to work, and she seems happy ... I also know someone who is in her 70s and still goes to work because not going is not an option”

5.2.4 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. A few believed that the government, consciously or unconsciously, had set up a competitive environment amongst agencies, which, in some regions, hampered inter-agency cooperation.

It was also pointed out that disparities went beyond financial matters, noting that not all agencies delivered the same level of services and there was no method in place for evaluating these services and ensuring the best quality of care for the participants. As one staff person reported:

“I’ve worked for two agencies and one provides significantly better support than the other. I think depending on the agency the quality of it can vary considerably. Some provide amazing support and others don’t.”

Concerns about inequities were not limited to those currently providing or receiving services and support. One parent who has had difficulties accessing services reported:

“There doesn’t seem to be structure or accountability. What you get and how much you get is subjectively related to who your social worker is ... you cannot have transparency when there is no structure to go back to and say you are getting this much because this is the guideline.”

5.2.5 Assessments

Another key concern was related to assessments. There are three types of assessments – assessments to diagnose an intellectual disability, assessments to determine what services and supports are needed, and assessments to identify and respond to specific disabilities.

In adulthood, accessing any one of these assessments is extremely limited and costly, and ensuring these individuals receive the necessary supports is very challenging. It was strongly stated that if proper assessments were performed in childhood, allowing for the proper resources and services to be put in place at an earlier age, far more persons with intellectual disabilities would be leading quality lives.

Regrettably, it was reported that securing assessments in childhood in some school divisions is also very difficult. One elementary school educator remarked, “It starts with us, unfortunately, and trying to get kids assessed is next to impossible. There is a waiting list that is extremely long”.

5.2.6 Eligibility Criteria

A concern closely related to assessments was that of the criteria for qualifying for CLdS services. The current criteria were seen to be limiting and a source of frustration for those working in the sector. The condition that an individual must be diagnosed before the age of 18 was regarded by both community-living and collateral agencies as being a hindrance to their ability to help people. One stakeholder explained:

“The criteria of Community Living disAbility Services is a huge frustration. I think it excludes the vast amount of people that are ‘falling through the cracks’ and I would say if one thing could be changed in our system we should change that criteria of how people are assessed and get rid of the magic 18.”

Unfortunately, some undiagnosed individuals, those who have “fallen through the cracks”, find their way into the justice system. This is much to the frustration of those working in corrections who believe these people would best be served in the CLdS system. One representative from Justice observed:

“These people are missing out on both ends – they don’t qualify for the people who have the training and resources that they need and then they are defaulted to us, who are coming from a law enforcement perspective. We are going to nail you every time you step out of line. But what we know about people with intellectual disabilities is that maybe their decision making process was not so great that day – and so we are setting people up. And once they enter our system there are just no resources to assess them to say whether we should divert them elsewhere.”

Stakeholders also discussed there being many individuals with inadequate adaptive skills, but because they have an IQ above 70, they are unable to get proper help because they do not meet the criteria needed to be considered to have an intellectual disability. One agency staff commented:

“Unfortunately, the eligibility criteria is still not where it needs to be ... right now the eligibility criteria still hinges on IQ scores, whereas when you have a disability like Fetal Alcohol, you can score over a 70 with your IQ, so you are not eligible for funding and supports, but your adaptive functioning, your ability to live your day to day life in a healthy fashion and understand the consequences of your actions and be able to plan for things, that area of the brain doesn’t work. The area of the brain that can help you score over 70 on an IQ test might be there, but your ability to actually live life – that you are able to pay your bills, keep a place, have work skills and the social skills to keep a job, stay out of addictions, understand laws – that part is not there.”

5.3 Cross System Collaboration

The need for better coordination and communication between major service systems (e.g., mental health, home care, health care, police, corrections, and addictions services) was a common theme in discussions of system 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. One focus group member stated, “It is so easy to dump people on other programs”. Another concurred, stating, “I feel the justice system is the dumping ground for people that are not being adequately assessed and aren’t being adequately resourced to remain in the community”.

