MaRS Solutions Lab

Residential Support for Adults with Developmental Disability

Challenge Brief

April 2014

1. THE PROBLEM

Ontario's developmental services system is in crisis. $1.15 billion a year goes towards residential support for about 18,000 adults with developmental disabilities. But there are still 7,300 estimated on the wait list. Ontario's 2013 Budget adds $42.5 million to the annual funding that is expected to help more than 1,000 adults and their families with new or additional supports[1]. Which still leaves 6,300 waiting. Meanwhile the Ontario Ombudsman has an ongoing special investigation[2] (as of November 2013) looking into a rapidly growing number of complaints.

Families are frustrated. Caregivers are at risk of burning out and giving up. Families are also worried about institution-like congregate living arrangements making a return despite the government's unequivocal position against congregate living models.

> *Over 800 (complaints) by the time this report was finalized for publication (Jul 2013)*
> Ontario Ombudsman
> 2012/2013 Annual Report

Ontario is not new to responding to challenges in the developmental services system. Ontario's most recent transformation initiatives began in 2004. In 2008 *The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* was passed and Developmental Services Ontario (DSO) was created. Despite the progress (*see 7 Appendices*), community living and residential supports for citizenship continue to be a complex and seemingly intractable challenge. Resolving the crisis will require more than increasing funding. We need to look for new approaches and new solutions, which can help change and further the transformation of the developmental services system.

The Ministry of Community and Social Services (MCSS) has partnered with MaRS Solutions Lab to develop and test such new approaches. This challenge brief gives the problem definition as we now see it and describes the process to develop solutions. For the next stage, we propose to research, explore and design solutions together with individuals, families, innovators and experts. These solutions can be seen as interventions that help change the system. Areas of interventions vary from looking at the waitlist to creative ways to increase supply without increasing costs. How can we redesign the system from a citizen-centred perspective? And do we have a common understanding of our objectives for the developmental services system? At the end of this stage, we aim to have answers and some prototypes ready to be tested.

2. WHY A LAB?

Around the world, governments face increasingly complex social challenges whereas public resources are decreasing. At the same time society's capacity for problem solving is stronger than ever. People are better educated and demand to be involved. There is more private capital available for social good. Technology connects us easily and enables society to organize complex, collaborative tasks quickly and cheaply. So, we need to solve these complex social challenges together: governments, corporations, non-governmental organizations, foundations, academia and the community.

This is certainly true for a challenge like this. This demands actions by many individuals and organizations throughout society, not just government. The MaRS Solutions Lab brings together stakeholders and develops new solutions collaboratively. The value of our lab approach for the Ontario Government can be described as follows:

- **Develop solutions with society**
  In the lab we convene stakeholders from different parts of society and develop solutions together. The lab acts as a neutral common ground. Government is just one of its partners. Solutions that come out of the lab are to be implemented and funded by all stakeholders, not just government.

- **Understand the problem from a citizen/user perspective**
  Many social problems are often defined from an institutional perspective. The lab takes a different view. Using tools from design thinking we try to gain a deep understanding of the problem from a citizen or user perspective. Not by just analyzing the numbers, but by also studying the people.

- **Offer opportunities to experiment and learn**
  An important value of the lab is experimenting and learning on a small scale. First of all to test what works before we make expensive large scale mistakes. But also because such complex problems can only be fully understood when you are trying to solve them.

- **Working towards scale and sustainability**
  More than doing one off projects, the lab offers a process to deliberately work towards scale to create system change. This means building receptor capacity in society to take up new solutions. It implies focusing on solutions that can become sustainable without prolonged support from governments or foundations. And it requires developing policies and building capacities for solutions to scale.

- **Having a long-term view**
  Solving social challenges and creating system change does not happen over night. It requires time, stamina and commitment. It may take years and multiple interventions before success can be claimed, and it often does. While many institutions need to focus on the short term, the lab takes a long-term view. We are committed to solving the challenge, however long it takes and whatever solutions are needed.

- **Better social outcomes against lower cost**
  Innovation is about finding better answers. For social challenges, the result of innovation should be better social outcomes at lower cost. Solutions that are developed in the lab may require investments, but in the long term need to result in cost savings to society.

3. WHERE TO INTERVENE

Ontario's developmental services crisis is highly complex. Recent efforts by government to transform the system have made great progress (see 7 Appendices). But the developmental services system is still plagued by:

- An opaque wait list of 7,300 suggesting supply/demand gap or administrative inefficiency/issues
- 800 (and growing) complaints to Ombudsman about transparency, accessibility and quality of services
- Not enough capacity to support community-based innovations
- Unclear system objectives that are largely measured by outputs – e.g. number of people receiving supports vs. number of people achieving personal citizenship goals

In the past 10 years, the province has committed more than $620 million in new ongoing funding for developmental services – a 63% increase[3]. Assuming a simple annual average cost of $64,000 per person[4] supports for 25,300 (18,000+7,300) would require $1.6 billion – a 39% increase from the current $1.15 billion.

The combination of the above suggests that merely increasing funding would not be a sustainable solution. The prevailing policy and program development approaches may also not be enough.

