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Proposal for a National Housing Strategy Inclusive of People with Intellectual Disabilities

Submitted to:
National Housing Strategy Team
Canada Mortgage and Housing Corporation (CMHC)

Submitted by:
Canadian Association for Community Living and People First of Canada

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CANADIAN ASSOCIATION
FOR COMMUNITY LIVING

ASSOCIATION CANADIENNE POUR
L'INTÉGRATION COMMUNAUTAIRE

Diversity includes. On se ressemble.

PEOPLE
FIRST
OF CANADA



PERSONNES
D'ABORD
DU CANADA

Issue

Over 100,000 Canadians with intellectual disabilities are not able to access affordable housing that meets their support needs, makes possible a home of their own and offers social and economic inclusion in their communities. Many cannot afford housing that meets their basic needs. Many live in poverty. Many rely entirely on aging parents for both personal care and economic assistance. There are many who are homeless and many have no options but group residences or seniors' facilities.

Canada Mortgage and Housing Corporation (CMHC) reports 10.6% of Canadians living in private households have “core housing need” meaning significant difficulties in accessing affordable, adequate and suitable housing. Among adults with intellectual disabilities the Canadian Survey on Disability shows core housing need increasing to 12.7% – or at least **20,500 Canadians with intellectual disabilities**; with an earlier CMHC study pointing to core housing need among adults with intellectual disabilities even higher at 18.5%.ⁱ Add to this group:

- adults with intellectual disabilities who are **over-represented among the estimated 35,000 homeless** population in Canada – how many we cannot estimate but available evidence points to a much greater likelihood of being homeless than the general population,ⁱⁱ with intellectual disability a pre-disposing factor to homelessness and particular vulnerability for this group;ⁱⁱⁱ
- **13,200 adults with intellectual disabilities** aged 30 years and older who are living with their parents because they do not have the resources or community support to live in their own homes. Their families have unsustainable caring responsibilities, are draining life savings and have *Nowhere to Turn*, as a recent Ontario Ombudsman's report names the problem for the estimated **10,000 adults with intellectual disabilities in Ontario alone** who are on waiting for residential services. As that report states, for too many people with intellectual disabilities, lack of access to housing and supports results in “institutionalization by default”;
- almost **30,000 adults with intellectual disabilities** currently placed in congregate residential facilities and group homes, only on the basis of their diagnostic label. Many want to have a home of their own but are unable to because of lack of affordable rental housing, financial barriers to securing mortgages and because they can only access staff support if they stay in the residential facility. There appears to be a re-emergence of these congregate options;^{iv}
- an estimated **10,000 adults with intellectual disabilities** under the age of 65 who are living in hospitals, nursing homes or long-term care facilities because they cannot get the personal supports and affordable housing they need (estimated over 5,000 in Ontario alone); and,
- perhaps **another 60,000 Canadians with mild intellectual disabilities** who have never been identified in surveys of Canadians with disabilities, an issue which Statistics Canada and Employment and Social Development Canada recognize.^v Population studies of people with intellectual disabilities on a global level point to population estimates of 1-3% of the population having mild to severe intellectual disability, or in Canada, closer to 700,000.

What does it add up to? Between 100,000 and 120,000 adults with intellectual disabilities in Canada who are still seeking to have the same choices afforded to other Canadians – living in a home of their own with the supports they need to live active and productive lives.

Barriers to Affordable Housing and Inclusive Communities

Research by Canada Mortgage and Housing Corporation (CMHC)^{vi} highlights a number of barriers that create the affordable housing and community access gap facing tens of thousands of Canadians with intellectual disabilities. These include:

- limited financial resources, and ‘clawbacks’ in income assistance that create disincentives to employment income;
- limited support services for individualized planning and transition to more independent living in the community;
- a service system geared to group living based on diagnostic label;
- concerns about safety in the community, given a victimization rate four times higher than among the general;^{vii}
- estate planning barriers that create tax disincentives for families planning for future economic security of their family members with intellectual disabilities;
- credit and mortgage rules that limit the flexibility individuals and their families need for home adaptations and home ownership;
- lending criteria not recognizing disability income assistance as assurance for mortgage payments; and
- municipal bylaws that impose building and safety requirements on housing that people with intellectual disabilities live in, imposing significant costs and an ‘institutional’ model.

In addition, rules preventing assets like ‘Registered Disability Savings Plans’ for investment in home ownership and no tax incentives to encourage family and private sector investment in affordable housing development for this group reinforce limited options and continued exclusion.