This was especially a problem for those with dual- or triple-diagnoses (i.e., mental disorders and addictions). These people tended to “fall through the cracks”, not being helped by any agency and not receiving the resources they desperately needed.

Comments included:

“Because [participants] don’t have the intellectual capacity to have a counselling program, they’re not going to be provided with anything. It prevents the people we support from getting the [mental health] resources they need.”

“All the different systems seem to have a road block built in that we need to remove. We are all here to support the individual with our different pieces, we all want to support that individual, but if the road block is in the system we get stuck.”

Focus group members noted that this situation was not only unfair to these individuals, but this lack of cooperation was also driving up costs which could be better used to fund front-line programming.

Finally, in several regions, communication amongst community-based agencies themselves was limited, resulting in a duplication of services and an overlap in administrative activities. Further, some stakeholders identified communication within some agencies (i.e., between management and direct workers) and between staff and family members as needing improvement.

5.4 Community Constraints

5.4.1 Accessibility

Stakeholders believed inaccessibility was a significant barrier to meeting the needs of participants. Transportation was a challenge for many, in particular in the rural areas which generally had no public transportation and long distances between services. Wheelchair accessibility, be it residential houses or local buildings, was also discussed. These barriers limited program participants' choices, potentially restricting their participation in certain day programs, volunteer/employment opportunities, outings, and activities, as well as narrowing their housing options.

5.4.2 Employment

Although there have been improvements in the area of employment, as was noted above, a number of the stakeholders believed that there was still a lack of opportunities for individuals with disabilities. A few stakeholders said there was still a need for greater acceptance and respect in the workplace. Wages, or lack thereof, were also a concern for some, with one feeling that the revisions to the Employment Standards code that require adults with intellectual disabilities be paid no less than minimum wage was preventing creation of employment options for participants who were only able to do part of the job or had low productivity.

5.5 Limited Choice

As noted above, an important feature of the existing system is that people with intellectual disabilities have greater choice. However, some stakeholders pointed out that real choice for program participants was significantly limited, primarily due to funding constraints. Examples raised included the elimination of one-on-one care, pressure to increase the number of residents per dwelling in some areas, and required participation in day program activities (i.e., participants are "forced" at times to engage in activities, work, or go on outings they may not wish to participate in). The following comment captures these concerns:

“One-on-one has gone the way of the dodo. We are having to put more and more people in each house and it is just assumed that a person will be attending a day program with a bunch of other people ... they are just lumped into doing whatever the day program is doing regardless of what that person’s interests are ... the person must get on the bus with everybody else to go do the same thing whether they like it or not. If you are an agency that is at all philosophically progressive, then that is really painful.”

Also, during the Spring Gatherings a number of participants expressed, both on cards and in videos, a strong desire to live on their own; however, for many different reasons independent living opportunities were limited.

6.0 What Changes are Needed?

Persons who attended Spring Gatherings and respondents to the online survey were invited to identify the single most important change that could be made to improve services and supports and to enhance inclusion in the community. Identifying a single change as the top priority was difficult for many people. As a result, almost ½ of those who shared their views identified more than one change.

Priorities for change were also explored as part of the discussions at each of the focus group sessions.

This section reports on the priority changes identified based on input and feedback gathered through all three of the methods used as part of the stakeholder engagement process.

6.1 Increased Wages

A large majority of persons who participated in engagement activities, regardless of the stakeholder group or region, indicated that the capacity to make significant improvements in services and supports was contingent on wage increases for direct support workers. Many reasons were provided as to why this would improve services, including that higher wages would attract a more professional, qualified staff and a pay increase would improve the likelihood of retaining these quality employees. Comments included:

“When you work for an organization that pays higher you see a big difference in the quality of the people that walk through the door and their resumes and you can give people better care with people that are paid more.”

