

**The Integrated Adult Services (IAS) Pilot**  
**INTERIM REPORT**  
**Summary Report**

Submitted to the Steering Committee on September 23, 2024

Authored by Dr. Terra Johnston, PhD  
Chalet Point Consulting



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## Introduction

This summary provides an overview of progress on several aspects of the evaluation and engagement workplan for the Integrated Adult Services (IAS) pilot. A detailed technical report corroborates the findings of this summary report and is available upon request to the IAS Steering Committee.

This summary is authored by Chalet Point Consulting, the external firm contracted to perform the evaluation and accessible engagement for the IAS pilot, with the disabilities community, over the period of 2023 to 2026.

## Brief Background to the IAS Pilot

Grounded by a precedent-setting human rights settlement, the Department of Families, Department of Health, and Winnipeg Regional Health Authority (WRHA) committed to developing a new service delivery model for adults with both a medical diagnosis and complex disability-related needs through the IAS pilot. With a focus on service coordination and integration, the IAS pilot serves to identify service barriers or gaps and works toward creative solutions that enhance the quality of life for pilot participants.

Through an accessible engagement process, the IAS pilot engages with and documents the lived experience of adults with a medical diagnosis and complex disability-related needs living throughout Manitoba, while addressing gaps in supports and service for 30 eligible adults in the Winnipeg Health Region<sup>1</sup>.

The IAS pilot supports 30 adults, living in the Winnipeg Health Region, who have both a medical diagnosis and complex disability needs, and are experiencing gaps in services and supports that prevent their full participation in home and community life.

The aim of the IAS pilot is to create and test a new service delivery model with identified participants and learn from the experiences and activities of the IAS pilot to implement long term, meaningful change in the overall service delivery system. The Government of Manitoba has committed to best efforts toward implementing the recommendations that arise from the Pilot.

## Brief Background to the IAS Pilot Evaluation

Given the IAS pilot is grounded by a precedent-setting human rights settlement, the evaluation of this initiative is informed by a Human Rights Impact Assessment<sup>2</sup> (HRIA) Framework. This HRIA framework ensures the IAS pilot is evaluated on how it upholds/does not uphold the human right to accessible services for the pilot participants.

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<sup>1</sup> Winnipeg Health Region serves residents of the city of Winnipeg, as well as the northern community of Churchill and the rural municipalities of East and West St. Paul.

<sup>2</sup> To learn more about HRIA, visit: <https://unglobalcompact.org/library/25>

In philosophical alignment with the HRIA Framework, the evaluation of the IAS pilot reflects the methodology of Participatory Action Research<sup>3</sup> (PAR). PAR is an inclusive type of research in which all participants contribute to the development and implementation of the evaluation, as well as the development and review of evaluation materials and reports, including ways of dissemination.

## Process Evaluation Findings

As part of the process evaluation, input was gathered by 11 pilot participants and 12 steering committee members, as well as 5 representatives of the research sub-committee (which included members of the pilot researcher and representatives of the steering committee), and 3 representatives of the selection sub-committee. The broad parameters of the evaluation of the IAS pilot were informed by the IAS pilot Steering Committee, including the following evaluation questions, answered below:

1. Did the recruitment and screening process involve participants that come from diverse backgrounds, age, gender identity, housing, and support situations, and did the project highlight a variety of gaps and needs? And were these gaps and needs used throughout to help inform the project?

Yes, mostly.

Findings from round 1 of the process evaluation demonstrate that the recruitment and screening process involved participants from diverse backgrounds, including age, gender identity, housing, and support situations.

2. Did the range and effectiveness of the activities and interventions employed by assigned staff support participants?

Yes, with some exceptions.

Findings from round 1 of the process evaluation demonstrate that the range and effectiveness of the activities and interventions employed by assigned staff do support many of the participants, though some participants stated their frustration with their experience with the pilot. The outcome evaluation will explore this question in detail, with a larger sample of participant respondents.

3. Did participants experience a timely, robust, empowering, and comprehensive discovery and assessment process that identified their needs, wills, priorities, and perspectives?

Yes, with some exceptions.