MaRS Solutions Lab proposes to research, explore and design interventions with individuals, families, innovators and experts to:

- Better understand who are on the wait list; and a wait list information strategy that better inform funding and investment decisions
- Change demand for developmental services by supporting family and caregivers to better supports
- Change supply of services by integrating with other sectors (e.g. healthcare)
- Transform administration by identifying critical services issues and designing citizen-centred alternatives
- Transform the system by increasing capacities and structures to support family- and community-led innovation in the developmental services system
- Clarify and quantify developmental services objectives and ensure they are citizen-centred

The following detail these six areas to intervene.

3.1. Strategic analysis of wait list information (understand pent-up demand)

Better analysis and understanding of who is on the wait list and why they are on it would be critical to exploring both short-term and longer-term interventions, and to inform future funding and investment decisions.

During the preliminary analysis, we heard many anecdotes about how unreliable the wait list numbers were, with variations from 7,000 to 12,000. The discrepancies are partially due to legacy wait lists data quality issues. We have also heard that parents concerned about the long wait time for supports have submitted applications regardless of when they need the services. Families also perceived the wait list to be opaque, with no consistent reasons for their positions in the lists, and what they were being advised to do to "get ahead".

Adults with development disabilities have a wide spectrum of personal life goals, abilities and require different types of supports because of their individual family and social circumstances, and resources available in the community. The different types of developmental disabilities, from Autism, Cerebral Palsy, Down Syndrome, Fragile X Syndrome, and others, causes different challenges but also gives people different abilities to thrive. Assessments and planning that focus on abilities as well as needs may help uncover alternate supports that can help adults with development disabilities exit the wait list.

Other than the abilities and types of supports needed, useful derived dimensions might include: "distance" to independent living and personal life goals. In conjunction with analysis and understanding about children and youth (currently receiving special education and developmental services), better demand forecasting and better decision supports for long-term investment that reduce the wait list.

Deepening understanding about whom and why they are on the wait list may also allow us to engage innovators, providers and families in different and difficult conversations. Examples of the use of wait lists, like the healthcare system wait lists in Ontario, and Canada-wide, have become key system performance indicators that has also driven multiple high impact innovations in policies and service delivery, including community-based investments in healthcare and homecare capacities. MCSS has already begun work on the analysis of the wait list.

3.2. Support families and caregivers needs (change demand)

Families and caregivers play crucial roles in support adults with developmental disabilities and reducing dependence on more costly residential supports. And they often do so to the detriment of their own health and lives. Better supports for caregivers can help reduce demand for developmental services and the wait list.

Caregiver support through respite and other services already exist but we have little evidence on whether caregivers are adequately supported or effective towards enhancing and promoting citizenship and reducing supports costs for adults with developmental disabilities.

Not paying attention to caregivers may lead to caregiver burnout situations that impact adults with development disabilities and may lead to otherwise unnecessary healthcare and social services costs. We have heard about many families applying for the residential support services in fear of the day they can no longer support their loved ones.

Adults with development disabilities often have complex developmental, medical or mental health conditions. Approximately 40% will experience a mental health difficulty or display significant challenging behaviour (often a symptom of a medical, emotional or psychiatric concern) during their lifetime[5].

The *2012 General Social Survey (GSS) on Caregiving and Care Receiving*[6] found that 51% of caregivers of people with developmental disabilities were spending at least 10 hours a week providing help – the most amount of time of all caregivers – "free" care that the government does not have to pay for. These caregivers are also at significantly higher risks of developing health care problems and chronic conditions. National Alliance for Caregiving's 2009 research found that 64% of family caregivers of children and youth with special needs reported physical strain, 34% reported high emotional stress, 60% reported lack of time for other family members and friends, and 27% reported strong financial hardship[7].

The current economic outlook will further stress caregivers struggling to balance work, life and caregiving. Better understanding and targeting of caregivers' needs is critical.

3.3. Integrate with other sectors (change supply)

Adults with development disabilities have residential support and daily living support needs that are similar to other vulnerable people in the community, e.g. seniors, people with mental health issues and people with acquired brain injuries. Exploring better services integration with others who need supports to keep living in the community may uncover better economies and more sustainable delivery models.

Ontario and its cities have invested in a suite of community-based supports, from low-income and social housing programs, Ontario's Ageing At Home strategy to other more recent efforts to address the needs of people with mental health conditions[8,9] and reducing hospital Alternate Level of Care volumes[10].

Preliminary research has indicated that developmental disabilities stakeholders will be concerned about linkages to the medical model after decades of fighting institutionalization of people with developmental disabilities, and the stigma of developmental disabilities as a sickness. Healthcare and community care stakeholders will likely be concerned by cost implications of serving more clients. Current government policies and funding restrictions may also be challenging community providers and families' abilities to work together on innovative interventions that can address the broader needs of the community.

Affordable housing stock is another major challenge. The most recent successes have been innovative partnerships between private sector developers, non-profits and government, e.g. Toronto's Bayside neighbourhood. Better coordination and strategic integration between housing projects and developmental services could yield substantial improvements in community living outcomes.

Other potential areas of integration include: financial planning and asset building with the financial and insurance sector, transportation with existing providers and new disruptors (e.g. Uber – a "network" transportation company that mobilizes private vehicle owners), home-making with the domestic and logistics services sector, etc.

