Cross sector complex care model: Evaluation report

Prepared by Cathexis Consulting Inc.
for the Cross Sector Partners

April 24, 2017

Cathexis

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The artwork displayed in this report was created by individuals in the cross sector program.

About this report

This report summarizes the findings of the evaluation of the cross sector complex care model, carried out by Cathexis Consulting Inc. for the cross sector partners.

Executive summary provides highlights of the evaluation in a brief, digestible format.

Chapter 1 provides an overview of the model and the programs where it has been implemented.

Chapter 2 describes the evaluation purpose and methods.

Chapters 3, 4 and 5 present a summary of findings related to each of the three evaluation questions (the benefits and drawbacks of the model, comparisons with alternative models, and implementation of the model).

Chapter 6 presents conclusions based on the findings, and makes recommendations for future use of this model.

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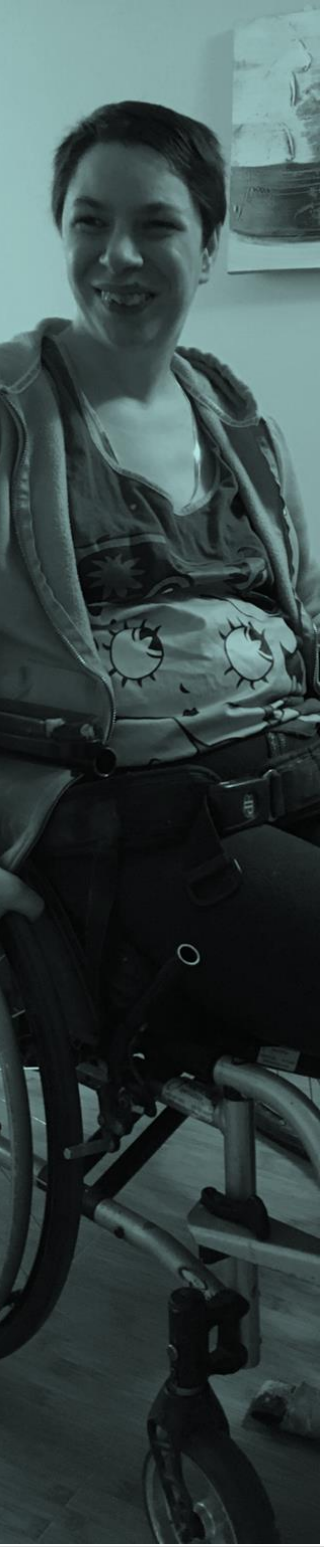
Chapter 1: Overview of the cross sector complex care model



Why is a cross sector model of care needed?

There is increasing concern among families, caregivers, and members of health and social services communities that the current approach for supporting young adults under 40 years of age with medical complexities and developmental disabilities is insufficient. There are approximately 500 individuals in the Central Local Health Integration Network (LHIN) in this population.

Population profile

- Young adults in their 20s or 30s
- No longer in school; may not have access to day programming
- Require support with activities of daily living, and to engage in community
- Complex healthcare needs (e.g., wheelchair dependent, seizures, G-tube, catheter care, bi pap at night, dietitian support)
- Not able to direct their care (may be non-verbal, may be fully dependent on others)
- Medical issues too complex for placement in traditional group home yet not appropriate for placement in LTC home or hospital
- Ongoing need for rehabilitation services, equipment, funding, exercises

The combined impact of complex medical conditions and cognitive functioning compromises individuals' capabilities to live independently. Because these young adults are not able to direct their own care, they don't qualify for existing health funded supportive housing attendant care programs.

As a result, young adults within this population often find themselves living at home with the support of their parents and other family members, with patchwork access to community support and medical care. This arrangement may be desirable for many families, particularly those who are able to coordinate their son/daughter's care. However, families often struggle to access resources, understand how information affects them, and navigate back and forth between health and social services sectors.

It also becomes increasingly challenging as family members/parents age and become less able to provide the social, emotional and physical support their son/daughter needs. Following a medical or psychological crisis (whether their own or a family member's), these young adults may find themselves in an extended length of stay in an acute care hospital (categorized by the Health system as an Alternative Level of Care, or ALC bed), or in a Long-Term Care Home (LTCH), because there is nowhere else for them to go.

Neither the developmental services sector nor the health sector is equipped, on its own, to support these individuals. Instead, there is a need for a pro-active integration of resources and services to support these individuals and their families through the lifespan, and to avoid health crises along the way.

Overview of the cross sector complex care model

> ***"Society creates more disabilities than there really are. Let's give them the support and watch those abilities come out." (supervisor)***

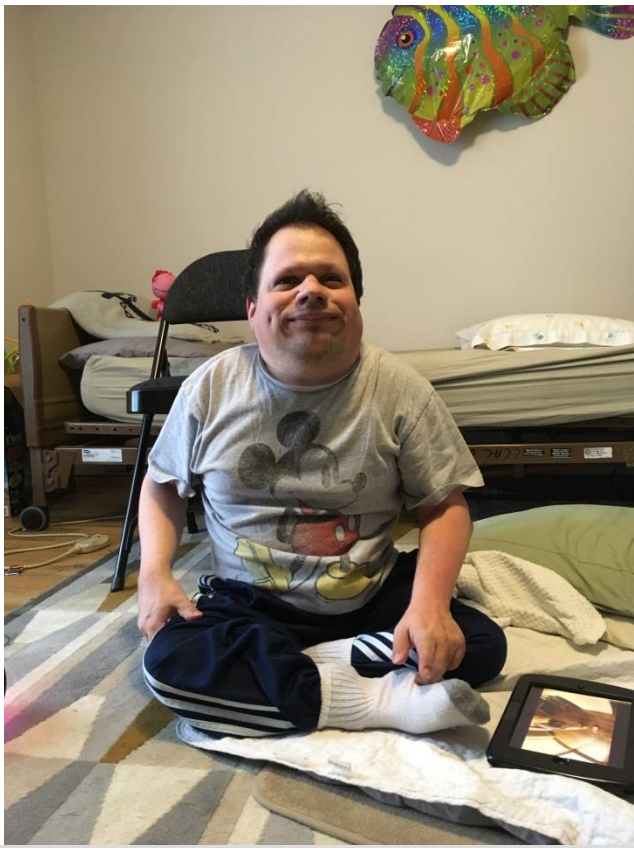
In York Region, an innovative approach has been developed for supporting individuals with developmental disabilities and medical complexities. It is referred to as the *Cross Sector Complex Care Model*. The model was designed and is being implemented on the ground by a cross sector partnership comprising the March of Dimes Canada (MODC), Reena, Community Living York South (CLYS), the Central Community Care Access Centre (CCAC), and York Region Housing. It is jointly funded by the Ministry of Community and Social Services (MCSS) Central Region and the Central LHIN.

Cross sector collaboration creates opportunities to better meet the needs of this unique population, who require both social supports and health care. The model enhances social determinants of health for the individuals supported by investing in access to health and social services, social networks, food and housing.

In addition to positive benefits for the young adults and their families, collaboration may also have positive outcomes for the health and social services systems (e.g., reduced costs, enhanced capacity).

There is considerable interest in the model across the province, both for its potential benefits and because of the following cross sectoral features:

- **Joint funding**: MCSS provides funding for residential and developmental services (such as those provided by Reena and CLYS), and the Central LHIN funds professional services and supports provided by the CCAC and the attendant care supports by MODC.
- **Collaborative development process:** The model has its roots in a 2012 collaboration of the GTA LHINs and cross sector partners, who formed an advisory group that included the voice of parents, to explore the potential for a cross sector strategy. The collaboration evolved into an advisory group, which developed a report, *Building the Transition towards Care, Inclusion and Participation* (2014).
- **Person-centred approach**: The model provides person-centred supports as young adults transition into community-based residential settings and person-centred services for health and social needs while they live there. The individual and his/her needs (physical, social, recreational, emotional) are understood and addressed holistically. These services follow the individual, which means that they are supported within the residential setting as well as outside in the community.



About the two programs implementing the model

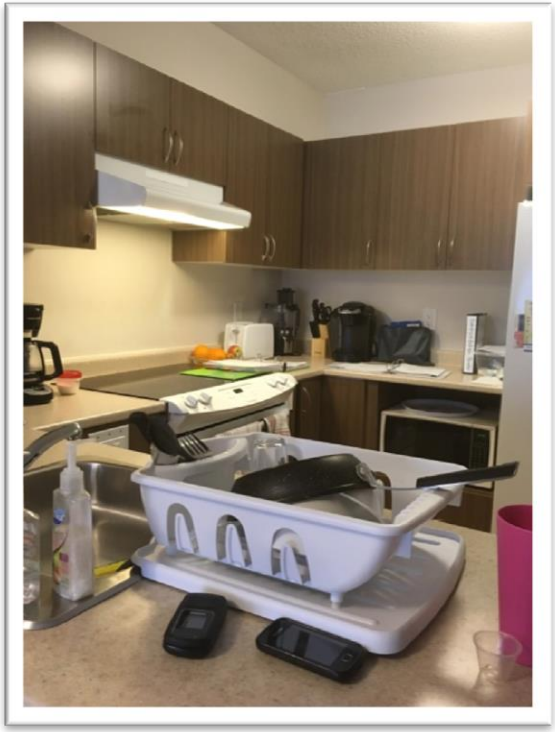
The model provides the direction for implementing two programs designed to support and serve nine transitional aged young adults living in two settings: Reena Community Residence and The Richmond Hill Hub. Key details are provided about each residence below.