Findings from round 1 of the process evaluation demonstrate that participants experienced a friendly, welcoming and accessible discovery and assessment

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<sup>3</sup> To learn more about PAR, visit: <https://www.participatoryactionresearch.net>

process that identified their needs, wills, priorities, and perspectives. However, many participants noted their frustration with the slow process for same.

4. Were participants' needs met using a variety of means and activities that can be replicated and sustained outside of the pilot project?

No.

While this evaluation question will be better assessed by round 2 of the process evaluation, the input so far by respondents suggests replication and sustainability of services for the pilot present an issue that requires attention for future planning.

5. Were a variety of voices and opinions of stakeholders with lived experience of disability and engaging with services throughout Manitoba well represented and heard throughout the project?

Yes, somewhat.

While the engagement work collected input from Winnipeg, Dauphin, and Brandon, further engagement in round 2 will target other communities, including additional rural perspectives. Further, while there is strong participation by community members on the steering committee, a perceived power imbalance among the government representatives and community representatives should be redressed through enhanced collaboration and consensus building efforts.

6. How was best practice information from the pilot researcher used to inform the pilot project?

Minimal success to date.

Findings from round 1 of the process evaluation suggest strengthening the relationship between the pilot researcher and the steering committee. This recommendation is further articulated in the next section.

## Process Evaluation Recommendations

The input of 11 pilot participants and 12 steering committee members was collected on the operations of the IAS pilot. The following recommendations reflect their input.

1. **Enhance recruitment efforts:** Future recruitment efforts related to the pilot (e.g., expansion, replication) should include concerted investments in promotion (e.g., media advertising, news release events) and rely less on word-of-mouth networking by the disabilities community.
2. **Broaden recruitment and selection catchment to include rural Manitoba:** Future recruitment and selection efforts related to the pilot (e.g., expansion, replication) should include applicants from rural Manitoba.

3. **Redress timeliness issues for the pilot:** Efforts for recruitment, selection, and discovery and assessment related to the pilot (e.g., expansion, replication) should be enhanced to mitigate issues felt by many participants related to timeliness.
4. **Strengthen the relationship between the pilot researcher and the steering committee:** Efforts to strengthen the relationship between pilot researcher (St. Amant Research Centre) and the steering committee could include adding a regularly scheduled research update into the steering committee's meeting agenda. Other suggested efforts could include strengthening the research capacity of the steering committee members through orientation and education materials, and / or strengthening knowledge translation materials in plain language by the pilot researcher for the steering committee.
5. **Plan and resource replication and sustainability efforts post-pilot:** The services delivered through the IAS pilot were reviewed favourably, largely due to the enhanced flexibility of eligibility criteria and the increased allotment of homecare support. These favourable services require system-level action planning (e.g., policy changes, funding increases) should they be continued post-pilot.
6. **Fully support the collaborative process:** Most steering committee members representing community expressed disappointment over the perceived power imbalances that impede truly collaborative decision-making. As this pilot is grounded by a precedent-setting human rights settlement, it presents a unique and time-sensitive opportunity for government decision-makers to respond to the expertise of the steering committee's community representatives, including their Creative Solutions report.
7. **Engage government leadership in the pilot:** Many steering committee members suggested that recommendations for system-level change stemming from the pilot evaluation and best practices research will need political endorsement and direction from top-level political decision-makers. To this end, efforts should be conducted now to engage this level of government leadership to best facilitate timely action planning related to potential policy changes.

## Accessible Engagement Recommendations

The qualitative data gathered from participants of 6 engagement sessions, held between November 2023 to February 2024, was analyzed to determine main themes. These themes are presented as recommendations, informed by the lived experience of 70 individuals (persons with disabilities and/or family members), as presented below.

### 1. Remove Barriers to Adult Disability Services System

Corroborated by participants, the current eligibility protocol for Manitoba's adult disability services system, Community Living DisABILITY Services (CLdS), presents a barrier for persons with disabilities who do not meet the IQ criteria. (Reviewing the application

practices of this IQ criteria policy falls outside the scope of this evaluation, and should be followed up by the St.Amant Research Centre).