Our preliminary interviews with families and policy experts highlighted a number of possible barriers: quality and safety concerns, inflexible funding channels, lack of business interests, fragmented information and payment channels, all potentially creating complications for the individuals, families and funding entities like DSO and MCSS.

Despite these barriers, the potential gains from leveraging and sharing resources are too great to ignore. Inter-ministerial support and a safe experimental design space for public, non-profit and private sectors would be essential and citizen-centred design would be key.

3.4. Explore citizen-centred services administration (transform processes)

The long wait list and the high number of complaints to the Ombudsman together suggest that the developmental services administration system is not serving people with developmental disabilities and their families well. Identifying the most common complaints can help us better

understand their needs and the critical administration processes that need to become more citizen-centric.

Developmental Services Ontario (DSO) was established by *The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2008)*. It is a new organization that has yet to be formally reviewed or evaluated. Undertaking user-journeys with people with disabilities and their families now can help suggest where the most crucial performance and quality strengths and weaknesses are, to improve upon current processes with more citizen-centric alternatives.

3.5. Clarify citizen-centred objectives (set incentives)

Residential support services currently do not have clear and measurable citizen-centred objectives. Performance of the system is largely measured in process outputs, e.g. number of persons served, number of housing supports delivered. This demonstrates how developmental services funding is being spent, but offers limited evidence of how effective supports are towards objectives like citizenship. Clarifying objectives and ensuring they are citizen-centred and measurable will help set the right incentives for everyone in the system.

The lack of clear citizen-centred objectives also complicates the challenge of determining where the most critical system problems are: whether the funding levels are sufficient, if we are getting the best outcomes possible, if the supports are effectively helping adults with development disabilities and families, or if the issues lie elsewhere. It also promotes the unsustainable direction to keep serving more people with less funding with little regards to their citizenship goals. $1.15 billion buys residential supports for 18,000 but we have little evidence about which supports are improving the lives of these individuals and their families.

While MCSS is mainly responsible for developmental services, there are at least four other ministries that impact residential supports, housing options and supports for community living: Ministry of Health and Long-Term Care's (MOHLTC) healthcare programs, Ministry of Municipal Affairs and Housing's (MMAH) housing programs, Ministry of Economic Development Trade and Employment's (MEDTE) accessibility programs, Ministry of Finance's (MOF) benefits policies. In addition, the Ministries of Education (EDU) and Children and Youth Services (MCYS) also deliver programs that impact the development of children and youth with developmental disabilities. Better coordination between the ministries with the citizen and families at the centre would be key to improving developmental services. Having common clear and measurable objectives would be an important start.

3.6. Increase capacity for family- and community-led innovation (transform system)

Innovation is key to transforming a system in crisis, but the developmental services system currently has no explicit innovation agenda. MCSS provides one-off innovation funding but there are no sustained programs to support families and communities in realizing their innovative ideas. The residential support challenge is so complex that we cannot depend on just government and service providers to innovate. We need to explore ways to increase capacity in the system to support families and communities innovation.

Parents who wanted better lives for their children started the original associations and developmental services providers. Exploring more robust ways to support and sustain innovation

from families and the community may yield more citizen-centric supports that better address adults with development disabilities and family needs.

The Trent-Fleming School of Nursing's "Intentional Neighbours" initiative, as an example of community innovation, provides a grant for tuition and housing to two nursing students per year in return for serving as "intentional neighbours" to people with a developmental intellectual disability in supportive, independent-living duplexes. The Developmental Services Sector-Ministry of Community and Social Services Partnership Table Housing Study Group[11] in their survey found 25 initiatives being actively developed or in the process of being implemented. The Housing Study Group has also recommended a capacity task force to be established.

Organizations like Family Alliance Ontario[12] and the Individualized Funding Coalition for Ontario[13] are great examples of families coming together to help families create better living solutions. In the UK, NAAPS UK ltd's *Shared Lives* matches individuals in need of living supports to compatible paid carers who act as 'extended family', with the individuals supported in their own homes or living in the carers' homes. The Australian Centre for Social Innovation's *Family by Family*[14] takes it one step further, matching families in crisis to families who have emerged from their own crisis to coach, to share their lives and experiences. The Canadian Association for Community Living's *My Home My Choice* project is working with families, group home providers and funders to transition residents into the community, and leading the discussion to unbundle funding how individuals are housed.

MCSS is proceeding to establish the Housing Task Force as recommended by the (Developmental Services Sector – Ministry of Community and Social Services Partnership Table) Housing Study Group's *Ending the Wait* report[15]. The Housing Task Force will help build community capacity to support families and increase innovation.

Increasing capacity to support families and communities innovation can help more examples like the above emerge, and begin to transform the way we provide residential and community living supports that are more effective and sustainable.

4. THE PROCESS FOR DEVELOPING SOLUTIONS

Before describing the process we propose to follow for this challenge in the coming months, here is some background on the MaRS Solutions Lab and its approach to clarify and give a better context.