 **Reena Community Residence**	 **Richmond Hill Hub**
5 residents living within this model (84 residents total; other individuals within the residence include people with acquired brain injury, people with physical and mental health issues and seniors)	4 residents living within this model (246 residents total; other individuals within the residence include seniors, singles and small families, youth who have experienced homelessness, and other adults with developmental disabilities)
Building opened September 2012	Building opened February 2016
Program fully operational as of April 2016	Program fully operational as of August 2016
Residence within the Lebovic Community Campus, which is part of a larger community development project with recreational and cultural facilities; this is a residential setting owned and operated by Reena	A Housing York Inc. affordable housing building, in which 3 units are rented for this program: 2 by CLYS and 1 by MODC
1-bedroom, 2-bedroom and 3-bedroom apartments (residents living in this model only use the 1- and 2-bedrooms)	1-bedroom and 2-bedroom apartments (residents living in this model are in 2-bedroom units)
Staff include MODC Support Service Attendants and Reena Support Workers, Team Leader and Supervisors	Staff include MODC Support Service Attendants and CLYS Support Workers, Team Leader and Supervisor

What the cross sector complex care model looks like at the Reena Residence and the Hub

The cross sector complex care model is different from any other residential option available to individuals with medical and developmental complexities. In contrast to the fragmented model of support that individuals receive when they live at home, the cross sector complex care model offers an individualized model of care that integrates services and supports into a single coordinated package to meet the multiple and complex needs of individuals. At the Reena Residence and the Hub, the package includes:

- **Accessible housing** that is safe for individuals with disabilities. Within an apartment-style setting, each suite supports 1 to 2 individuals and is outfitted to accommodate the individuals' unique physical and medical needs. Residents at Reena have access to common areas and program rooms, and residents at the Hub have access to a gym space that is shared with *360 Kids*.
- **Person centred transition** that supports individuals and their families before, during , and after the move.
- **Person-centred services** to support activities of daily living and community participation (see the following page for typical day-to-day activities). Personal attendant care is available typically at a ratio of 1:1, 1:2 or up to 1:5. Ratios are determined by the needs of the individual, the complement of needs in a cluster, and roommate compatibility.
- **Access to appropriate and timely health and medical services,** accompanied by a member of the care team.
- **Community integration** through structured day programming and individualized programming. Reena is reported to offer more options for formal daily programming and community activities than does the Hub, in part because participants have access to two on-site programs at the Reena Residence location. At the Hub, individuals need to travel to access similar services, which means that group outings or events may be cancelled if one individual or staff member is ill, or if an individual has a behavioural issue.
- **Care coordination/case management:** Support workers from the community organizations (Reena and CLYS) and MODC are cross-trained and operate as a team to provide seamless support (see the following page for details). The individual's care needs and supports, interests, goals, and activities are documented in an integrated Individual Support Plan (ISP) (in electronic format at Reena and paper-based at the Hub).
- **Equipment and supplies** necessary for managing declining health conditions and changing physical needs (for example, hospital bed and/or reclining chair, standing device, ceiling lift, Hoyer lift, commode, walker, wheelchairs of all sizes, specialized walking device, shower chair, oxygen, medical supplies, medications, and supplements).
- A **system of supports** available as needs change.



"I can change my clothes. I clean my clothes with support at a room down the hall… [I dress] with support. Sometimes I do my own cooking, bathing and eating." (individual supported)

Day-to-day activities

An individual's typical day within the program might include:

- Personal hygiene care and activities in the morning and evening
- Programs:
  - Channels, a life skills program and Pathways, a social recreation program, both offered at Reena
  - Coffee and Conversation, a social meet-up offered at the Hub
  - Other (personal choice)
- Meals in apartment or shared kitchen
- Outdoor events and outings in the evenings or on Fridays
- Overnight support

Blended staffing

The design of this model has resulted in a unique opportunity to leverage the respective strengths of each sector across the entire workforce. As a result, the support workers from Reena, CLYS and MODC operate as a smooth, multi-skilled team to provide seamless support for the individuals around their daily activities, as described below.

MODC areas of strength:

- Physical/personal care
- Use of supportive equipment
- Managing changing physical status

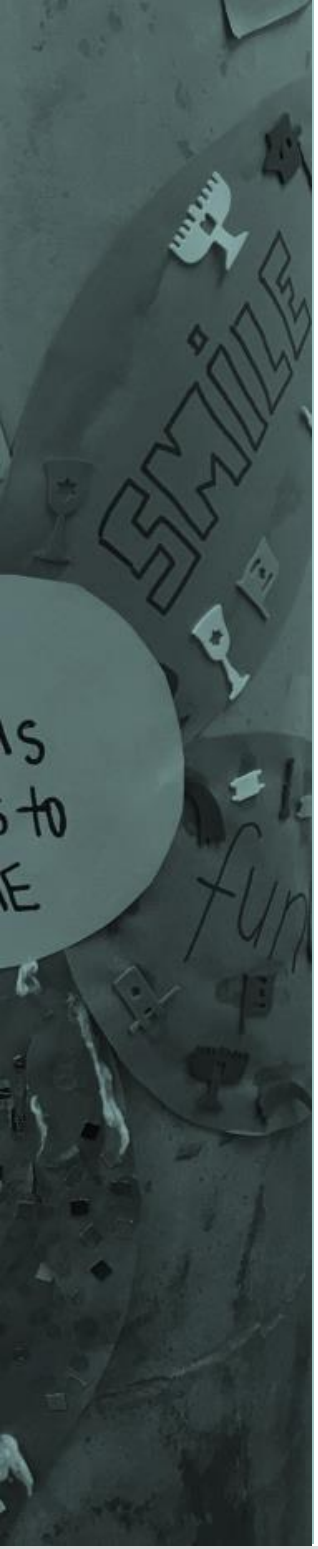
Shared responsibilities:

- Assist with personal care, cooking, household management
- Organize and attend medical appointments
- Day-to-day medical tracking and treatment
- Transfers/lifts
- Arrange programming (e.g., art therapy, guitar), outings and social events
- Social interaction and moral support
- Day, evening and overnight shifts

Reena and CLYS areas of strengths:

- Behavioural and mental health
- Community participation with a focus on supporting inclusion and development
- Assistance with personal finances

Chapter 2: Overview of the evaluation



Evaluation purpose and questions

Evaluation purpose

There is considerable interest in this model across the province because of its innovative approach to integrating services across sectors. The evaluation is intended to be used by the funders, the partner organizations, and other organizations across the province, to:

- Guide similar initiatives in other regions of the province;
- Inform future funding investments;
- Inform spread and scaling;
- Inform future conversations, collaborations, and actions for joint-funded work between the LHINs and MCSS.

To achieve these purposes, this evaluation was designed to answer the following questions:

1. What are the **benefits and drawbacks** of the model?
2. What is the **value of this model in relation to alternative models**, considering both costs and benefits?
3. How was the model **implemented** within the two residential settings? What were the key success factors, challenges, and **lessons learned**?

Evaluation methods

The evaluation was carried out in February and March, 2017 by Cathexis Consulting, an independent evaluation firm. The evaluation was planned collaboratively with the evaluation steering committee.

Information to answer the evaluation questions was gathered in the following ways. All interviewees gave informed consent to participate in the evaluation. Informed consent was obtained to use all photographs in this report.

8 individuals supported were interviewed in person about their experience living at the residence, what they like about it, what they would like to be different, concerns they have, and whether they would still choose to live there now.

7 family members/guardians of the individuals supported were interviewed in person or by phone about why they were drawn to the program, prior living arrangements and available supports, the impact of the program on their son/daughter's access to medical and support services, its impact on themselves and the family, what they think is working well, and what they would like to be different.

15 supervisors and staff from involved organizations were interviewed by phone or in person about the benefits and challenges of working within the model, support in their role, and what is needed to support future success. Interviewees were from MODC (4), Reena (6), Community Living York South (4), and St. Elizabeth Health Care (1).

Cross sector partners were interviewed by phone about the model as implemented at program sites (policy, financing, delivery, partnership). Other topics discussed: how the program compares to other approaches, strengths and challenges of the partnership, and what is needed to support success.

Administrative records were reviewed to gather information about integration of services, service use, access and the appropriateness of services accessed, and to understand change over time in individuals' health and independent decision making. Sources included individual client records and Resident Assessment Instrument-Home Care (RAI-HC) scores maintained by the CCAC. Information about program costs was provided by the partners based on program financial records.

Strengths and limitations of the evaluation

Readers can be confident that the evaluation captured a full range of perspectives about the program, because interviews were carried out with the people most closely involved in the cross sector program, including all but one of the individuals supported, their families, and staff/supervisors.

There are some limitations to the conclusions that can be drawn: the program is still quite new, so there isn't yet enough data to support firm conclusions about longer-term impacts on health, safety and quality of life.

However, the evaluation looked closely at costs, benefits and implementation. This kind of analysis develops understanding of its potential to fill a gap in the system, while also meeting the unique needs of individuals.

Chapter 3: Summary of benefits and drawbacks of the model

Benefits and drawbacks of the cross sector complex care model: An overview

The cross sector model of care is a promising approach to service for adults with medical complexities and developmental disabilities whose needs are not being met in traditional models of care (i.e., home or traditional group home settings).

One of the most promising contributions of the model is that individuals develop friendships and lasting relationships with peers in a natural social environment – with people who are not family and not staff. And they do this while living independently in their own residence, actively connected to the wider community.

In the supported environment, individuals show potential to increase participation in directing their own care, express choice, and feel socially included. They are as independent as they can be.

From a health perspective, the model enables *access* to *appropriate* health care and developmental services that would be limited in the family home. It increases the capacity to secure appropriate care which has the potential to decrease worsening of symptoms and unnecessary complications in a vulnerable population that may be cognitively challenged to communicate the decline of their own health.

For families, the model provides assurance that their son/daughter can live in an environment where they are understood and cared for. Parents report that they experience less stress, their health is restored, and they have the opportunity to fulfill their roles as parents (rather than caregivers) for the first time in their lives.