“In order to have happy, quality, long-term staff, you need to make those people feel appreciated and give them the resources they need to live satisfying lives. The higher turnover rates, burnout, and poor quality of service is often related to support staff feeling undervalued and exploited.”

As these comments suggest, it was felt that increasing wages would result in better trained and more dedicated staff and decrease turnover rates, thereby reducing subsequent adverse physical, emotional and mental impacts on participants.

Some stakeholders commented that raising wages would likely increase the cost-effectiveness of current services, not only by increasing quality, but also by reducing expenditures related to dealing with staff turnover. One staff person went so far as to say that fewer employees might be necessary if those in place were properly trained and compensated. She stated, “if wages were higher we

would need less staff because the job would be done. We could lower the number of positions just based on people doing their job”.

6.2 Improved Government Resources

As discussed above, many families were frustrated with the services they were receiving from Manitoba Family Services. A frequent turnover in CSWs and the lack of response to queries and requests left many feeling isolated and desperate. One common suggestion for improving this working relationship was to decrease the number of cases being handled by each CSW. The following comment captures this view:

“Allow CLdS staff to have a lower caseload so that more intensive support can be offered to all families that need it. Sometimes the highest needs cases take over and the ‘quiet’ cases don’t get much attention.”

A further suggestion was that regularly scheduled meetings, monthly or bimonthly, be held to allow for family members, participants, and CSWs to “touch base”.

A number of parents, in particular those of participants who had recently transitioned from child to adult services, were upset by the challenges they faced when accessing information on different services and program options for adults. It was felt that CSWs could be more forthcoming about what was available to adults with intellectual disabilities. One suggested that clear written information be provided to parents by CSWs outlining the options and potential resources available to their adult child, along with the rights of family members and program participants and the responsibilities of CSWs.

A number of others felt that a centralized resource should be created for families to access both general and detailed information on services and supports. Yet another felt there needed to be better communication between community-based agencies and that these organizations could cooperatively provide information on the existing services and programs.

Many family members were concerned that authority to grant or deny services appeared to be held by one individual, the CSW. One family member stated that they only met with their CSW once a year and from that meeting this worker made decisions on the needs of, and services to be given to, their family member – “It’s not fair that one person gets to decide your accessibility to services”. It was suggested that open and transparent processes should be established to improve fairness and accountability.

Finally, one family focus group member stated that it was essential for the government to be mandated to provide a full range of services and support to

adults with intellectual disabilities, not simply address statutory requirements under *The Vulnerable Persons Act* (VPA). This family member emphasized that:

“One thing we have been told over and over again over the years, especially when we got to the adult side, is that the government is not mandated to provide any kind of service for people with disabilities. I personally think, unless that changes, it is going to be hard to change some of the other things.”

6.3 Improved Service and Systems Coordination

Community-Based Agencies

A range of suggestions was made to improve coordination among the 100 plus community-based agencies that deliver services and support to adults with intellectual disabilities. While acknowledging that there are already strong relationships among some agencies and in some regions, it was felt that much could be gained through the increased sharing of ideas, successes, resources and training. One staff member suggested that Abilities Manitoba should play an expanded role in facilitating agency collaboration.

The question of whether there should be some consolidation of services and agencies was raised during focus group sessions with staff. Some staff indicated that this would simply not work, in particular in the rural areas. Other staff identified the potential to reduce the cost of overhead through the consolidation of management functions and administrative services.

Yet others were concerned that amalgamation might limit the options available to participants. While supporting the concept of reducing the number of agencies providing services, one staff shared “...when I think of the menu out there – I like that for families. Those that are seeking services have a lot of options to choose from, so the services they’re getting are close to what they feel they want or need”.

Another staff member had a different perspective, stating:

“I think we all try to reinvent the wheel and I think we all try to cover every base. Every agency has their own day program, their own employment program, their own counselling services, their own this and that, when it would make more sense for each group to pick a different area to be responsible for and focus solely on that. We are all trying to expand our programming when maybe we should be shrinking our programming to more focused areas.”