The MaRS Solutions Lab

The MaRS Solutions Lab helps to tackle complex social challenges that require system change. We provide support and space for multiple stakeholders to collaborate, experiment and learn. We introduce new approaches, perspectives and players. Applying new approaches like design thinking, social innovation and behavioural economics. Providing new perspectives on the basis of a thorough understanding of the citizen, looking outside in. Bringing new players into the game, which can give fresh ideas. The MaRS Solutions Lab partners with government and is a linking pin between government and society. We develop solutions, create support systems and build capacity for change to improve the lives of people and strengthen the resilience of communities. Our working model has four stages:

1. Hypothesis
In this first stage the problem is defined, scoped and framed from a system perspective. On the basis of preliminary research, interviews and some stakeholder workshops we formulate our hypothesis and an approach for how to tackle the challenge. The end result of this stage is a challenge brief, which in this case is the document you are reading now. It provides a guideline for the team, our partner(s) and key stakeholders.

2. Conceptualization
The second stage is about analyzing the problem and developing potential interventions or solutions. This starts with extensive user research in order to get a better understanding of the citizens involved in this challenge. Through interviews, observations and ethnographic study we want to understand the choices and considerations that are being made or how policies and procedures really work. After that we do a systems mapping exercise, which provides us with even better insights where to intervene. This is done through data research, expert interviews and different types of review. Taken together this gives a design brief with a thorough analysis of the problem. It is input for the ideation (idea generation) phase to develop interventions (or solutions). They are developed into prototypes, which are first tested in a lab environment. End products of this stage are one or more intervention plans to test these prototypes in a real life situation. We make sure that in ideation we involve users, stakeholders, experts and innovators. They form a first community of change, which can later grow into a movement of practitioners that promote change. The analysis and ideas can also be used to start to create support for future policy change.

3. Intervention
Change and tangible results are only being realized by taking action. In the third stage, we intervene by prototyping ideas that have been developed in stage two. These prototypes are projects that we undertake ourselves in partnership with others, or where we help others to undertake them. The role of the lab is above all to monitor the progress, reflect and learn. And make sure everyone involved learns from it. We help grow this learning community, reaching out to early adopters in the field. We help to gather evidence on what works, as well as input for future policies that can help scale and sustain these prototypes. And if

needed we help to redesign. End products are evaluated prototypes with evidence of what works and around them a vibrant community of change agents.

4. Synthesis
In the final and fourth stage, we synthesize all activities into a strategy for system change. This consists of three types of strategies. First, we develop strategies to scale prototypes that work. That can be done in many ways. Second, we translate the evidence into strategies for policy change, which supports and helps to sustain the innovations, and we help to achieve that. This will also enable scaling. Third, we grow the learning community by reaching out to the early majority. This means helping to establishing materials, toolkits, learning programs etc. That also is a way of scaling and sustaining the innovations. Taken together we have a synthesis. The end product is a strategy document, and hopefully scaled innovations, new policies and a large-scale community of people that are engaged in making the change happen.

With this challenge brief, formulating our hypothesis, we can now go towards stage 2, which is to conceptualize new solutions on the basis of a good understanding of the user and the system.

The challenge

Beginning in Spring 2013, MaRS Solutions Lab conducted a series of discussions with MCSS staff and developmental disabilities innovators. In the course of the discussions, the following wicked questions emerged:

- If supported community living produces better outcomes than group homes, why are we still running group homes?
- Why do we provide integrated special education to children then ask them to wait for years to be supported in the community when they graduate from schools?
- How do we help families, caregivers and communities to better care for adults with developmental disabilities? How can we help them turn their ideas into reality?
- What outcomes are we aiming for? How can we have better outcomes and a sustainable developmental services system?

Suggested areas included: streamlining and redesigning developmental services from a user-centric perspective, supporting and enabling community innovation, social enterprises.

MaRS Solutions Lab proposes that we organize the next phase of our work on analyzing the challenge and conceptualizing solutions based on the following challenge question, goals, principles, strategies for intervention and design process:

What would homes and communities need to look like for citizens with developmental disabilities to achieve citizenship: to live in the communities they choose, to grow and lead full lives? How can these solutions benefit others who need community living supports?

This challenge question reframes the problem as an open co-design challenge to families, communities, providers and government. System change for better residential supports will require support and ingenuity across the system. It also re-emphasizes citizenship as the core objective.

This represents a complex challenge without easy solutions and is broad enough to allow for creativity and authentic social innovation and system change yet specific enough to bring focus to the change process.

Design Goals

1. Develop better understanding of how residential and community living supports in homes and communities contribute to citizenship people with development disabilities and other people in the community with similar needs

2. Collaborate with families, communities, innovators, experts and stakeholders to

   i. Better understand pent-up demand (the wait list) in the system; and strategy to utilize the information to inform future decisions

   ii. Change demand for developmental services by supporting family and caregivers

   iii. Change supply of services and supports by integration with other sectors

   iv. Transform administration processes with citizen-centred alternatives

   v. Transform the system by increasing capacities to support family- and community-led innovation in the developmental services system

   vi. Clarify and quantify developmental services objectives that are citizen-centred

3. Develop interventions that can be scaled to create system change

4. Provide opportunities for public service leaders to learn and gain skills to apply design thinking and develop public services from a user-centred perspective

Design Principles

The following design principles will guide the process:

- Start with the citizen users (in this case, people with developmental disabilities and families)

- Create solutions with users and stakeholders, not just for them

- Always look for the smallest possible intervention with the largest possible impact