As told by engagement participants representing rural Manitoba noted several concerns with eligibility barriers to CLDS, especially for those with acquired brain injury, seizure disorder, or other medical conditions that prevent persons from safe and independent living in the community. As these individuals are not eligible for CLDS supports, including supportive housing, engagement participants fear the individuals are forced to live in the hospital or in personal care homes—housing options that are not their preferred choice and are also very expensive for the provincial government.

Further, many engagement participants stated their disappointment that equipment costs that had once been covered when they were under 18 years old are not covered once they become adults (e.g., new seat cushions for wheelchairs). This disparity between children’s disability services and adult disability services was a common theme cited by participants across all engagement sessions, with many suggesting the barriers and gaps experienced in the adult disability services system could be easily redressed by adopting the funding and service approaches of the children’s disability services system.

## **2. Redress Inadequate Income Supports**

According to engagement participants, more funding is needed to meet the basic needs of persons with disabilities such as accessible housing; transportation; specialized diets; para-health services; and the additional living expenses that persons living with a disability incur. Additionally, engagement participants noted income support programs like EIA need to be more flexible to better meet the needs of persons with disabilities.

Engagement participants also stated that financial assistance is inadequate to support access to necessary para-health services such as physiotherapy, occupational therapy, and speech therapy, as well as health products (e.g., incontinence supplies).

Further, many individuals we heard from, who earn a part-time income, experience claw backs of income and/or the loss of benefits. EIA funding allocated for dental, eye-care, and other extended health benefits are not enough to pay current cost rates; and this makes finding quality, accessible healthcare providers who are willing to provide services at a reduced cost rate very challenging.

Moreover, the cost of respite services is higher than the provincial benefit provided to individuals. This means that for many of the engagement participants we heard from, they must pay out of pocket for the mileage expenses of their respite workers.

Additionally, respite services must be paid out of pocket by individuals, and reimbursement for same takes 30 days – a financial strain that burdens individuals already experiencing inadequate income to support the additional living and care expenses associated with their disability.

## **3. Provide Better Support for Family Caregivers**

A positive result of deinstitutionalization is that more people with disabilities are living in the community. However, according to engagement participants, many parents and family members are now called upon to support their adult child or loved one in living independently (e.g., helping to manage care plans or providing services themselves), and these family caregivers need more help. Parents who are primary caregivers for their children (some live with them, and some live in the community) are experiencing burnout. As respite is difficult or even impossible to access, parents and siblings often play the unpaid role of caregivers. Put simply, they need reliable support like home care and respite to avoid burnout.

Additionally, engagement participants expressed disappointment that as family members / family caregivers, they are not allowed to hire other family members to provide respite to fill the gap in respite capacity across the province. Further, the lack of home care and skilled nursing staff in rural areas is particularly low.

Some engagement participants stated that the expectation on family members to provide care for their loved ones is unrealistic. Many family members work full-time and have limited time to support the care needs of their loved ones. Moreover, many family members are retired / retiring and, as they age, are coping with their own increasing medical needs. These parents feel increasing stress about what will happen to their child when they inevitably pass away (this issue is discussed further in a subsequent finding).

#### **4. Provide More Support to Families for Future Care Planning**

Many engagement participants stated that they provide regular support for their adult children so they can live independently. These adult children do not qualify for public assistance and as such, are supported by their parents / family caregivers. However, as parents / family caregivers age, they will no longer be able to provide such care. In turn, their adult children will require future care and support through the province's adult disability services system. Planning for this inevitable influx must begin early to ensure seamless transitions for these adult children, and to ensure Manitoba's adult disability services system is resourced appropriately.

#### **5. Increase Care Hours to Match Care Needs and Enhance Care Provider Training – Especially in Rural Manitoba**

Many engagement participants stated that there is not enough access to homecare, nurses, and direct support professionals. Further, of the current complement of care providers, many require more training. There is also a lack of service providers who deliver services in rural communities. As such, many persons with disabilities who live in rural Manitoba often commute to Winnipeg for services, a costly and time-consuming burden.

Additionally, engagement participants stated that home care is an important service for many Manitobans who live with disabilities. Unfortunately, there's often a lack of sufficient home care hours to meet the needs of those requiring assistance, especially for those who live in rural Manitoba. Further, the lack of consistent care providers burdens the person receiving services to use their often-limited energy and time to



provide ongoing training. Moreover, the option of self-managed home care is often not available for persons who live in rural Manitoba or who do not have strong family supports.