For the health system, the model provides a safe and medically appropriate alternative that could alleviate strain on LTC homes and reduce the number of individuals occupying beds in hospitals that are deemed ALC. Although it is too early to know with certainty, based on the information so far, the model shows promise that having the right supports in place may decrease length of stay in hospital, and reduce risk of transfer to LTC. As each of the sites train their staff with the right mix of skills to support individuals with both medical and developmental complexities, the model exemplifies the blended workforce needed to support these individuals.

The drawback is that, as of today, the wider system is simply not designed to fund, scaffold or facilitate replication of the cross sector model in other locations or regions. The pioneering nature of this model meant that strong leadership from both sectors and considerable time and energy were invested to successfully launch the program. By sharing the approach and lessons learned, the model is a demonstration of an innovative cross sector collaboration within the wider system.

Partnership approach enables:

- Effective cross-ministry dialogue, laying the foundation for future collaboration.
- Cost, liability, and risk for health and safety to be shared across sectors dedicated to improving health from a social determinants of health perspective.
- Inclusion of CCAC in the partnership builds confidence and trust that medical needs are being met through an integrated suite of services customized for each individual.

"I don't feel like a caregiver nurse…[we] play chess….[go for] walks and ice cream. For the first time in many years we are treating them and acting like sons and mom and dad." (parent)

Individual experience

Individual experience with the program includes specific attributes that contribute to the individual's quality of life, such as choice, independence, opportunities to foster relationships with same age peers, and engagement in social and recreational activities.

Individual experience was explored primarily through semi-structured interviews with 8 of the 9 individuals supported, supplemented by interviews with staff and family members. Findings showed that quality of life was generally high for the individuals: they reported they are happy with the choices, relationships, and independence they experience through this model, and would like even more choice and independence.

"I have freedom compared to living at home." (individual supported)

Highlights

- All or nearly all individuals supported are very happy with how they spend their time; the opportunities they have to make personal choices, such as what to eat and what to wear; their friends, social life, and the emotional support they receive from people around them; and where they live in the residence. All or nearly all said they want to continue to live in the residence.
- Individuals are satisfied with their choice of activities, but also request more outings, and events that connect them to community e.g., volunteer work, return to work or camp.
- Individuals are frustrated that their independence is constrained by their disabilities or medical conditions, especially in situations where there is loss of mobility or function.
- With the exception of one, all individuals interviewed mentioned one or more friends or relationships in the building with people who were not family or staff.
- With the supports provided, staff say that all of the individuals have been able to engage in and direct their own care at some level, whether verbally or nonverbally.
- The Cognitive Performance Scale from RAI-HC suggests that engagement in decision-making improved for two individuals since moving to the cross sector model.

What contributes to success?

- Supported physical environment, and access to equipment and support staff create greater mobility and independence, which contributes to happiness and better health.
- Philosophy among staff toward supporting independence and choice allows individuals to direct their own care and make decisions.
- Formal learning and social programs available on site provide a convenient, consistent, and age-appropriate forum for social and recreational exploration.
- Apartment style residence, with higher numbers of tenants, offers better odds of making friends with similar peers compared to a family home or group home.

Family experience

Family experience includes aspects of family quality of life such as level of demand placed on the family, stress or anxiety, the family's degree of involvement with their son/daughter or sibling, and feelings of satisfaction with the supports provided.

Family experience was assessed through semi-structured interviews with 6 family members and with an online satisfaction questionnaire.

Most families found the transition to the model emotionally challenging, but feel that the model is a good fit for their son/daughter, are satisfied with their level of involvement, and are relieved to have a more seamless team of supports in place.

Highlights

- Five parents had been the primary caregivers to 6 individuals (one family has two children living in the model). Parents naturally experience a range of emotions as they cope with a change of this magnitude. They reported a sense of relief, but also experienced grief and loss during transition and if/when their child's health deteriorated.
- Parents talked about having greater flexibility to take vacation, socialize, or return to work.
- Parents reported that they felt less caregiving stress after moving their son/daughter to the cross sector program, but that moving did not eliminate their stress altogether; moderate to low levels of stress remained. Family members continue to worry about the general wellbeing of individuals, and about declining health in some cases.
- Some family members are more satisfied with the supports than others. Areas of concern relate to: confusion in roles among staff, family involvement in caregiving, quality of meals, need for more stimulation and activity, and confidence that staff are on top of signs of deterioration.
- In spite of their concerns, all or nearly all family members agreed the residence is a good fit for their son/daughter. Overall, no one had regrets about moving to the residence.
- Families felt that their voice was valued by staff and were satisfied with their involvement in the service plan.
- Staff and family members/caregivers are required to work through very challenging dynamics at times. Family members often want to continue directing the care of their son/daughter as they have been doing all their lives at home. Positive relationships between staff and family members are tested as parents are not used to their children directing their own lives.

What contributes to success?

- Regular updates/communication build trust between family members and staff, support successful transitions, and enhance ongoing satisfaction.
- Flexibility and relationship skills among staff and supervisors/managers contribute to positive relationships and trust between staff and family.
- Some parents understand the model is new and needs improving. They persevere to work with staff to make the model work for their son/daughter.

"[my child] has CP, MS, progressive osteoporosis, disability, anxiety disorder and he is happy and calm and amazingly comfortable in his apartment. I would never have imagined him living away from home and on his own with support in my wildest dreams." (parent)

Appropriateness of services and supports

Services and supports are appropriate when the right services are provided at the right level, by the right people, at the right time. The cross sector model is designed to provide more appropriate supports for this unique population.

Appropriateness was assessed through semi-structured interviews with individuals supported, family members, and staff. Administrative records indicated the nature and volume of services and any changes in individuals' health or abilities, as well as family services prior to the transition (e.g., recreational, developmental, financial). Findings suggest that use of health and developmental services is appropriate, and that the model is helping to reduce inappropriate levels/types of care (e.g., in hospital or LTC home).

Highlights

- The model reduced time in hospital or LTC (which would have provided inappropriate supports) for 2 individuals who transitioned from a hospital bed or LTC home into the cross sector model.
- A third individual whose needs resulted in hospitalization was able to leave hospital sooner than expected, as appropriate residential supports were in place.
- For some individuals with RAI-HC data prior to and after the move, improvements in health and functional abilities were noted. Recognizing that patterns in health vary, observing these changes suggests that performance of the model may be sensitive to some of the tools used in the RAI-HC.
  - ✓ MAPLe score decreased, indicating that the individual is less likely to be a candidate for placement in LTC within 6 months (1 individual)
  - ✓ CHESS scores were maintained, suggesting risk of serious decline is being managed (data was available for 5 individuals, all of whom live with chronic or complex conditions)
  - ✓ Instrumental Activity of Daily Living scores were maintained (available for 8 individuals)
- Some individuals experienced fewer maladaptive behaviours, improved moods and greater social engagement, according to staff and family members.
- While these findings are promising, it was unclear what risk prevention strategies are in place to identify and prevent deteriorating health conditions. Implementation of such strategies would boost family members' confidence in the care being provided.
- Supports are bolstered when necessary, e.g., one individual with challenging behaviours received 1:1 behaviour management support, and overnight staff was added for another individual after discharge from hospital.
- Staff are developing understanding of scope of practice and are instructed to call 911 for medical issues.
- Since individuals entered the model (between Fall 2015 and Fall 2016), there were reports of 9 Emergency Department visits among four individuals. Reasons were: change in health status, falls, seizures, and challenging behaviours. Better data and documentation would help to establish appropriate baselines for this population and to contextualize what is appropriate ED use, and what is potentially avoidable, through implementation of prevention strategies.

What contributes to success?

- Regular meetings between staff and families ensure everyone is aware of changing circumstances.
- Open communication channels with CCAC Senior Manager.
- Staffing model: cross training and use of float staff ensure daily activities are consistent with support plans.
- Individuals with challenging behaviours are supported by a familiar team with expertise in behavioural management; this helps to de-escalate situations and avoid the need for more intensive supports.

Integration of services

Integration is represented by evidence that developmental, health, and social needs are identified and met in a seamless, person-centred way. For individuals and family members, a top priority is continuity of care. Consistent, familiar staff decrease individuals' anxiety, lessen behavioural episodes, and improve staff ability to detect changes in health.

Integration of services was explored using four criteria: (1) Integrated Support Plan (ISP) is in place and includes cross sector supports; (2) meetings with cross sector service providers take place regularly; (3) interviews with family members and staff suggest efforts were made for coordinated transitions; and (4) family members report satisfaction with their involvement in planning. Interviews with staff and family members identified efforts to integrate health and developmental services.

Highlights

- Most or all individuals supported had:
  - ✓ An Individual Support Plan (ISP) in place that includes health, social and recreational needs
  - ✓ Regular cross sector meetings (every 4-6 weeks) to discuss changes, improvements or issues
  - ✓ Coordinated, planned transitions from their previous setting to this model
  - ✓ Family member and individual involvement in developing the individual support plan
- OT, PT, SLP, Nurse, and Dietitian are involved at intake, in care planning and as needed thereafter.
- Staff attend medical appointments with the individuals. This ensures individuals have a voice at appointments and that their concerns are understood by health care providers. It also contributes to continuity of care.
- Achieving continuity of care providers has been identified by family members as one the greatest challenges. Efforts have been made to "get it right" for each individual (e.g., limiting use of agency staff, using pagers assigned to specific staff, prolonged transition periods).
- Reena, CLYS and MODC have begun the integration of forms across providers and organizations, using common methods to capture, track, and share information. These practices help to decrease redundancy, and promote compliance, accuracy, and completeness.
- A number of shared communication tools have been put in place to support integration of care, such as electronic client records, e.g., Share Vision (used at Reena), AIMS (used at Hub), communication planning and medical binders, pagers, etc.