- No action without reflection, no reflection without action

- Combine to diagnose problems, to galvanize change and to deliver concrete improvements

- Create a safe environment for ideation and collaboration

Strategies to intervene

We propose to identify 4- 6 high impact community-based interventions, which will enable citizenship through sustainable community features and supports. We will:

- Convene partnerships across the 4 – 6 ministries of the government
- Deepen understanding about citizens with developmental disabilities and citizenship
- Explore pent-up demand and information strategies to inform future decisions

- Explore and co-design citizen-centred alternatives that
    - Change demand for developmental services with better supports for families and caregivers to care for their loved ones
    - Change supply of services and supports by integration with other sectors to achieve better economies and effectiveness
    - Transform administration processes by replacing critical processes with the most complaints with citizen-centred alternatives
- Transform the system by exploring how to increase capacities to support family- and community-led innovation in the developmental services system
- Clarify and quantify developmental services objectives that are citizen-centred

Convene partnerships across government

Prior to beginning this design phase, we will convene the seven provincial ministries to identify interests and establish partnership: Ministry of Community and Social Services (MCSS), Ministry of Health and Long-Term Care's (MOHLTC), complex care and community care), Ministry of Municipal Affairs and Housing (MMAH, social housing), Ministry of Economic Development Trade and Employment (MEDTE), Ministry of Finance (MOF), Ministry of Education (EDU) and Ministry of Children and Youth Services (MCYS).

Deepen understanding about citizens with developmental disabilities and citizenship

We will begin by broadening and deepening understanding about citizens with development disabilities and how they can achieve citizenship, their families and their communities. The research will include interviews, focus groups and ethnographic studies with citizens with development disabilities and families, interviews and focus groups with providers and experts.
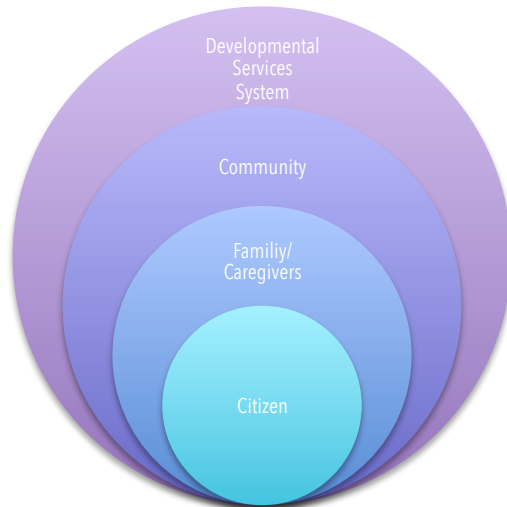

Figure 1 Citizen-System Change model

As illustrated in Figure 1 Citizen-System Change model, we would approach the research focusing on nesting levels of citizens, families and caregivers, community. We will also collaborate with experts to better understand how experiences at the individual, family and community level can be meaningfully reflected at the system level.

Ontario's Transformation of Developmental Services is guided by six principles: citizenship, fairness and equity, accessibility and portability, safety and security, accountability, sustainability.[16] These six principles were confirmed as key pillars of transformation following consultations conducted in 2006. These principles have also continued to receive support from families and stakeholders. These six key principles would be used as key dimensions of the experiences of citizens with development disabilities, families and caregivers, and community.

Table 1 Proposed research framework and sample questions

dimensions	Citizen	Family/Caregivers	Community	Developmental Services System
citizenship	What does meaningful choices and decisions for different citizens with development disabilities regarding their residential and living supports look like? What does meaningful participation for different citizens with development disabilities look like? How can we enable citizenship meaningfully? How can we measure citizenship?	How can we protect the health, work and life quality of family/caregivers? How does citizenship for different citizens with development disabilities improve health, work and life of their family/caregivers? How can we measure the impact on family/caregivers?	What features in the community enable citizenship? How do these features impact businesses and other lives? How can we sustain these features? How can we measure the impact on the community?	How can we determine / demonstrate how residential supports increases citizenship? How does citizenship advance Ontario's social and economic agenda? What does a balanced investment strategy look like?
fairness and equity	What is fairness and equity for different citizens with development disabilities? Is the system fair and equitable? How can we improve/ensure fairness and equity?	What is fairness and equity to family/caregivers? Is the system fair and equitable to family/caregivers?	What is fairness and equity in a community? What features in the community enable fairness and equity? How can we sustain these features?	How does fairness and equity in the system relate to fairness and equity for citizens with development disabilities and family? How can we determine / demonstrate fairness and equity?
accessibility and portability	…	…	…	…
safety and security	…	…	…	…
accountability	…	…	…	…
sustainability	…	…	…	…

Existing research and information from government and other partners will be leveraged and not duplicated.

Insights from the research will be part of the Design Brief used to inform participants in the subsequent ideation and design workshops, and interventions design.

Explore pent-up demand and a strategy to inform future decisions
We will work with civil servants and agencies staff to unpack and analyze the wait list information, to validate understanding and develop new insights about the individuals on the wait list and why they are on it.

In combination with insights from the prior research we will explore information strategies to utilize the wait list information for future investments and other decisions, and to engage families and communities in ongoing constructive conversations.