Last, the requirement that persons must have a backup plan to receive home care services presents a barrier to access for individuals who do not have family or social supports (persons who are often most at need for home care supports).

## **6. Implement System Navigation Services to Connect People to Resources**

Many participants stated that identifying and accessing publicly available services and programs can be challenging. For people living with disabilities, the energy and ability needed to research and navigate the complex rules and requirements may be limited. Service navigators, it was suggested, would help many individuals who are experiencing difficulty in navigating the school system; the transition to adulthood and the adult services system; Employment Insurance Assistance and other income / living expense-related benefits.

A lack of system navigation may also limit access to full participation and inclusion in the community for persons with disabilities, especially those who do not have strong family supports.

## **7. Enhance Disability Services in Rural Manitoba and Provide Compensation for Travel Expenses Incurred by Individuals Living Outside of Winnipeg**

As cited above, many disability services are unavailable in rural Manitoba (i.e., Dauphin and Brandon), such as Occupational therapy, physiotherapy, wheelchair repair. As such, service providers must often commute to rural communities to provide needed care to persons with disabilities, a costly and time-consuming burden.

Additionally, public transportation options to Winnipeg for persons with disabilities who live in rural Manitoba are often inaccessible; costly; and, in many rural communities, unavailable.

Engagement participants representing Brandon and Dauphin stated that most appointments for required para-health services, care specialists, and wheelchair repair services require individuals to make a round trip to Winnipeg of 6 to 8 hours.

## **8. Ensure Public Buildings and Spaces are Fully Accessible**

According to engagement participants, the lack of accessibility in public buildings and spaces adds another layer of barriers to accessing public services. Participants suggested an audit of physical accessibility in Winnipeg and rural communities be undertaken to demonstrate the extent to which public services are inaccessible to persons with disabilities. For example, a provincial building that provides services for wheelchair users is inaccessible (it does not have an automatic door). Further examples include hospitals without accessible washrooms or accessible main entry doors; schools without accessible entry doors within the building; medical and MRI service settings that do not have a mobility lift; and a lack of handicap parking stalls at public buildings.

## **9. Redress the Inadequacy of Manitoba's Wheelchair Services**

A functioning and safe wheelchair is critical to living in community. However, according to engagement participants, the process to get repairs and maintenance done is challenging, and the criteria for same is too restrictive. Given that the mobility needs and bodies of individuals age / change over time, modifications to wheelchairs must be facilitated in a timely manner to ensure quality of care for wheelchair users. As stated by one participant, wheelchairs do not last forever; they need to be replaced after years and decades of daily use.

Further, the waitlist for repair service and regular wheelchair maintenance is growing and is forecasted to grow significantly in the upcoming decades, as Manitoba's population ages. However, the capacity of Manitoba's wheelchair services program has stagnated. As such, the already overburdened provincial wheelchair services program will soon reach a crisis point if capacity issues are not addressed as soon as possible. Additionally, because Manitoba's wheelchair services program is solely based in Winnipeg, wheelchair users who live in rural Manitoba face additional barriers in accessing wheelchair services, including cost and time related to transportation requirements, as stated earlier (bullet 6).

## **10. Enhance Coordination and Integration of Service Provision**

According to many engagement participants, navigating and accessing required care services and programs is an onerous task. In Manitoba, each provincial department and non-profit organization operates independently. Several engagement participants reported that they have never meet or spoken directly with their case manager. Application forms and proof of qualifications must be submitted to each department or organization separately and none of them know what the other is providing (or not providing).

One engagement participant cited the person-centred approach taken in Australia in delivering disability services. Accordingly, every person with a disability is assigned a case manager at birth or upon acquiring a disability; and this case manager provides system navigation support, program application support, and personal advocacy as needed. This type of personalized care and support was cited as an approach many participants wished they had.