The NHS Opportunity – Getting Innovations to Scale

The Government of Canada is launching a National Housing Strategy (NHS) because it “believes that all Canadians deserve access to housing that meets their needs and that they can afford” and is exploring “housing approaches that contribute to a more inclusive society, reduce social isolation and poverty and improve life prospects”. These commitments and values are the right place to start. But finding a place in the NHS for the 100,000plus Canadians with intellectual disabilities who have significant housing need will require a multi-faceted approach and new community-based, private/non-profit/public sector partnerships.

The NHS should provide opportunity to build on the leadership of local, provincial-territorial and national organizations which have concrete, practical solutions to address the unique affordable housing and social inclusion needs of this group. Many organizations could bring to the table significant housing stock currently attached to outmoded congregate service delivery approaches, a commitment to reinvest and develop these assets for inclusive approaches, and some experience in transformative approaches that result in housing security and community inclusion. With the right policy and program framework and incentives, they could do this by: unbundling support services from housing stock and attaching them to individuals, providing person-directed planning support, and delivering individualized support services to enable people to live in the community in a home of their own.

Thousands more Canadians with intellectual disabilities could enjoy housing choice, affordability and inclusion if we could build on these assets, take advantage of this existing commitment, support

transformative community leadership, and scale up what we know works. To make it happen, we need the partnerships to tap individual and family investments, leverage existing housing and service assets, link with housing developers and mobilize networks for safer, more inclusive communities.

What do we need from the National Housing Strategy to get inclusive housing and community solutions to scale, rather than more small-scale micro initiatives and demonstrations?

Proposed Elements of an Inclusive National Housing Strategy

Increased investment and collaborative efforts are urgently needed to get solutions to scale and close the housing gap for tens of thousands of adults with intellectual disabilities in Canada. To this end, the Canadian Association for Community Living and People First of Canada recommend the following elements be integral to the NHS policy and program framework.

Guiding Principles:

- Housing investments for people with intellectual disabilities must be directed to options that ensure affordability, adequacy and suitability while supporting independence and ensuring inclusion in the community.
- A social inclusion lens should be systematically applied to all NHS investments to ensure that they are not being invested in congregate housing models for people with disabilities, but enable affordability and access to housing markets like all other Canadians.
- Income transfers for housing and disability-related supports must enable individuals to direct housing choices and support options.
- Affordable housing is not enough – flexible supports and community connections for safety and inclusion are essential to make a home and good life possible for people with intellectual disabilities.
- Coordinated, community-based leadership is essential to transforming existing residential and service provision in ways that enable housing affordability, choice and opportunity for people with intellectual disabilities in safe, supportive and inclusive communities.

NHS Objectives to meet the needs of people with intellectual disabilities:

We urge that the NHS incorporate the following policy and program objectives, in order to be fully inclusive of people with intellectual and other disabilities:

- ***Increase access to the mix of affordable housing and personal supports*** that adults need to live independently in the community with safety, security and inclusion.
- ***Provide incentives to leverage investments in existing congregate housing models*** to expand re-investment and re-purposing for inclusive affordable housing and needed supports.
- ***Grow social infrastructure*** to assure safety and facilitate social and economic inclusion of adults with intellectual disabilities.
- ***Develop policy solutions*** to incentivize individual, family and private sector investment in affordable housing for people with intellectual disabilities, and bridge the housing and supports gap.

Inclusion-based Policy Lens:

An inclusion-based policy lens must guide policy options in order to shift current investment in congregated, segregated housing units and support provision – so that history is not repeated and good intentions do not result yet again in more congregated, segregated and institutionalized arrangements, instead of real homes in inclusive communities. The *Disability and Inclusion Based Policy Analysis*^{viii} developed by IRIS – Institute for Research and Development on Inclusion and Society provides an ideal framework to guide policy and analysis and options development that will ensure the NHS results in outcomes consistent with the government’s commitment to social inclusion.

Program Drivers – Strategic Partnerships:

To achieve these objectives and guided by an inclusion lens and the operating principles above, the NHS should incentivize and support local-to-national strategic, proactive and integrated partnerships. Our experience to date shows these partnerships are needed to activate inclusive housing and community development for people with intellectual disabilities. At the city and local community level, local providers of residential and other supports to people with intellectual disabilities and self-advocacy and family networks must become organizationally ready to drive housing development and access in ways that advance social and economic inclusion. Only with their leadership capacity ‘readied’ can they help initiate and drive the partnerships needed to activate an inclusive housing and community development trajectory. As these partnerships become embedded in community wide and municipal strategies, visionary leadership for inclusion can sustain the inclusive development path.