What contributes to success?

- Shared vision, among partners, leaders and staff, for creating a seamless, person-centred experience places high expectations on teamwork.
- Leadership style is relationship-centred, which supports positive interaction between staff, families and individuals. Staff are supported by attentive on-site supervisors.
- Team leads and supervisors with coordination roles help keep front line staff focused on supporting individuals.
- CCAC Senior Manager attends meetings related to individual care and serves an important coordination and case management function.
- Cross training of staff means 4 or more staff are familiar with one individual's needs.
- Planned approach to transitions ensures knowledge about care and support is carried into the residence.
- Access to client records among team members ensures timely communication of changing day-to-day needs.

***"We do* with *and not* for."** (supervisor)

Access to services

The access domain examines the extent to which individuals living in the model are sufficiently connected to a range of health services, personal support, and social, recreational and educational activities in a way that provides for the "whole person".

Access was assessed through client records pertaining to: having a family doctor, attending at least one appointment in the last 6 months, and having attended at least one specialist appointment and/or health care provider appointment in the last 6 months. Individuals' daily calendars were reviewed to document attendance in recreational programs and social events, while interviews with family members revealed prior activity levels. Findings suggest that access to health care providers is managed and sought with support of staff, although records across sites are inconsistently documented. Individuals are indeed engaging in programs that are of interest to them. This was also confirmed in the individual interviews.

What contributes to success?

- On-site programming, and options for community and recreational engagement.
- Residence located geographically near community amenities, health centres
- Wheelchair accessible transportation options (van, taxis, TTC).

Highlights

- Individuals have access to external health services relevant to their needs:
  - All individuals have a family doctor. In some cases, families continue to take their son/daughter to appointments. Visits are occurring, but documentation may be incomplete because of reliance on families to update records. Therefore, the frequency of visits for all individuals was not available.
  - Most individuals have documented visits with other health care providers, including: dentist, neurologist, audiologist, specialist, ENT, optometrist, counselling, and dietician. A support person always accompanies individuals to appointments (family member attendance is optional).
  - 6 individuals are receiving PT/OT as needed.
- Moving to the cross sector programs substantially increased most individuals' opportunities for community participation.
  - The 8 individuals collectively participated in approximately 55 outings, recreational and social activities in the last month, either as a part of daily programming or individual choice.
  - Prior to moving to the cross sector model, many individuals lived at home in a basement or top floor unit and spent their time playing computer games or watching TV. One individual attended a day program that was unengaging and promoted long periods of immobility.
  - Complex health issues/behaviours often limited day program options for some individuals, creating a negative cycle, as inactivity and poor stimulation may increase behavioural issues. This limits access to services within the family home because CCAC/PSWs are not typically trained in behaviour management and so the most challenging behaviours are left for family members to manage.
  - Prior to transitioning to the model, individuals received 8-21 hours of support service per week, with 1 individual having overnight nursing. In the model, individuals typically attend programs during the day; attendant care ranges from 4-6 hours per day unless 1:1 support is needed 24/7 (4 individuals).

"At home I was happy. I like it here better. It's fun." (individual supported)

Safety

Safety includes both being safe (i.e., minimizing risks of harm) and feeling safe. The evaluation explored the extent to which individuals living in the programs and their family members perceive the environment to be secure. It also looked at whether staff are sufficiently trained and assigned to support the unique needs of each individual when there are significant challenges (e.g., medical, behavioural).

Safety was examined through staff interviews and client records to understand methods used to ensure safety and to identify safety concerns. The evaluation examined staff ratios, training, and frequency of medical and behavioural crises that occur, and also asked family members in the questionnaire if they felt their son/daughter was safe in the residence.

Safety is considered important at different levels; the main concerns were with managing challenging behaviours and with food preparation and handling. There was also a feeling that too much emphasis is placed on safety while more should be placed on social programs.

Highlights

- Staff-to-individual ratio per shift for individuals within a cluster is typically 1:2, 1:3, or 1:1, and family members did not express concerns about this level of support.
- Safety in terms of security of personal space was not a concern for anyone. Three of four family members strongly agreed that their son/daughter is safe at the residence. The fourth expressed neutrality.
- Staff training for challenging situations includes safe management of behaviours, CPR, First Aid, and management of seizures. Staff reported feeling confident that their training prepared them to support individuals. Staff are trained to address crises that are out of their scope of practice by calling nursing staff or 911 in an emergency.
- All significant challenges (medical, behavioural) are documented.
- Individuals' unexpected challenging behaviours can (and, in one case, did) result in injury to staff or other individuals in the cluster.
- Family members raised concerns about food handling and storage safety.
- The organizations providing service are clearly placing a high priority on the safety of individuals and staff. Family members - who are accustomed to 'making do' with limited support at home - have sometimes had a hard time adjusting to necessary safety procedures that may delay social and community engagement (e.g., needing to wait for an additional staff member in order to perform a lift).

What contributes to success?

- Comprehensive staff orientation and ongoing training.
- Physical environment that conforms to safety and fire standards.
- Physical environment that is suited to individuals' mobility i.e., spaces that accommodate large wheelchairs.
- Suitable healthcare equipment (e.g., Hoyer lifts).

Costs

Program costs include one-time costs incurred as individuals transition into the program, and ongoing operating costs. In addition, the core team has invested significant time planning, implementing, and providing day-to-day oversight for the programs.

It costs approximately **$15,000 to transition** an individual into the cross sector program (see sidebar), and **$248,900 annually** to support them within the program. These annual costs include external supports that individuals would receive in most other settings as well (CCAC supports and the Passport Program).

The cost figures presented here are annualized amounts averaged across the 9 individuals, and were provided by representatives from MODC, Reena, Community Living York South, and the CCAC. The time required of the leadership team has not been included in the cost calculations.

Annual operating costs

Annual operating costs include accommodations, staffing, meals, health supplies, therapies, transportation and community participation support. The per-person operating costs are outlined in the table below.

Operating costs	Source of funding	Average cost per individual supported
▪ Attendant care staffing (provided by MODC) ▪ Health supplies and other health expenses ▪ Maintenance of health equipment	LHIN	$100,394
▪ CCAC home care supports (not exclusive to this model - would be provided in other settings as well)	LHIN	$16,547
▪ Developmental services staffing (provided by Reena and Community Living York South) ▪ Accommodations and meals ▪ Community participation support ▪ Behaviour therapy	MCSS	$112,965
▪ Passport program funding provided to individuals for community participation, 1:1 support, etc.	MCSS	$18,994
	Total operating costs	**$248,900**

One-time costs (transition)

There were two costs incurred as an individual transitioned into the program:

1. **Approx. $10,000: Service team visits** to the individual's residence (90 minutes, twice a day for a period of 2 weeks - at minimum - to 4 months, as required) – funding from both the LHIN and MCSS.
2. **Approx. $5,000: Health equipment** (lift systems, door openers) – funding from the LHIN.

Funds required to retrofit existing space were not included in this analysis (the Hub was a new build and the Reena Residence had been designed with accessibility in mind, although space modifications were made for some individuals). Retrofitting costs will be a consideration for others wanting to implement this model within existing housing stock.

Chapter 4: Summary comparison with alternative models

How the cross sector complex care model compares with alternative models

We compared the costs and benefits of the cross sector model with four alternatives (see the following page for a brief description of each comparator, and why it was selected):

- The family home
- Traditional group home/residential setting
- Long-term care home
- Acute care hospital setting

We compared these alternatives with the cross sector model across the following domains, which align with the domains reviewed in the previous section:

1. **Cost:** to the health system, the social services system, and families for attendant care, healthcare services, accommodations, respite, and recreational activities.
2. **Individual experience:** Individual choice, level of independence, recreation and social engagement (especially with same-age peers).
3. **Family experience:** Family interaction, opportunity to be involved, and demands/stress associated with caregiving.
4. **Access to appropriate and integrated services and supports[1]:** Access to services and supports, appropriateness and quality of the services/supports received, continuity of care, coordination of care, and integration of care.
5. **Safety**: Family perceptions of safety, safety of physical environment, staff training to manage medical, physical and developmental needs, adequacy of staffing.

[1] This combines three of the evaluation domains.

For the cross sector model, assessments of the quality domains (items 2-5) were based on the evaluation findings. As similar information was not available for the alternative models, a cross sector panel of experts was assembled, with representation from Reena, Community Living York South, March of Dimes Canada, Central CCAC, and the LHIN. Assessments of the quality domains for alternative models were made by the panel on a consensus basis.

To compare the costs of the different models (item 1) , we used actual costs for the 9 individuals wherever possible. When actual costs were not available, we used proxy measures to estimate the costs – see pages 27-28 for details.

For this population, the cross sector model is slightly less expensive than a traditional group home would be (assuming additional supports were provided to address the individuals' medical needs). The cross sector model also offers increased integration of care, which is important for increased independence and full community participation.

While the family home is considerably less expensive than the alternatives, there are downsides to this setting. Quality of care, safety, and individual experience are highly variable across families, giving rise to inequities in access to appropriate care. In the absence of necessary supports, individuals and care providers are placed at significant risk. Finally, the stress of providing 24/7 care may cause the family to go into crisis and result in requirement of an immediate placement.

Given long waits for group home and the poor match between this population's needs and the typical staffing model in a group home, these individuals would likely end up in LTC (inexpensive but inappropriate) or acute care (very expensive), which are not suitable living environments for this population.

About the alternative models

Most young adults with developmental disabilities and complex health needs live in their family home with parents and/or siblings.

When they need or want to leave their family home, they would ideally move to a group home, a place that maximizes independence and inclusion.

Unfortunately, there are few spaces available in group homes. Individuals with complex health needs, who require additional supports, tend not to rise to the top of the wait lists, and if they do, the available spaces may not be appropriate for their needs.