Service Systems

The importance of service systems working effectively together was identified frequently during the focus group sessions. These individual systems (e.g.,

mental health, home care, addictions services) need to be encouraged to work as a network in order to provide the best services possible, to prevent individuals from being “bounced” around, to avoid having people “fall between the cracks”, and to reduce the repetition of services. As one service provider observed:

“It is always a challenge to coordinate when you are dealing with different agencies – to determine what you have to offer and what they have to offer and how we access it ... I always find that there is – ‘oh, they don’t meet that criteria, so they cannot access that support.’ That is the frustrating part. If we could blur those lines a bit, instead of black and white, for the sake of the [participant], their family and what their needs are – that would be wonderful.”

Government Departments

It was suggested that the Ministers and Departments of Justice, Education, Health, and Family Services needed a greater awareness about people with intellectual disabilities and the current level of involvement their departments have with them. It was also suggested that departmental “watch dogs” be created to ensure that people with intellectual disabilities were being treated fairly. Finally, several collateral agency participants discussed the value in having a Department of Disabilities Services, which would bring together all necessary governmental supports under one portfolio.

6.4 Standardized Training

A number of focus group participants felt that there should be a “professionalization of the field”, meaning all direct service workers should receive standardized, mandatory training. One staff person emphasized:

“We need standardized training for all staff, including classes on developmental disabilities, understanding assessment, documentation, basic medication, nutrition training, and dealing with behavioural challenges. And they should have to pass a standardized test in order to gain a diploma and work in the field.”

Professionalization would encourage more dedicated people to enter the field, people who would wish to make this job a career not simply a “stepping stone” on the way to something else.

The standardization of training would have to be accompanied by a raise in wages, for as one person pointed out, who would pay for training and then make just above minimum wage. Another suggested that wages be dependent on level of training. As summed up by one staff person:

“[We must] find staff who are here for the people not just “a job”. Any person can walk off the street and apply, but in order to get things done we need properly trained people. The way to get that is education and money.”

6.5 Policy Changes

There were a number of suggestions for additional policy changes, which included:

Eligibility Criteria: As mentioned in Section 5, being diagnosed before age 18 and possessing cognitive skills without adaptive skills were both criteria that focus group members thought should be reconsidered.

Service Funding and Per Diems: Many staff in focus groups said that current funding inequities needed to be addressed.

Individualized Funding: A number of stakeholders stated that funding should not be associated with an agency but rather assigned to an individual. This would give families greater flexibility to choose the programs and services that best meet their family member’s needs and allow them to transfer their services to other regions of the province.

System Flexibility: It was believed important that there be flexibility within the system to allow agencies to respond to individuals who do not fit into traditional service options, allowing them to devise a way to best meet their needs without onerous red-tape and licencing requirements. One family member requested, "more person centered and directed services and supports opposed to asking people to fit into the systems that already exist".

6.6 Increase Front End Investments, Reduce Downstream Costs

Both staff and collateral representatives suggested that greater front-end investments will result in fewer individuals “falling through the cracks” or failing to reach their full potential, and would reduce unnecessary downstream costs.

Many believed that the reactionary nature of the system is driving up expenditures. Stakeholders felt that early provision of services – i.e., “investing in services for someone before they are in crisis” – could significantly reduce overall system costs. As expressed by one staff member:

“As a system, I feel like we are far too reactive and not proactive enough. We don’t justify spending money on anyone until their problem has gotten so large it is almost unfixable ... we don’t step in to try to help someone until they are so far gone that the help we give is not effective and the money we spend is astronomical.”

One of the primary front-end expenditures requiring more adequate funding is assessment. Early intervention (i.e., in childhood) is essential.¹¹ An early diagnosis could ensure that an individual receives the necessary supports and resources needed to lead a fulfilling life.