## **11. Enhance Transition to Adulthood Supports and Services**

According to some engagement participants, the School Transitions Protocol<sup>4</sup>, aimed at smoothing students' transition from school to adult life, faces accountability issues and insufficient funding from the Department of Education, hindering its effectiveness. Parents worry about post-school plans as their child nears adulthood due to limited support in adult employment services; long waitlists for crucial assistance like resume writing; and challenges faced by individuals with specific needs (e.g., mobility issues) in

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<sup>4</sup> Find protocol here:

[https://www.edu.gov.mb.ca/k12/docs/policy/transition/bridging\\_to\\_adulthood\\_protocol\\_en.pdf](https://www.edu.gov.mb.ca/k12/docs/policy/transition/bridging_to_adulthood_protocol_en.pdf)

finding suitable employment opportunities. These issues signal significant shortcomings in the current system and the implementation of the school transition protocol.

According to several engagement participants who discussed Manitoba's public school system, accessibility services available to students with disabilities decrease once they enter high school grades. For example, we heard that some high schools do not offer speech therapy or occupational therapy. Further, several engagement participants stated there is a concerning lack of life skills education programs in schools.

For example, some engagement participants representing a rural community said that the inclusion goals of schools once achieved years ago have since fallen apart. Students with disabilities in these schools need services and life skills education, beginning at an early age and continuing throughout high school.

Engagement participants suggest there is a lack of accountability and capacity to ensure the school transition protocol, as the provincial Department of Education does not resource schools to fully implement the protocol.

## **12. Ensure Dignified Housing and Assisted Living Options**

According to engagement participants, the current state of assisted living for individuals with disabilities in Manitoba is deeply concerning, raising issues of dignity, rights, and quality of care. Families struggle to visit their loved ones due to cramped conditions in group homes and disruptive environments. Inadequate staff training and shared facilities contribute to an institutionalized atmosphere, rather than a nurturing one.

Further, there is inadequate funding for home modifications (e.g., ramps, lifts); indeed, many persons with disabilities do not receive any funding support for their necessary home modifications. As a result of a lack of accessible housing options and/or home modifications to remove accessibility barriers, some persons are forced to move into personal care homes.

## **13. Establish a Provincial Advocate for Persons with Disabilities and Family Caregivers**

According to engagement participants, individuals with disabilities face challenges advocating for themselves due to various barriers like needing assistance with reading and paperwork. One engagement participant, a person with a brain injury, stated feeling unfairly treated by their insurance carrier, but lacks the support to advocate effectively. This example indicates the significant disadvantages experienced by persons with disabilities who do not have family caregivers to help them and advocate alongside

Similarly, parents of an adult child with autism stated they struggle to access specialized care in their home community and worry about the future of their child without adequate support. These parents were experienced with and connected to the service system, but still expressed struggles in advocating for needed supports for their adult child. These

examples highlight the need for an accessible advocacy service for individuals with disabilities and their family caregivers.

Further, it was suggested that a provincial advocate, arms-length to service provision, is needed, separate and apart from the public guardian and trustee. As was stated by one respondent, an advocate for enhanced services or greater access to services, cannot also be the gatekeeper to such services. To this end, the provincial advocate should be publicly funded to ensure equitable, province-wide support, but must also be seen as non-government affiliated, much like the Manitoba Advocate for Children and Youth or the Manitoba Ombudsman.

Additionally, one engagement participant cited the person-centred approach taken in **Australia** in delivering disability services. Accordingly, every person with a disability is assigned a case manager at birth or upon acquiring a disability; and this case manager provides system navigation support, program application support, and personal advocacy as needed. This type of personalized care and support was cited as an approach several participants wished they had. As such, exploring this approach to support may be an area of research the steering committee may wish to assign the pilot researcher.

## Next Steps

A second round of engagement is slated for November 2024, and a second round of the process evaluation is slated for April 2025. These second rounds of data collection will provide further corroboration of the findings and recommendations found in the interim report. Post-intervention data collection related to the outcome evaluation is expected to begin April 2025, and data analysis of same is expected to begin June 2025. **The final report of engagement and evaluation findings will be completed September 2025.**

Alongside the evaluation and engagement work, research to explore best practices in service delivery for adults with both a medical diagnosis and complex disability is being conducted through a comprehensive literature review by the St. Amant Research Centre. This research will continue in the next phase for the IAS pilot, and it is expected that findings from this research will be integrated into the final report.