Individuals can end up in long-term care or acute care settings because there is nowhere else for them to go and these settings are mandated to respond with minimal to no wait list.

Family's home

7 individuals lived in their family's homes before transitioning to the cross sector program

At home, individuals receive support from family members or other caregivers 24/7.

Families may receive some healthcare support through their CCAC. They may also receive Passport funding from MCSS that they can use for recreational activities, respite support, and/or fee-based group programming. In-home services are typically focused on providing physical support (i.e., attendant care, OT, PT) and may at times be fragmented. There may be long wait lists and/or caps for certain services.

Group home (with additional supports to address medical needs)

0 individuals lived in group homes before transitioning to the cross sector program

A group home provides a residential environment with developmentally appropriate supports. Many group homes are not staffed to support individuals with complex health needs, and the physical premises may not be fully accessible to individuals with mobility challenges.

Wait list are long. In the Central East region, 2,257 individuals are waiting for the approximately 60 placements that opened up this fiscal year (1,141 seeking immediate placement). At least 12 of the 2,257 would be eligible for the cross sector model. (The number of individuals waiting for service with a similar profile may be higher but not all of those waiting for residential have been assessed for medical complexity at this time).

Long-term care

1 individual lived in a LTCH before transitioning to the cross sector program

Long-term care homes are designed for seniors and are equipped to handle healthcare needs associated with aging (e.g., advancing dementia) They are not staffed to meet the needs of younger adults with developmental disabilities and medical complexities.

Acute care

1 individual lived in acute care before transitioning to the cross sector program

Acute care settings (hospitals) were never meant to be long-term residences. They are equipped to handle acute healthcare needs, but not to provide a stimulating living environment.

How does the cross sector model compare to the alternatives?

The cross sector model provides appropriate, well-integrated care within a safe environment, and delivers a high quality individual/family experience. All of the alternative models had limitations on at least one of these dimensions. The cross sector model is more expensive than the family home or long term care, slightly less expensive than a traditional group home, and much less expensive than acute care.

Details of the comparison are shown in the tables on this page and the next. Additional details about cost calculations are provided on pages 27-28.

	 **Cross sector model**	 **Family home**	 **Group home (with additional supports)**	 **Long-term care**	 **Acute care**
Annualized per person costs	▲ **Moderate**: $249k total, including: ▪ $116k LHIN ▪ $132k MCSS	● **Low**: $147k total, including: ▪ $74k LHIN ▪ $21k MCSS ▪ $52k family	▲ **Moderate**: $262k total, including: ▪ $42k LHIN ▪ $220k MCSS	● **Low**: $89k total, including: ▪ $70k LHIN ▪ $19k MCSS	⊘ **High**: $470k total, including: ▪ $450k LHIN ▪ $19k MCSS
Individual experience	● **Promising**: High levels of choice, opportunities for interaction with same age peers. Moderate levels of independence.	▲ **Varies across families**: Many opportunities for interaction with family members. Independence, choice, and interaction with same-age peers may be limited. Social engagement relies on access to day programs.	● **Promising**: High levels of choice, opportunities for interaction with same age peers. Moderate levels of independence.	⊘ **Poor**: Participation in social/recreational activities may be limited due to inadequate staff support. There may be little choice and independence, and there are few opportunities to interact with same-age peers.	⊘ **Poor**: The environment is not set up for social and recreational activities. There is little choice and independence.
Family experience	● **Promising**: Low demand on the family, but families still have opportunities to be involved. Some families may desire greater involvement.	▲ **Mixed**: Allows family members to interact with the individual daily. Very high demand on the family, requiring in many cases that they give up jobs/careers. Over time, the stress of providing 24/7 care may cause the family to go into crisis (not sustainable). Passport funding is insufficient to provide adequate support/relief.	● **Promising**: Low demand on the family, but families still have opportunities to be involved. Some families may desire greater involvement.	▲ **Mixed**: Low demand on the family. Families have opportunities to be involved. Some may feel a sense of assurance that the individual's accommodation and medical care are secure, but others may be concerned that the care is not appropriate based on age of residents and staffing ratio.	⊘ **Poor**: Low demand on the family. Families have few opportunities to be engaged. Families may feel a sense of assurance that the individual's accommodation and medical care are secure, but may have concerns that staff don't have skills to support the individuals.

	 **Cross sector model**	 **Family home**	 **Group home (with additional supports)**	 **Long-term care**	 **Acute care**
Access to appropriate and integrated health/developmental services and supports					
	● **Promising**: Staffing model intentionally combines healthcare, physical and developmental services. Staff are cross-trained so that all have base level competencies in providing care that is appropriate to individuals' health and developmental needs. They are also supported by supervisors who know the individuals. Most individuals have an integrated care plan.	▲ **Varies across families:** Access to appropriate services is very dependent on family's ability to advocate for and obtain them. There is little continuity of care, or clinical oversight, when contracted providers are used, so families may become dependent on a small set of providers. Integration of services is dependent on the family's ability to coordinate care providers from multiple organizations.	▲ **Mixed**: Staff are well-equipped to provide appropriate developmental supports, and are supported by supervisors who know the individuals. Access to healthcare services may be limited. There is little continuity of care, or clinical oversight, when contracted providers are used. Integration is dependent on individual care providers taking the initiative to work collaboratively.	▲ **Mixed**: Staff are equipped to provide appropriate healthcare. Developmental services providers may or may not be brought in to provide support. Integration is dependent on individual care providers taking the initiative to work collaboratively.	⊘ **Poor**: Staff are equipped to deliver acute healthcare, which is not what is needed. Developmental services providers may or may not be brought in to provide support. Integration is dependent on individual care providers taking the initiative to work collaboratively.
Safety					
	● **Promising**: Most families perceive this environment to be very safe, but some may have concerns. All staff are cross-trained to respond to medical, physical and developmental needs, and medical equipment (e.g., Hoyer lifts) provides additional safety for both individuals and caregivers. Staff ratio (typically 1:2) is sufficient to handle complex health needs, 24/7.	▲ **Varies across families:** Safety is dependent on the family having the training to deal with developmental/ health/ physical needs (e.g., transfers) and/or having qualified support workers. The home is not always designed to meet the individual's needs, and may be too small for equipment that would enhance safety. While the family knows the individual's health and developmental needs, they incur risks in providing care.	▲ **Mixed:** Staff are fully trained to respond to developmental needs, but may not be able to head off or respond appropriately to medical crises. Staff may be insufficient to handle complex health needs, so contract nursing would need to be purchased. Staff ratio varies across homes, depending on resident needs.	▲ **Mixed:** Most families perceive this environment to be very safe because staff are trained to deal with medical needs. Most facilities have staff ratios of 1:8 during the day and 1:20 overnight, which does not allow for sufficient levels of supervision. Additional nursing support (beyond the standard levels) would need to be provided.	▲ **Mixed:** Most families perceive this environment to be very safe because staff are trained to deal with medical needs. Staff may not be able to head off or respond appropriately to critical incidents related to mental/behavioural aspects of developmental disabilities. Most facilities have insufficient levels of supervision.