As noted earlier, individuals with intellectual disabilities who enter the justice, addictions, mental health and health systems are often those who are undiagnosed or inadequately supported. It was anticipated that spending at the front-end on assessment and appropriate, timely services would reduce the pressure on these systems and result in net decreases in the overall costs for assisting this population. One representative from Justice suggested that:

“Maybe some funding could be taken out of Justice and given to other service providers to do front-end screening of people that were flagged.”

6.7 Service Quality Assurance

Many staff and family members noted that there were significant disparities in the quality of services being provided by the over 100 community-based agencies delivering services to adults with intellectual disabilities in Manitoba. Several staff commented on this fact. For example:

“Although there are agencies working hard to provide excellent quality of services, there are still too many agencies that are not.”

“We have come a long way, however supports are not consistent within agencies, across agencies, or within regions. There are many people who are not engaged in a meaningful day or have a lot of time wasting activities.”

It was suggested that a standards manual be developed for day programs and residential services to address inequities and establish consistent expectations. It was also suggested that increased quality assurance measures would be helpful, along with a greater emphasis on measuring participant outcomes.

6.8 Better Planning throughout Lifespan

As was discussed in Section 5, stakeholders expressed considerable concern over inadequacies related to the lack of planning and consistency in support as people with intellectual disabilities transition into adulthood and as they age.

¹¹ As discussed in the footnote in section 5.2.2, current waiting lists for early interventions for young children diagnosed with autism seem to reflect a tradeoff between lower investments now for much higher costs over the long term.

Regarding, the transition to the adult system, it was suggested that planning for adulthood begin as early as 10 years old and that efforts be made to promote equity in the nature and extent of services and supports between the education system and the CLdS system. It was suggested that differences between government policies with regards to when an individual becomes an adult also need to be addressed.

One parent felt there should not be a “transition”, but rather it should be a continuum of services and supports available to those with intellectual disabilities from birth to death. This echoed the concerns of another parent who stated, "18 year olds do not lose their diagnosis, why do they lose their services?"

In terms of aging, it was suggested that careful consideration needs to be given to whether it is best to have individuals enter personal care homes, age in place, or some combination thereof. A stronger relationship with the Department of Health must be established and planning for this population must be done conjointly. Areas that need to be addressed in planning include:

- Increasing funding to agencies and participants to cover costs related to equipment, house modifications and medications.
- Devising means to ensure this population receives respectful treatment while in hospitals and social stimulation while in care homes.
- Providing staff with proper training to administer medical procedures or have it be established that home care is responsible for providing support to individuals living in residential homes.

6.9 Expanded Employment Opportunities

Agency staff, collateral agencies, families and program participants agreed that there needed to be an expansion of the employment opportunities available to adults with intellectual disabilities. Some family members discussed the need for more training and apprenticeships, a focus group member suggested changes to the minimum wage legislation to accommodate job carving, and discussions were had regarding supplementary funding being provided to employers to offset the costs of employing individuals with intellectual disabilities. A few family members noted that opportunities need not only be with private employers, but that the government should also be making more openings for people with intellectual disabilities.

6.10 Increased Political Will

Stakeholders felt that most politicians do not understand the needs of persons with intellectual disabilities or the challenges they and their families must

confront everyday - “Are they aware of any people with disabilities and what we’re facing on a daily basis? And for the future?”. One mother felt that if one had not lived this life, it would be difficult to understand. She shared, “before we had my son, disabilities were nowhere on my radar. I’d never even met anyone before, and, I’ll be honest it just wasn’t something that mattered to me”.

It was suggested that both expanded lobbying and the communication of personal stories were required for politicians to gain a better understanding of the day-to-day challenges faced by individuals with intellectual disabilities and their families endure.

It was discussed in one focus group that there was no political champion for peoples with intellectual disabilities and in another session it was stated that, “no government is going to get re-elected because they threw all kinds of extra money into community living. It’s not on politicians’ agendas”. It is believed that a public education and awareness campaign that promotes understanding and inclusion will increase people’s level of concern, in turning pushing the government to take action.