Explore and co-design citizen-centred alternatives
We will work with citizens with development disabilities, families, innovators and experts to explore promising ideas, the best investments in residential supports, community features and supports that can:

- Reduce demand for developmental services by exploring how families and caregivers can be better supported
- Change supply of services and supports by exploring integration with other public sectors as well as private and non-profit sectors to achieve better economies and effectiveness
- Transform administration by exploring citizen-centred alternatives for critical processes with the most complaints

The work will be done through a combination of workshops and working group efforts. We will work closely with civil servants from MCSS, DSO staff and other public sector staff to ensure we leverage expertise and building partnerships and trust throughout the process. We will incorporate learning from and coordinate with innovative projects like the Canadian Association for Community Living's *My Home My Choice.*

Explore ways of increasing capacities to support family- and community-led innovation
We will work with citizens with development disabilities, families, innovators and experts to explore existing and new innovation supports that can encourage innovation by families and communities, beginning with

Social Innovation Supports - additional supports for innovation, e.g. citizen- and family- centric social services incubator or accelerator might help drive more innovation and successes.

Innovation Incentives - additional incentives for social innovators and service providers to innovate can help speed up transformation, e.g. leveraging direct funding options as catalyst.

We propose working with the Developmental Services Sector-Ministry of Community and Social Services Partnership Table Housing Study Group on its recommendation of the creation of a Capacity Building Task Force on this suite of interventions. We will also work closely with social innovation incubator and accelerator initiatives at MaRS and others, e.g. JOLT, Impact 8 (the next cohort will be sponsored by St Elizabeth Foundation to tackle community living).

Clarify and quantify developmental services objectives that are citizen-centred
We will clarify system objectives based on the six principles of Ontario's Transformation of Developmental Services: citizenship, fairness and equity, accessibility and portability, safety and security, accountability, sustainability

We will work with citizens with development disabilities, families, civil servants, innovators, experts and partners to suggest a starting set of objectives that are:

- Clearly linked to the six principles
- Measurable
- Relevant to and actionable for individuals, families, service providers, government

Based on discussions with MaRS Solutions Lab partners, we have also identified some early opportunities. Please see the *Appendices* for more details.

5. DESIGN PROPOSAL

The proposed phase consists of four streams:

A. (Research) Deepen understanding about citizens with development disabilities, community living
B. (Ideation) Design interventions and prototypes
C. (Development) Develop strategy of prototype implementation and quick wins
D. (Capacity) Build network of citizens with development disabilities supports and inclusive communities innovators, stakeholders, experts and early adopters

A. (Research) Deepen understanding about citizens with development disabilities, community living

Results:

Design Brief synthesized from: 1) Insights from field research, including interviews with innovators; focus groups, interviews and ethnographic studies with citizens with development disabilities and their families; interviews with service providers and experts; 2) An environmental scan of current residential supports for citizens with development disabilities and other community members who need community living supports; rapid literature scans, best practices; 3) Profiles of citizens with development disabilities on the wait list.

MaRS Solutions Lab will undertake the three streams of research with partners, prioritizing and drawing on existing work and ongoing efforts whenever possible. The research will begin as early as possible while addressing the key areas identified by Stream A workshop participants and interviewees.

Actions:

A.1. Insights about citizens with development disabilities and families from field research

A.1.1   Interviews with 6 - 12 Canadian and international innovators

A.1.2   4 focus groups with 10 - 16 citizens with development disabilities and families per group

A.1.3   Ethnography studies of 8 citizens with development disabilities and families

A.1.4   Interviews with 12 - 15 residential and other developmental services providers

A.1.5   Interviews with 12 - 15 other community services providers

A.1.6   Interviews with 12 – 15 business leaders

A.1.7   Interviews with 12 - 15 experts

A.2. Environmental scan

A.2.1   Inventory of current residential supports for citizens with development disabilities, housing options and community living supports for other vulnerable people

A.2.2   Scans for promising practices, rapid literature and jurisdictional review

A.3. Profiles of citizens with development disabilities, families being served and those on the wait list, their communities by mining DSO and other government records

A.4. Finalize Design Brief, including system map

B. (Ideation) Design interventions and prototypes

Results:

4 – 6 interventions and prototypes (Including quick wins) ideas that have the potential to be the best investments in residential supports, community features and supports that can drive the greatest changes in the developmental services systems and 1) are co-designed with citizens with development disabilities and families and innovators; 2) have clear outcomes goals and measures.

Actions:

B.1. Design ideation workshop (citizen-centred alternatives) with 24 – 36 citizens with development disabilities, families, community/developmental services providers, social innovators and experts

B.2. Design ideation workshop (to increase innovation capacities) with 24 – 36 citizens with development disabilities, families, business entrepreneurs, innovators and experts

B.3. Develop wait list information strategy and suggestions for citizen-centred developmental services system objectives with citizens with development disabilities and families, community service providers and developmental services experts

B.4. Design ideation workshop with 80 – 120 citizens with development disabilities, families, experts, innovators, leaders

B.5. Develop interventions and prototypes models

C. (Development) Develop strategy of prototype implementation and quick wins

Results:

1) Strategy for prototype(s) implementation and testing; 2) execution strategy for early opportunities and quick wins with families and partners

Actions:

C.1. Prototype(s) development and planning with citizens with development disabilities, families and partners

C.2. Prototype(s) tests and simulations with citizens with development disabilities, families and partners

C.3. Develop interventions and prototype implementation plan with citizens with development disabilities, families and partners

C.4. Collaborate with the Housing Task Force on increasing community capacity and developing design supports to accelerate ongoing and new initiatives (as identified in the *Ending the wait* report)

D. (Capacity) Build network of innovators of citizens with development disabilities residential supports and community living, experts and early adopters

Results:

An active community for learning, connecting innovators with citizens with development disabilities, families, community service providers, experts and early adopters to help drive creativity and innovation through this design phase and the next prototyping phase, and to nurture capacity for the scaling phase.