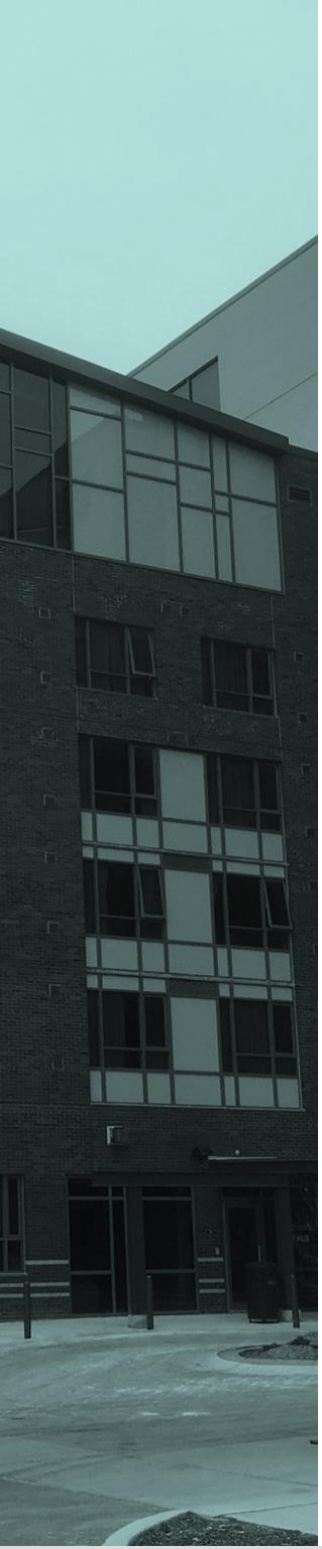
Detailed costing methodology

Cost item	Description	Cross sector model (N=9)	Family home (N=7)	Group home (with supports)	LTCH	Acute care
LHIN annualized funding to MODC	Attendant care staffing, health supplies, occasional health care, maintenance of health equipment.	Annualized actual costs from MODC records for 9 individuals , averaged across all 9 individuals.	N/A	N/A	N/A	N/A
LTCH bed, with co-payment subsidy (funded by LHIN)	Basic accommodations (ward), recreational and therapeutic programming, personal care and standard nursing support.	N/A	N/A	N/A	Per diem rate x 365 days - Health Data Branch Web Portal -OCDM	N/A
Acute care bed (funded by LHIN)	Basic accommodations (ward), personal care and standard nursing support.	N/A	N/A	N/A	N/A	Per diem rate x 365 - Health Data Branch Web Portal - OCDM
Attendant care - MODC (funded by LHIN)	Attendant care provided in the family home prior to transition.	N/A	Annualized cost of attendant care that the 7 individuals were eligible for (only 1 was receiving attendant care prior to transition, but all were eligible), averaged across 7 individuals.	N/A	N/A	N/A
CCAC home care supports (funded by LHIN)	Nursing and personal support.	Annualized actual costs from CCAC records for 9 individuals (only 1 was receiving nursing), averaged across all 9 individuals.	Annualized actual costs from CCAC records for7 individuals (1 was receiving nursing, and 5 were receiving PSW support), averaged across all 7 individuals.	Assumes 7 hours PSW support per individual per week and up to 28 nursing visits per week, where required.	N/A	N/A
Supplementary clinical supports (funded by MCSS)	Any additional supports required to enable individuals with complex health leads to live in a traditional group home setting	N/A	N/A	Estimated nursing support required beyond the 28 visits/week.	N/A	N/A
MCSS annualized residential funding	Accommodations, staffing, community participation support and related expenses, and behaviour therapy.	Annualized actual costs from Reena /Hub records for all 9 individuals, averaged across all 9 individuals	N/A	Estimated based on level of day-to-day support individuals would need if not in complex care model - assumes 1:2 staff ratio with 1:1 ratio on peak hours.	N/A	N/A
Passport program (funded by MCSS)	Funding provided to individuals/families for community participation, respite care, 1:1 support, etc.	Annualized actual amounts from Reena /Hub records for 9 individuals (7 received Passport funding), averaged across all 9 individuals	Annualized actual amounts from Reena /Hub records for 7 individuals (6 received Passport funding), averaged across all 7 individuals	Assumed that Passport amounts would be the same as for cross sector model	Assumed that Passport amounts would be the same as for cross sector model	Assumed that Passport amounts would be the same as for cross sector model
Costs to the family	Financial proxy: Value of family time as full-time caregivers to their son/daughter.	N/A	Calculation: 65 hours/week, 52 weeks using government PSW wage ($16.50/hr), for 6 of the 7 individuals, averaged across all 7	N/A	N/A	N/A
	Financial proxy: Value of accommodations in family home.	N/A	Calculation: $600/month for rental of 1 room in York Region minus $214 ODSP for shelter portion of board & lodging x 12 months	N/A	N/A	N/A

Detailed cost breakdown

Cost item	Description	Average cost per person per year Cross sector model	Family home	Group home (with supports)	LTCH	Acute care
LHIN annualized funding to MODC	Attendant care staffing, health supplies, occasional health care, maintenance of health equipment	$100,394	-	-	-	-
LTCH bed, with co-payment subsidy. (funded by LHIN)	Basic accommodations (ward), recreational and therapeutic programming, personal care and standard nursing support	-	-	-	$70,455	-
Acute care bed (funded by LHIN)	Basic accommodations (ward), personal care and standard nursing support	-	-	-	-	$450,000
Attendant care - MODC (funded by LHIN)	Attendant care in the family home	-	$22,795	-	-	-
CCAC home care supports (funded by LHIN)	Nursing and personal support *(does not include costs for rehabilitation supports, which are variable)*	$16,547	$51,196	$42,131	-	-
Supplementary clinical supports (funded by MCSS)	Additional clinical supports required to enable individuals with complex health needs to live in a traditional group home setting	-	-	$10,724	-	-
MCSS annualized residential funding	Staffing, accommodations, community participation support and related expenses, and behaviour therapy	$112,965	-	$190,535	-	-
Passport program (funded by MCSS)	Funding provided to individuals/families for community participation, respite care, 1:1 support, etc.	$18,994	$20,850	$18,994	$18,994	$18,994
Costs to the family *(does not include out-of-pocket expenses, which are variable)*	Financial proxy: Value of family time as full-time caregivers to their son/daughter	-	$47,803	-	-	-
	Financial proxy: Value of accommodations in family home	-	$4,632	-	-	-
Average total cost per person per year		**$248,900**	**$147,277**	**$262,384**	**$89,449**	**$468,994**

Chapter 5: Summary of implementation process and lessons learned



Overview of the implementation process

There were 7 foundational steps to implementing the cross sector model in York Region.

1. Establish a strong cross sector leadership team	Implementation was guided by a cross sector leadership team of service providers and funders whose members are extremely committed to the project, are well-connected within the community, are influential within their own organizations, and work well together. This provided a strong foundation for success.
2. Secure cross sector funding	Both the LHIN and MCSS committed funding to the program. By working collaboratively, the core team members were able to use that funding to implement a streamlined, unified initiative, despite the funds flowing through separate organizations and having different budgetary and reporting requirements.
3. Secure appropriate housing stock	Finding accessible, subsidized housing was a big challenge. Reena was able to commit to five spaces within its community residence structure. The core team members were eventually able, by leveraging their connections within the community, to find a second building that was suitable for the program.
4. Identify candidates for the program	Individuals who were high priority within both the health and developmental services sectors had to be identified manually, as there was no common database, no wait list, and no unique identifier that was common across the two systems.
5. Hire and cross-train staff	Each individual has a dedicated support team. Staff are hired by different organizations and have different skillsets, but need to function as a unified team. Common management, common training, and cross-training are used to cultivate a ”we are one team providing seamless support” mentality.
6. Plan for smooth transitions	Transitions are planned carefully to help the individual and their family become ready for the move to the program. The transition period can take a few weeks, or as long as 3-4 months. It includes daily visits from the support team, and helping the individual imagine their future life in the program.
7. Arrange opportunities for community participation	Linkages were established with formal programming, with programming available on site at the Reena Residence, and outside programming arranged at the Hub. In addition, individualized programming/activities were arranged on an ongoing basis according to individual interests (see page 9 for details).

Step 1: Establish a strong cross sector leadership team

Why this is important

Strong leadership was critical to getting the cross sector program off the ground. As one partner pointed out, this model is "something that is new and innovative that people aren't familiar with." As such, there are myriad barriers to be overcome: systemic (e.g., funding policies that don't lend themselves to cross sector projects), logistical (finding appropriate housing), and psychosocial (helping people accept new ways of doing things). It takes considerable imagination, resourcefulness, and stamina to overcome these challenges.

Description

Implementation was led by a cross sector core team that included representation from funders (MCSS, LHIN) and front line agencies from the health sector (MODC, CCAC) and the developmental services sector (first represented by Reena, followed later by involvement with CLYS). The organization leadership involved had strong connections within the community, including the housing sector.

The partners developed a project charter with clear goals and an implementation plan. They established standing meetings starting in June 2015; as of March 2017, this group continues to meet weekly if needed.

Lessons learned

- Implementation should be guided by a cross sector leadership team of service providers and funders whose members are extremely committed to the project, are well-connected within the community, are influential within their own organizations, work well together and are willing to explore uncharted ways of working.
- Partners should be prepared to invest heavily in relationships. This will take time and energy, but is critical to success.

What supported success?

- **Strong pre-existing relationships**: the partners had built mutual trust, respect and understanding through previous projects, which helped them work effectively together.
- **Strong commitment to a shared goal, at all levels**: Partners at all levels were committed to the success of this project, and were willing to go the extra mile to make it work.
- **Open communication and flexibility**: The partners' willingness to communicate with openness and flexibility enhanced their ability to work through differences and challenges.
- **Influential and well-connected champions**: The partners leveraged their networks to obtain resources, such as housing, that were critical to the success of the project. They were also able to use their personal influence to navigate roadblocks quickly and effectively.

What was challenging?

- ▲ **Degree of commitment required**: Working so collaboratively took a lot of time and energy.

Step 2: Secure cross sector funding

Why this is important

This model does not fit easily within the existing MCSS or LHIN funding structures. Each sector is accustomed to funding certain types of services in certain ways, and the two differ substantially:

- LHIN typically funds health care services, equipment and supplies. It does not usually fund supports for community participation. Funding is based on a functional approach to services (go in, do what is needed, and get out). Services often require individuals to be able to direct their own care, which is problematic for a population with developmental disabilities.
- MCSS funds developmental services, with a focus on inclusion, activities of daily living and community participation. Its approach is holistic and long-term, addressing many different aspects of an individual's life (transportation, food, shelter, social engagement, personal choice, etc.), with the important exception that MCSS does not typically fund health services.

Neither the LHIN nor MCSS would therefore fund a comprehensive set of supports for young adults who have both developmental disabilities and complex medical needs. There is little communication or coordination between MCSS and the LHIN, resulting in no opportunities for the type of coordinated long-term joint funding that would make it feasible for service provider organizations to serve this population.

Description

The health services side of the project was initially funded through a Request for Proposals (RFP) from the Central LHIN, which had identified younger adults with developmental disabilities and medical complexities as a priority population. MODC submitted a proposal on behalf of the partnership. The LHIN RFP required that services be delivered in partnership with an agency funded through MCSS, so joint funding was an explicit expectation. MCSS committed to funding for the residential and developmental services portion of costs for up to 10 individuals. LHIN funding flowed through the MODC, and MCSS funding flowed through Reena and CLYS.

The project presented challenges from a budgeting perspective in part because staff roles overlap and are not always clearly attributable to a specific budget line. A further challenge is the difference in budget process including timing and reporting requirements. However, the funders have demonstrated a willingness to find ways to overcome these challenges and find better ways of working together.

Lessons learned

- To provide truly seamless, person-centred supports, there needs to be some blurring of roles and functions across typical ministry funding lines, which would, in an ideal world, be supported by a fully integrated budget. For now, the project has demonstrated that it is possible to implement a jointly-funded initiative, even if funds flow through separate organizations and have different reporting requirements.

What supported success?

- **Alignment with LHIN priorities:** The LHIN had identified this population as a priority group, and was interested in stronger cross sector collaboration.
- **Strong relationships with funders**: Through their networks, partners had a good understanding of MCSS priorities, so were able to make a compelling case for the ministry to provide matched funds.
- **Funders' commitment**: Willingness on the part of funders to prioritize the work and to try the new model, despite challenges.