6.11 Enhanced Programs

Finally, staff, participants and families stated they would like to see enhanced programming in many areas, including:

- Increased one-on-one care
- More life skills training
- Greater access to experts (e.g., OTs, physiotherapists, dieticians, behavioural psychologists, 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.

7.0 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 engagement activities was to ask those most directly affected by the adequacy of these services to help identify the key 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. This final section of the report highlights major themes that emerged from these discussions.

All the stakeholders expressed strong interest in participating in the planning process. Collateral agencies felt that their systems and agencies shared a strong interest in improving services for adults with intellectual disabilities. They also recognized that the level of their involvement would need to be determined on an issue-by-issue basis. Fairly extensive involvement was seen to be required, for example, in efforts to address matters related to systems coordination.

In general, collateral agencies indicated that they would like to be consulted at various points throughout the planning process. In order to provide meaningful input, advanced notice would be required, along with the sharing of materials ahead of consultation events.

CLdS-funded agency staff also indicated that they and their colleagues want to participate in the inclusive planning process. It was suggested that consultative events held as part of regular agency staff meetings provide one method to build engagement among staff. It was also suggested that engagement options be pursued through the auspices of the newly established Manitoba Alliance of Direct Service Professionals.

Several options were discussed on how to best engage family members in an inclusive planning process. One family member stated that getting parents out to discuss issues was “almost an impossibility – they are too tired to get involved”, while another felt no matter how tired and frustrated they were, family members would come forward. Another family member suggested a parents’ retreat be organized for which respite supports could be provided while they attended the event and engaged in planning. Another suggestion was to establish a Family Members Advisory Council to play an ongoing role in the planning process. Other suggestions included on-line think tanks/chat rooms.

No focus group sessions were held with program participants. As a result, suggestions for how best to engage them in the planning process were not explored directly with them. The experience gained through the Spring

Gatherings, however, suggests that informal consultative methods hold considerable promise.

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 needs to move well beyond setting a vision for a better future. The focus group members felt that it was essential that planning processes establish change objectives, adequately resourced strategies for achieving these objectives, and clearly identified and time-bound deliverables.

Appendix A

Abilities Manitoba Action Card



Any society, any nation, any province is judged on the basis of how it treats those who are most vulnerable.

I/we know that you share our deep concern for the safety, well-being and quality of life of Manitobans with intellectual disabilities.

Based on this shared concern, I/we ask that you:

- Establish an inclusive planning process to ensure the long-term sustainability of services upon which so many now depend.
- Ensure that planning fully incorporates the voices of persons with intellectual disabilities, their families, as well as service agencies, their employees and the public.
- Provide immediate support to those agencies already facing serious financial challenges in maintaining basic services.
- Take measures needed to provide reasonable wages for agency employees who are among the lowest paid human service workforces in Manitoba.
- Ensure that other funding decisions made in the short term do not diminish the quality, scope and viability of current services.

Please fill in your name and return mailing address:

Name: _____

Address: _____

Town/City: _____ Province: _____ Postal Code: _____



Minister Kerri Irvin-Ross
Minister of Family Services
Room 357 Legislative Building
450 Broadway
Winnipeg, MB R3C 0V8

Appendix B

Stakeholder Engagement Activities

Central Region (Portage la Prairie)

May 28, 2014 Collateral Agencies Focus Group
Community-based Agencies' Staff Focus Group
Spring Gathering

Interlake Region (Selkirk)

May 29, 2014 Collateral Agencies Focus Group
Community-based Agencies' Staff Focus Group
Spring Gathering

Parklands Region (Dauphin)

June 11, 2014 Collateral Agencies Focus Group
Community-based Agencies' Staff Focus Group
Spring Gathering

Westman Region (Brandon)

June 12, 2014 Collateral Agencies Focus Group
Community-based Agencies' Staff Focus Group
Spring Gathering

Norman Region (Thompson)