Actions:

D.1. Create network and online community with challenge partners and participants

D.2. Maintain network and online community with highlights and insights from challenge activities, including interviews, workshops, focus groups and research

- o Produce bulletins, briefs, presentations, videos and other collaterals and share with participants and partners
- o Collect and synthesize feedback on work stream products from network

6. END NOTES

[1] *Spotlight on Transformation, Issue 35 – July 2013*. Government of Ontario. Retrieved 2013-08-04 from http://www.mcss.gov.on.ca/documents/en/mcss/publications/spotlight/Issue35_July_2013.pdf

[2] Ontario Ombudsman André Marin today (November 29, 2012) announced an investigation into the province's services for adults with developmental disabilities who are in crisis situations, after several desperate families complained their loved ones risked being sent to homeless shelters or jail because there was nowhere to care for them. Ontario Ombudsman. Excerpt retrieved 2013-11-07 from http://www.ombudsman.on.ca/Newsroom/Press-Release/2012/Ontario-Ombudsman-to-investigate-provinces-servic.aspx

[3] *Enhancing Support for Adults with a Developmental Disability: Ontario Government Reducing Waitlist Pressures, Improving Services for Those at High Risk*. Ministry of Community and Social Services, 2013-07-30. Retrieved on 2013-09-15 from http://news.ontario.ca/mcss/en/2013/07/enhancing-support-for-adults-with-a-developmental-disability.html

[4] $60,000 is the simple average of $1.08 billion divided by 18,000 recipients of residential supports. Co-incidentally, long-term care stay in Ontario's healthcare system is also estimated to be $60,000 average per person annually

[5] Source: Ontario Chapter of the National Association for the Dually Diagnosed. http://www.naddontario.net/

[6] *2012 General Social Survey (GSS) on Caregiving and Care Receiving*. Statistics Canada. Retrieved on 2013-07-12 from http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm#a7

[7] National Alliance for Caregiving. *Caregivers of Children: A Focused Look at Those Caring for A Child with Special Needs Under the Age of 18, 2009*. Retrieved on 2013-04-28 from http://www.caregiving.org/data/ Report_Caregivers_of_Children_11-12-09.pdf

[8] *Ontario's Comprehensive Mental Health and Addictions Strategy*. Government of Ontario. Retrieved on 2013-09-15 from http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/mentalhealth/strategy.aspx

[9] *Ontario's Mental Health and Addiction Strategy*. Canadian Mental Health Association, Ontario. Retrieved on 2013-09-15 from http://ontario.cmha.ca/public-policy/context/mental-health-reform/ontarios-mental-health-and-addiction-strategy/

[10] *Emergency Room (ER)/Alternate-Level-of-Care (ALC) issue*. Ontario Hospital Association. Retrieved on 2013-07-12 from http://www.oha.com/currentissues/issues/eralc/Pages/eralc.aspx

[11] *Ending the wait: An action agenda to address the housing crisis confronting Ontario adults with developmental disabilities*. Developmental Services Sector-Ministry of Community and Social Services Partnership Table Housing Study Group, 2013-09.

[12] Family Alliance Ontario. Retrieved on 2013-06-20 from http://www.family-alliance.com/

[13] Individualized Funding Coalition for Ontario. Retrieved on 2013-06-20 from http://www.individualizedfunding.ca/home.html

[14] Family by Family is a new network of families helping families. It finds and trains families who have been through tough times, pairs them with families who want things to change, and coaches families to grow and change together. Retrieved on 2013-05-30 from http://www.tacsi.org.au/solutions/family-by-family/

[15] *Spotlight on Transformation, Issue 37, February 2014*. Ministry of Community and Social Services. Retrieved on 2014-02-28 from http://www.mcss.gov.on.ca/documents/en/mcss/publications/spotlight/Issue37_february2014.pdf

[16] *Why Transformation?* Developmental Services Ontario, Government of Ontario. Retrieved on 2013-09-15 from http://www.dsontario.ca/why-transformation

Opportunities and Actions: Transforming supports in Ontario for people who have a developmental disability. Ministry of Community and Social Services, May 2006. Retrieved on 2013-09-15 from http://www.mcss.gov.on.ca/documents/en/mcss/publications/developmental/DSreport.pdf

7. APPENDICES

A BRIEF HISTORY OF DEVELOPMENTAL DISABILITIES

Ontario used to have institutions where people with developmental disabilities could live. This started in 1876, the first being the *Orilla Hospital for Idiots and Imbeciles*. By 1960 more than 10,000 people with developmental disabilities were living in similar institutional settings rife with complaints about poor living conditions. In 1960s, societal attitudes began to change driven by families who wanted better lives for their children. Families started programs, advocated for inclusive education and communities. People with developmental disabilities began to speak out for their right to participate in their communities. As demand grew, the Government of Ontario began to fund more services and supports in the community[i].