What was challenging?

- **Communication challenges between the LHIN and MCSS:** Inter and intra-ministerial communication challenges meant that that not all the appropriate government representatives were informed in a timely fashion as the RFP was moving forward.
- **Different requirements**: MCSS and LHIN approach budgeting differently (templates, reporting requirements and timelines).

3. Secure appropriate housing stock

Why this is important

There is a shortage of affordable, accessible housing units in most Ontario communities, and York region is no exception. Housing availability is a major challenge in planning a new residential program.

Description

The initial plan was to provide a choice of settings for individuals. Reena was able to commit to five spaces within its community residence structure. The LHIN was able to work with York Region to identify a new affordable housing build, the Hub, to house the remaining four residents. It took several months to secure the additional housing.

The units and buildings were adapted to accommodate the physical needs of the individuals. Funding was available through the LHIN for purchase and maintenance of equipment such as lifts and door openers.

The Reena Residence is designed for individuals with various physical, developmental and psychological challenges. Property managers at The Hub received training to work safely and effectively with the individuals (e.g., crisis intervention, conflict de-escalation).

Lessons learned

- Housing for this population requires thoughtful, long-term planning and early collaboration between housing and service delivery partners.
- Considerations include accessibility (AODA), fire safety, layout of units according to resident needs, meeting/social spaces, space for staff.
- Rent subsidies are crucial; ODSP funds are insufficient for housing needs.

"Our biggest fear was of a 'group home' feel and [my child] needs a home that looks like a home. At HUB his room is decorated in a similar manner to his room at home." (parent)

What supported success?

- **Connection with municipal housing:** Partners' existing relationships made it easier to engage municipal housing.
- **LHIN equipment funding**: This funding allowed installation of equipment that enhances independence and protects both individuals and staff.

What was challenging?

- **Lack of housing:** housing is in short supply, and neither ministry has funds to easily develop new housing.
- **Limited ability to customize space**: The Hub was already under construction when York Region was engaged. Earlier connections with housing resources would have allowed for more appropriate customization of the space (i.e., during the design phase).
- **Multiple buildings**: Efficiency and continuity are compromised with residents in different buildings. A single site would have been preferable.

4. Identify candidates for the program

Why this is important

There was no wait list for residential programming that identified individuals as having both medical and developmental complexities. The core team had to find other ways of identifying individuals who would be eligible for the program.

Description

The priority population for this program was determined based on CCAC and developmental services records of "high priority" clients. Eligibility was determined based on high levels of CCAC use and urgency of need, as identified by developmental services. Priority was given to families who were particularly challenged or in crisis, for example, where:

- there was more than one child with a disability,
- an adverse incident had occurred in the home,
- parents were aging and/or no longer able to provide the same level of care,
- the individual could not be left alone/support staff were needed,
- support was needed with 1:1 transfers,
- the individual had many medical appointments, or
- the individual did not qualify for other forms of care (nursing home, group home).

There was no common database in place, or unique identifiers that could link individuals across the two systems. Developmental services and CCAC representatives thus each compiled their lists of high-priority individuals, then met to cross-reference the lists manually.

In making their final selections, the partners also considered the need to match suitable roommates.

Lessons learned

- A better process should be developed for identifying eligible clients (e.g., using a common identifier across systems, developing a wait list with qualifying criteria and processes, developing a system for referrals). The ideal strategy would be to provide service prior to families going into crisis.
- Program promotion and communications must be enhanced.
- There is a need to define discharge criteria (not just eligibility criteria).

> ***"My mom supported her full-time. When my mom died, my brother and I needed to take time off work to support my sister. We are just getting to a place where we are able to return to work now." (sibling)***

What supported success?

- **Perseverance of the partners**: The partners persevered in finding a way to identify high-need candidates.

What was challenging?

- **Databases were not aligned**, making the process very time-consuming (required manual searching/cross-referencing of clients).
- **Families/individuals selected were in crisis**, making transition especially challenging; more work is needed to determine eligibility criteria for smooth transitions (i.e. readiness vs acting upon crisis).

5. Hire and cross-train staff

Why this is important

Blending skills of several classes of support workers, i.e., Personal/Developmental/Community Support Workers, and Support Service Attendants in staffing the cross sector model adds capacity to the system, creating a workforce that is trained to properly support this population.

Description

Staffing within the programs is grounded in the values of independence and dignity. For example, toileting with two staff to transfer is chosen to enhance dignity, rather than reliance on incontinence products.

Each individual in the program is matched with a support team: a fixed staff complement that is consistent and familiar. Within the support team, the staff ratio is typically 1:2 or 1:1, but can be up to 1:5 for individuals living in a cluster, with float staff. Several considerations are taken into account, e.g., skill set, prior experience, and training already completed. Most staff interviewed were willing to undertake more training as needed to ensure appropriate match with an individual's needs.

Staff are hired by, and are managed and paid by, their respective organizations (MODC, Community Living York South and Reena). Typically, positions are first posted internally and if no candidates are found the search goes external. Interviews involve a mixture of pre-screening, in-person behaviour-based interviews, an onsite visit and a criminal background check.

There is considerable overlap in staff roles and responsibilities (see the Venn diagram on page 9), which allows the staff to function as a unified team, providing seamless supports to the individual.

The integration of roles is supported by cross-training and knowledge exchange across sectors. Formal training and certification are also provided in core areas (e.g., First Aid, lifts and transfers, CPR, behaviour management of challenging behaviours) as well as specialized areas related to the medical and developmental needs of the individuals supported.

New staff are trained through a sequenced approach: "classroom learning" is followed by "shadow" training. The new staff then work directly with the individual under direct supervision of their mentor. Individuals ultimately decide when staff are ready to be left alone with them.

Lessons learned

- To truly integrate support services, it is essential to begin with a "we are one team providing seamless support" mentality. In the early days of the program, there were different roles and expectations for staff from the different organizations. This made it difficult to provide seamless supports to the individual, and was frustrating for everybody.
- When short staffed, the use of agency staff to fill in (e.g., for illness or vacation) does not work well. Individuals become anxious about the change and problems ensue.

What supports success?

- **Good supervision**: On-site supervisors who are attentive, able to manage conflict and are solution-focused quickly identify skill gaps and assign training.
- **Consistent direction and management**, regardless of partner organization, promotes unity and integration.
- **Joint responsibilities within limits:** Staff need to recognize scope of practice and role boundaries in relation to other professions, e.g., nursing.
- **Common training:** Each member of the team supporting an individual is trained the exact same way to do the same things.

What was challenging?

- **At the outset, staff had different roles** based on which organization had hired them. This approach made supporting the individual difficult to coordinate, created conflict, and was confusing for individuals and frustrating for families.
- **Differing expectations**: Front line staff aim to maintain professionalism, while family members see staff as extended family.

6. Plan for smooth transitions

Why this is important

It is not easy for families to make the adjustment to a new living arrangement. In most cases, parents have been providing very intensive, full-time care to their son/daughter for 18 or more years. It can be difficult to let go of that role, and the process takes time.

Description

Transitions are a period for learning, relating, and building trust. They are carefully planned and highly individualized periods that can range from weeks to 3-4 months. The following activities have been incorporated to support a smooth transition:

- Time in respite helps individuals and families get acquainted with living outside the home.
- The support team visits the house, LTC home or hospital regularly (e.g., 90 minutes, twice a day) to get to know the individual and his/her support needs.
- The support team learns through observation from PSWs, nurses, OT, PT and family members.
- Social story books are shown, i.e. picture books of the residence and people they will meet.
- Individuals are encouraged to personalize apartments by choosing accessories before moving in.
- Family members are highly involved in planning and transition.

Lessons learned

- Transitions need to be carefully planned, based on what the family and individual need in order to become ready for the program.
- Transition is not a one-time event; it continues after the person supported has moved into the residence and affects family members in different ways.
- Transition should be a collaborative process with the family and all providers, so that everyone is on the same page by the time the individual transfers to the program.
- Parents may need support adjusting to the new role they play in their son/daughter's life. They may conflict with staff about important decisions, i.e., how support is provided, medication administration. The transition from full-time caregiver to parent of independent adult is difficult.

What supported success?

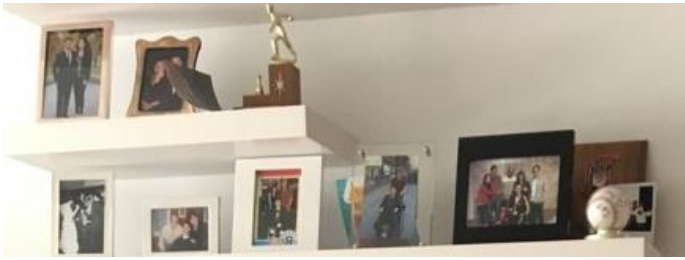
- **Developmental service providers' past experience with transitions**: providers were able to convey families' struggles and issues.

"It was made way less difficult because there had been this lengthy process of them coming into our home… [for] 3 months, 2-3 days per week, where they really got to know our son and his daily process and how he eats and everything." (parent)

What was challenging?

- **Expectations that transfers would happen quickly**: Health sector stakeholders expected individuals would move in as soon as space was available, but in many cases the individual or family wasn't ready.
- In the beginning, there was too much **variation in documentation practices**, making it challenging to know what had happened across shifts.
- **Disagreements between staff and family about support provision**: e.g., supporting an individual's choice might mean he/she refuses physiotherapy.

7. Arrange opportunities for community participation



Why this is important

Individuals with developmental disabilities and medical complexities experience several barriers to community participation. Individuals may not feel well enough to attend programs outside of their homes, yet still crave friendships. Other barriers include: limited availability of appropriate local programs, limited family resources to coordinate attendance, and the additional cost to families if attendant care is required. Individuals with behavioural challenges experience additional barriers to accessing programs because of the unpredictability of episodes and the special skills required to manage behaviours in a social context.