June 16, 2014 Collateral Agencies Focus Group
Community-based Agencies' Staff Focus Group
Spring Gathering

Eastman Region (Steinbach)

June 19, 2014 Focus Group with Families of Participants Seeking Access
to Services
Community-based Agencies' Staff Focus Group
Spring Gathering

Winnipeg Region

June 23, 2014 Focus Group with Families of Participants Seeking Access
to Services
June 24, 2014 Community-based Agencies' Staff Focus Group
Spring Gathering
June 25, 2014 Spring Gathering

Appendix C

Regional Coordinating Agencies

Central Region (Portage la Prairie)

Coordinated by Visions of Independence

Interlake Region (Selkirk)

Coordinated by Community Living Selkirk

Parklands Region (Dauphin)

Coordinated by Parkland Residential & Vocational Services and Grandview Gateways

Westman Region (Brandon)

Coordinated by Brandon Community Options and Prairie Partners

Norman Region (Thompson)

Coordinated by Juniper Centre

Eastman Region (Steinbach)

Coordinated by enVision Community Living

Winnipeg Region

Coordinated by St. Amant and Community Living – Winnipeg

Appendix D

Ratings of the Quality and Availability of Services

All persons who attended the Spring Gatherings and all who completed the online survey were invited to rate the overall quality and availability of current services and supports. In total, 504 ratings were received as part of the stakeholder engagement process. A total of 244 (48%) ratings were provided by those who attended the Spring Gatherings. Those who completed the online survey provided the remaining 260 ratings (52%).

Issues Related to Processing the Ratings

A key difference in the methodologies used to collect the ratings contributed to minor differences in results. While both methodologies used the same scale (1=poor, 2= fair, 3=good, 4=very good and 5=excellent),

- Those who attended the Spring Gatherings were asked to write down their rating on a sticky note and post this on the wall under a large print out of the scale. While most participants chose one of the rating points on the scale, some gave ratings between the points (e.g., 2.5, 3.5).
- Those who completed the online survey were only able to select one of the 5 discrete ratings, though respondents could alternatively indicate that they did not wish to or have enough information to rate services (only 10 of the 270 online respondents chose not to rate services – their responses have been excluded from the ratings analysis).

The ‘half way’ ratings from Spring Gatherings ratings have been adjusted to provide consistency with the discrete ratings used on the ratings scale and as available in the online survey. There were 24 such ‘half way’ ratings. One half of these were rounded down to the nearest discrete rating. The other half of these were rounded up.

Two ratings of “0” were also received at one of the Spring Gatherings. These have been interpreted having meant a rating of less than “poor” (1). To provide for consistency in analysis, these have been converted into “poor” ratings.

The detailed rating results from the Spring Gatherings and the online survey are presented on the following pages.

Detailed Ratings Results in Tables

Spring Gatherings

Region	Rating					Total
	(1) Poor	(2) Fair	(3) Good	(4) Very Good	(5) Excellent	
Central	2	4	4	6	6	22
Interlake	10	1	10	7	0	28
Parkland	0	2	4	5	2	28
Westman	4	2	4	5	2	17
Norman	0	4	8	1	1	14
Eastman	0	6	6	3	2	17
Wpg. 1	10	20	17	13	9	69
Wpg. 2	3	6	12	20	8	49
Total	29 (11.9%)	51 (20.9)	72 (29.5%)	58 (23.8%)	34 (13.9%)	244 (100.0%)

Online Survey

Relationship	Rating					Total
	(1) Poor	(2) Fair	(3) Good	(4) Very Good	(5) Excellent	
Current program participant	0	1	2	1	0	4
Family of a current program participant	7	30	12	11	2	62
Friend of a current program participant	1	1	2	1	1	6
Employee of a service-providing agency	12	49	80	24	3	173
Other	4	7	8	1	0	20
Total	24 (9.2%)	88 (33.8%)	104 (40%)	38 (14.6%)	6 (2.3%)	260 (100.0%)