In summary, four key partnerships are need:

- 1) partnerships for local residential supports providers to link with self-advocacy and family networks and get organizationally ready to transform current housing/supports provision into pathways to affordable housing and community inclusion;
- 2) partnerships linking residential providers, self-advocacy and family leaders, housing developers and civic and community leaders to create non-profit and market housing that includes people with intellectual disabilities;
- 3) inclusive cities and community partnerships to design social infrastructure people need to be fully included in their communities – including health, social, recreational, settlement, protective, justice and other community services; and,
- 4) knowledge networks that link policy analysts, thought leaders, development partners and academics to generate and disseminate the knowledge tools key partners need to plan and execute effective inclusive development.

These four partnerships are described below:

- **Partnerships for Local Leaders** – are needed to develop and deliver training and capacity-building to assist self-advocates with intellectual disabilities, families and residential and support agencies to become organizationally ready for affordable housing and individualized planning and support initiatives. There is an urgent need for community capacity to support individualized planning, leverage family assets and build capacity to create housing and support options for a life in the community for adults. The priority is for those living with aging families, in group homes who want to live more independently, and those who are living in homeless shelters or are inappropriately place in long-term care or hospitals. To drive the transformation and development process it is essential to build the leadership

and organizational capacity of: self-advocacy and family networks to better connect with individuals and aging families in their communities; volunteer boards directing community residential and support agencies; their executive leadership; and, their staff who provide direct supports to individuals and families. At the provincial-territorial (PT) level, these partnerships must also engage government departments responsible for housing and community services which have a stake in the group home housing stock owned by community agencies.

- ***Inclusive Housing Development and Supports Partnerships*** – are needed to link community residential and support agencies, self-advocate and family leaders, financial institutions, housing developers and government partners to develop and deliver affordable housing, individualized planning services, and individualized, flexible personal supports in select communities. Pilot initiatives have forged these partnerships to invest in new housing development, leverage group home assets, and deliver individualized planning and support to individuals and families for a home of one's own and supports in the community. These initiatives are assisting aging parents now supporting adult children at home and residential and support agencies to transition from inadequate housing/support arrangements and group home provision to independent living in the private sector and non-profit housing markets. Examples of person-directed planning and flexible support services and leveraging and re-investment of group home assets in communities across Canada provide a number of good practice examples which can be consolidated to create more systematic approaches for wider dissemination and scaling up.
- ***Inclusive Cities and Communities Partnerships*** – are needed to link municipal and community leaders and partners from diverse groups facing housing affordability issues, social exclusion, marginalization and victimization in their communities. Community leaders, local governments, police, health, community, protective and justice services, self-advocacy and family-to-family networks and residential support agencies partner to advance community inclusion and the social infrastructure to sustain it in cities and communities across Canada. Through partnership building, nurturing shared understanding across diverse groups and systematic auditing of community services they are identifying service and support gaps that leave people vulnerable. Together, they are creating shared strategies to motivate welcoming and supportive communities for all.

Evidence from our pilot initiatives designed to create this cross-sectoral social infrastructure demonstrates positive impact of collaborative approaches. Co-constructed solutions across population groups who experience marginalization strengthen the capacity of community agencies and networks to address the multi-faceted nature of social exclusion and personal victimization to a much greater extent than the usual 'silo' approaches delivered to particular population groups. These cross-sector partnerships are creating what we call 'safe and inclusive community networks' to close gaps in service delivery and community connections and are thus better positioned to confront barriers to safety and belonging for those traditionally marginalized and at higher risk of victimization. Such networks are essential to ensure people who access housing in the community are also attached to support systems that address diverse and changing needs.

- ***Learning Partnerships and Knowledge Networks for Inclusive Housing and Communities*** – are needed to link policy researchers, thought leaders, and representatives

from the financial sector, housing developers and the disability community to identify good practices and enabling policy options, for example:

- creating a pool of capital for social financing of home ownership by people with intellectual disabilities who would not otherwise be eligible for mortgages;
- providing for investment of assets from Registered Disability Savings Plans in home ownership for first time home buyers ways to ‘take stock of housing stock’ owned by local associations;
- applicability of a ‘low-income housing tax credit’ modelled on the U.S. provision to spur investment in affordable housing through family and private sector investors;
- valuating current housing stock and real property owned by community-based residential providers and examining options for leveraging and re-investment in options for affordable housing and inclusive community development; and,
- policy solutions to assist residential agencies ‘unbundle’ their housing stock and support services, by shifting the financing of support services away from facility-based programming and towards more individualized approaches that provide adults with intellectual disabilities flexible support provision and access to the housing market so they can live more independently in the community.