Description

Community participation is a key feature of the program, with staff supporting individuals to be involved in a variety of activities. Staff bring unique skills that help individuals to connect with the community in a personally meaningful way. Individuals design their daily routines in an environment that enables them to be part of a community of friends that may not be available to them otherwise.

"My son says 'I have a disease. I can't help my disease but at least I can go meet with my friends. At home, I'm a person that is sick.' (parent)

Sample activities include:

- Coffee and Conversation
- Shopping/going to the mall
- Going to the movies
- Meals out
- Relaxing in the Snoozelan room
- Going to the park or swimming
- Pathways or Channels day program
- Visiting family
- Vocational and life skills (e.g., banking, cooking)
- Volunteering
- Watching TV with family
- Arts and crafts, playing cards
- Attending sports games
- Medieval times
- Guitar lessons
- Bingo
- Dog therapy
- Karaoke
- Church

What supported success?

- **On-site programming**: Having high quality, on-site programming at the Reena Residence made it easy for individuals to participate and enhanced personal choice.

What was challenging?

- **Cancellations of planned outings**: At the Hub, individuals need to travel to access similar services, which means that group outings or events were sometimes cancelled if one individual or staff member was ill, or if an individual had a behavioural issue.

Lessons learned

- At first, staff are needed to actively encourage participation because individuals may be withdrawn, anxious, lack social skills or feel too unwell to engage socially.
- Community participation is set in motion through a mix of formal learning programs, planned and spontaneous outings and events, invited guests, weekly social events, and many opportunities to explore and act on personal interests in a natural social environment.

Chapter 6: Conclusions and recommendations

Conclusions and recommendations

The model is a promising approach

The cross sector model implemented in York Region is a **creative cross sector housing solution** for young adults with medical and developmental complexities.

By providing an integrated package of health care and developmental supports, the model enables individuals to **live independently in their own residence, participate actively in their community, form friendships, and have more voice in directing their own care.**

It is still too early to draw firm conclusions about the longer-term benefits of the model, but the early findings are extremely positive, and suggest that the model shows promise for meeting needs of this population in all domains that were examined: quality of life, access to integrated services, and safety. Comparator settings did not consistently share this promise, which suggests that the population's unique needs are not adequately met in these alternate settings.

The model has the potential to fill gaps in the system. Compared to the family home, this model appears to be **safer**, provides **more appropriate care** (in most instances), and is more **sustainable** in the long run, because it does not rely on aging family members to be lifelong caregivers. For this population, it allows for **greater integration of care** than a traditional group home, at a **comparable cost, which is shared across two ministries**. While the findings are preliminary, the evaluation suggests that the model may also contribute to reductions in downstream healthcare costs (e.g., by preventing hospitalizations, reducing length of stay in hospital and delaying admission to LTC homes). This is an area worth monitoring as these individuals age.

A worthwhile pilot project would test the replicability of the model elsewhere, to ensure these gains are not specific to this context.

A great example of cross-ministry collaboration

A unique feature of the cross sector model is its mobilization through joint funding and delivery of supports between the MCSS central region and the Central LHIN. As a regional model, it embodies what can be achieved when funders, partners, leaders, and staff from different sectors work together to deliver integrated, individual-focused service.

Nonetheless, the implementation process was not simple, and highlighted some of the real challenges in collaborative cross sector initiatives at the regional level.

The three biggest systemic barriers to collaboration were:

1. **There are few cross sector communication channels** at the regional and provincial levels. As a result, there is limited understanding of how the other sector works.
2. **Funding mechanisms don't align** across the two systems. There are different funding timelines, geographical boundaries, and reporting requirements.
3. There is **no easy way to identify individuals who need both developmental and health supports**, since each system maintains its own records, with no common identifier.

Opening up lines of communication at the regional and provincial level would provide a foundation for future collaboration by (a) building mutual understanding of how healthcare and social support needs of individuals and families are defined, tracked and prioritized; and (b) supporting joint sector strategies to prevent and mitigate crises in high-risk families and individuals.

Recommendations for MCSS and the LHINs

Recommendation 1: Building on lessons learned and the experiences of cross sector partners in York Region, test the replicability of the cross sector model in other regions of Ontario.

Recommendation 2: Examine policy and legislative barriers to integrated cross sector programming with an eye to their mitigation or elimination. (e.g., pilot a joint funding project, harmonize reporting requirements, or explore options for a common identifier).

Recommendation 3: Create incentives for regional collaborative efforts to meet the needs of individuals with medical and developmental complexities. This could take the form of joint funding pots used to incentivize leaders in local organizations to replicate, innovate or evaluate current initiatives.

Recommendations for cross sector work in other regions

Individuals or groups who wish to implement cross sector initiatives can benefit from the experiences and lessons learned by the cross sector partners in York Region. The following are some recommendations for these groups.

Strong leaders and strong relationships

Strong leadership was critical to getting the cross sector model off the ground. The core team experienced many barriers and had to adapt quickly to new directions. Building bridges across ministry boundaries required strong relationships and a long-term commitment.

Recommendation 4: The team responsible for a cross sector initiative should include funders and service providers from both sectors, as well as housing. To support a successful initiative, team members should be committed to the initiative, well-connected within the community, influential, flexible, tenacious, and above all resilient.

Strong relationships supported the success for the York Region cross sector program. The partners from the various sectors had worked together on a past project. They understood each other's organizations and how they worked. The also enjoyed working with one another, which helped keep them going when things got really challenging.

Recommendation 5: CCACs and DSOs should establish and maintain relationships (formal and informal) with one another at multiple levels, to build mutual understanding and support cross sector collaboration.

Implementing the cross sector model elsewhere

The following recommendations are for individuals and groups who wish to implement this model in other regions.

Recommendation 6a: Plan to have an integrated budget, even if funding streams remain separate. This will support a more seamless experience for individuals supported and their families.

Recommendation 6b: Secure housing stock early in the planning stage. This involves identifying options that ensure accessibility and safety. Clustering individuals in close proximity creates staffing efficiencies, and facilitates continuity of care, which is mandatory for this population. The apartment style residence increases opportunities for socializing and making friends.

Recommendation 6c: Plan to include day programming that is age appropriate. In the York Region program, it was really beneficial to have high quality programs available on-site.

Recommendation 6d: Develop practical systems for identifying, following and prioritizing individuals and families across sectors, preferably before families go into crisis.

Recommendation 6e: Invest in a blended workforce. A "blended workforce" is needed with a mix of healthcare and developmental support worker skills. These individuals are likely going to require additional training by the organizations implementing the model.

Recommendation 6f: Build a "one team" mentality from the start, providing seamless support. A one-team mentality is supported through a number of strategies: inclusive job descriptions (overlap in roles), leaders supporting staff cohesiveness, cross training, staff access to shared electronic records, and having standardized and specialized training programs.

Recommendation 6g: Don't rush transitions. Plan to give time and supports needed for individuals and families prior, during and after the transition. Transitions were particularly challenging for some families experiencing crisis. It may be helpful to introduce strategies that enhance preparedness earlier (i.e., prior to finishing high school) so that families are not entering the transition phase while in crisis.

Recommendations for the York Region team

The evaluation findings **support many of the core team's current plans**, including plans to:

- Develop an integrated budget that combines the funding across partners and funders.
- Develop standardized forms and procedures.
- Transfer paper files to shared electronic records.
- Continue to foster a "one team" mentality in both sites.

Based on the evaluation findings, the following are ways the current program could be strengthened.

Preventing / managing health deterioration and incidents

The evaluation examined ED visits and incidents, but more data are needed to know under what conditions these or other incidents are avoidable. A better understanding of circumstances surrounding health services use is needed in order to more accurately know the impact of the model on health system outcomes.

In circumstances in which deterioration of health is anticipated (e.g., neurological diseases), families may be anxious that staff will not notice key markers of deterioration early enough to take preventative action. This anxiety may be alleviated through formal processes for staff to learn the signs and symptoms of changes in health, and the actions they must take to prevent further deterioration.

Recommendation 7a: Document and review health utilization and critical incident data periodically to determine if any ED visits or critical incidents are potentially avoidable through prevention strategies.

Recommendation 7b: Establish formal processes for staff to learn signs and symptoms of changes in health status (both short- and longer-term), and the protocols for management of specific diseases. Involve families in these processes during the transition period.

Measurement and evaluation

Scores on RAI-HC show the potential of using health outcome data for monitoring decline as well as for program evaluation. However, the RAI-HC scores do not tell a complete story for this younger population. Future evaluations will be more definitive if valid, reliable tools are used that assess individuals' health and quality of life over time.

Recommendation 8: Continue to identify/develop assessment tools that are appropriate for this population, i.e., young individuals who are challenged cognitively, with complex/chronic conditions, and physically disabled. Administer these tools on a regular basis (e.g., annually, or more frequently, if appropriate) and include them in performance reports and evaluations.

Clarifying program boundaries

The intent of this model is to provide an "age in place" program, which will continue to support these 9 individuals throughout their lifespans. As the individuals age, the program will need to be able to address more complex care requirements over time, including palliative care. There is some ambiguity about the boundaries of the program, and families are unsure if there will come a time when the program can no longer support their son/daughter (e.g., if their needs become too complex). Boundaries need to be well-articulated to users of the service, their families and staff, and appropriate transition strategies need to be developed in advance so that potential moves can be handled sensitively and appropriately.

Recommendation 9a: Maintain open communication about program boundaries with individuals, staff and families.

Recommendation 9b: Develop criteria for transition and processes for transition to an alternative environment. If applicable, also begin to develop structures and processes to support palliative care.