In 2004, the Ontario Government began to look into how services for people with developmental disabilities could be improved. The *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* was passed to makes sure that quality services and supports are offered to people in their own communities. Developmental Services Ontario (DSO) was created to implement key components of the legislation, including eligibility clarity, streamlining of application, fair decisions, consistency in services and supports quality and flexibility and choice for people.

SIX PRINCIPLES TO TRANSFORM THE DEVELOPMENTAL SERVICES SYSTEM

Ontario's Transformation of Developmental Services is guided by six principles:[ii]

- **Citizenship**: People will make their own decisions and participate in their communities.
- **Fairness and Equity**: People will be treated fairly when they ask for help and supports.
- **Accessibility and Portability**: It will be easier to ask for help and to apply for services. When people receive funding, they will be able to keep that funding if they move to another part of Ontario.
- **Safety and Security**: Services and supports will help people find ways to participate safely in their communities.
- **Accountability**: Services and supports will serve people properly. Funding will be used responsibly.
- **Sustainability**: Services and supports will be available to people today—and in the future.

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[i] Excerpt from *Brief History of Developmental Services*. Developmental Services Ontario, Government of Ontario. Retrieved on 2013-09-15 from http://www.dsontario.ca/brief-history-of-developmental-services

[ii] *Why Transformation?* Developmental Services Ontario, Government of Ontario. Retrieved on 2013-09-15 from http://www.dsontario.ca/why-transformation

PROGRESS OF DEVELOPMENTAL SERVICES SYSTEM TRANSFORMATION

- Established province-wide eligibility criteria defined in legislation and regulations (2010).
- Implemented a standard provincial application package and assessment process (2011).
- Created Developmental Services Ontario (DSO) to serve as single points of access for adult developmental services (2011).
- Introduced province-wide quality assurance measures for service agencies and DSOs (2011).
- Created a single direct funding program for adults with developmental disabilities, by transferring the adult portion of the SSAH program to the Passport program, which will now provide individualized funding for community participation supports and caregiver respite (2012-13).
- MCYS, MEDU and MCSS are working together to integrate processes for transition planning so that, effective fall 2013, each young person would have a single plan that helps them prepare for the transition to adulthood (2013-14).
- Invested an additional $42.5 million as part of the 2013 Budget to help individuals and families in urgent need, reduce waitlist pressures and provide additional direct funding.
- As part of the budget initiatives, the government is also promoting Registered Disability Savings Plans (RDSP) and initiating work related to supported decision-making.
- Working with the MaRS Solutions Lab to identify innovative residential options

EARLY PARTNERSHIP OPPORTUNITIES & QUICK WINS

We also propose partnering with innovators who are already working on initiatives with principles and goals that are aligned with this challenge. Working with these innovators will give us the opportunity to observe and quickly prototype ideas building on existing research, resources and networks.

Social Business Supports for Community Innovation

The Housing Study Group, convened from members of the Joint Ministry of Community and Social Services-Developmental Services Sector Partnership Table, in the *Ending the Wait*[11]report identified 25 initiatives being actively developed or in the process of being implemented. Suitable initiatives could be selected to help co-design and test social business incubator or accelerator models specific to the developmental services "market".

A community innovation model that provides both business development supports and funding or capital can help accelerate the initiatives growth into sustainable businesses.

MaRS and other members of Ontario Network of Entrepreneurs have proven track records of supporting social innovation and social entrepreneurship. Building on these existing resources could be a quick way to prototype and test social business supports to grow community innovation.

My Home My Choice: From Group Homes to Community Living

My Home My Choice is a *Canadian Association for Community Living (CACL)* initiative to help group home providers transition to providing community living supports. For its first phase, six group home providers in four provinces, including Ontario, will be working together to prototype new business models and to transition group home residents into supported community living arrangements in their communities.

Rapid/urgent placement prototypes

The Housing Study Group's *Ending the Wait*[11] report recommended "*MCSS commitment to fund housing needs for adults with developmental disabilities whose parental care givers are over the age of 80 …*". An age-based prioritization system would not hold up to a human rights challenge (discrimination based on age). An alternative approach would be required to identify an individual's risk based on the parent's risk of inability to continue caregiving. Select cases could be co-design candidates for prototyping rapid/urgent placement models.

Financial planning supports

Financial supports and benefits are important resources for adults with developmental disabilities and their families. Banks and other financial institutions may have a role to play.

Navigating the federal, provincial and municipal programs and their eligibility criteria and misconceptions can be very challenging. Currently, developmental services providers address these needs. Banks and other financial institutions may be able to supplement their services from the alternate lens of longer-term financial independence. Banks may also have revenue incentives to address misconceptions (e.g. about contributions to the Registered Disabilities Savings Plan, leveraging Canada Disability Savings Grant and Canada Disability Savings Bond and the income-linked benefits cut-offs for Ontario Disabilities Support Program) as bundled advisory services.