Conclusion – A National Housing Strategy for All

We believe an inclusive National Housing Strategy can help deliver on shared priorities for increasing affordable housing, reducing poverty, growing inclusive social infrastructure and improving housing access for *all* Canadians, including those with intellectual disabilities. If the NHS is to *be* inclusive, and *result* in inclusion, it must be about more than housing stock. It must create the policy context and provide innovative social and financial investment tools to forge needed linkages between residential and community support agencies, adults with intellectual disabilities, families, financial institutions, housing developers, community networks designing safer and more inclusive communities, thought leaders and government partners. It must provide communities the tools needed to confront the path dependence and barriers to access that have left people with intellectual disabilities outside of affordable housing markets and community access for generations. In so doing, the National Housing Strategy could become a key ingredient in helping to break the cycle of poverty and exclusion that affects so many people with disabilities.

We need a strategy that brings investment tools to people with intellectual disabilities, their families and communities to increase housing choices and opportunity, grow individual assets and income security, seed innovative investment options and strengthen social infrastructure. It must take us beyond interesting pilots and demonstrations. It must create the program context, establish the incentives and invest in the drivers needed to get to scale what we know works. Designed appropriately, the National Housing Strategy could be a game changer for housing access and social inclusion for generations to come. We would look forward to being a part of what could be a defining national initiative for inclusion.

Our Organizations

The Canadian Association for Community Living is a national association of over 40,000 members, 300 local, family led Associations for Community Living and 13 provincial/territorial Associations representing the over 750,000 Canadians with intellectual disabilities and their families.

We are families, people with intellectual disabilities and our supporters working together to ensure all people:

- Have the same rights and access to choice, supports and services as all other people.
- Have the same opportunities as others to live in freedom and dignity, and have the needed support to do so.
- Are able to voice and realize their aspirations and rights.

Founded in 1958, CACL provides leadership on the issue of inclusion and human rights of people with intellectual disabilities. We promote public awareness of our cause and foster leadership of families in their communities. CACL leads community change through partnerships with key sectors; and puts research to work to inform, lead and support efforts for full inclusion of people with intellectual disabilities in Canada and around the world.

People First of Canada is the national voice for people who have been labeled with an intellectual disability. We are about rights – human rights, citizenship rights, accommodation rights, and language rights. We believe in the right to freedom, choice, and equality for all.

We see ourselves as self-advocates and full citizens of our country – living equally in the community. We see ourselves as people first, and as people who have taken back control of our lives from families, policy makers and professionals such as support workers, doctors, social workers, and others, who, for far too long, made decisions for us.

Endnotes

ⁱ See Canada Mortgage and Housing Corporation (July 2010), “2001 Participation Activity Limitation Survey: Issue 7—Profile of the Housing Conditions of Canadians aged 15 Years and Older with a Developmental Disability” (Ottawa: Author).

ⁱⁱ For U.S. prevalence study, see PM Oakes and RC Davies (2008), “Intellectual disability in homeless adults: a prevalence study,” *Journal of Intellectual Disability* (December: 12(4):325-334).

ⁱⁱⁱ C. Mercier and S. Picard (2011), “Intellectual disability and homelessness,” *Journal of Intellectual Disability Research* (April: 55(4):441-9).

^{iv} See Housing Study Group (Developmental Services Sector – Ontario Ministry of Community and Social Services Partnership Table) (2013), *Ending the Wait: An Action Agenda to Address the Housing Crisis Confronting Ontario Adults with Developmental Disabilities* (online: <http://www.dsontario.ca/news/ending-the-wait/>).

^v Statistics Canada and Employment and Social Development Canada are aware that the disability surveys conducted to date have done well in capturing adults with moderate and severe disabilities but miss many adults with mild disabilities. To improve coverage, these two departments have joined forces with academics and the disability community through a ‘Technical Advisory Group’ and have developed a strategy that will better capture ALL Canadians who experience barriers because they have limitations in their activities related to a health problem or disability-related condition.

^{vi} See Canada Mortgage and Housing Corporation (2006), *Housing for Adults with Intellectual Disabilities* (online: https://www.cmhc-schl.gc.ca/EN/INPR/REHI/REHI_o18.CFM).

^{vii} See Samuel Perrault (2009), *Criminal victimization and health: A profile of victimization among persons with activity limitations and other health problems* (Ottawa: Statistics Canada).

^{viii} See IRIS – Institute for Research and Development on Inclusion and Society (2012), *Disability and Inclusion Based Policy Analysis* (online: https://irisinstitute.files.wordpress.com/2012/01/is-five-190142-iris_disability_inclusive_lens_eng.pdf).