

## Securing Positive Futures: A Shared Responsibility

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### The Issue:

There is no framework to enable individuals or families to collaborate on plans that would allow people to live in their homes when primary caregivers are no longer able to support them.

### Current status:

- Government recognizes in a very public way that persons with disabilities and seniors want to continue to live in their own homes, wherever possible.
- There is a large constituency of persons with disabilities whose continuing ability to live in their own homes is threatened or eliminated at a point when primary caregivers are no longer able to provide support.
- The lack of disability supports, or a loss of existing supports, cannot fall solely to government, nor can it fall solely to individuals and families.
- Health care costs as a percentage of governmental budgets (GDP) are rising and are in crisis.
- The limits and caps on program funding for disability supports do not adequately address the needs of many individuals in the absence of family members who are critical to independent/supportive living.
- The range of options for a diverse population are inadequate and re-institutionalization is emerging at a rapid pace.
- Persons with disabilities are the first generation living longer than their parents, often outliving those who are needed as primary caregivers.
- Exemptions around the Registered Disability Savings Program (RDSP) and Support Trusts provide a mechanism for individuals and families to provide options for wealth transfer. The potential and the impact of these mechanisms are greatly under-estimated, given the grants, bonds, long term compounding interest and favourable tax treatment.
- The unintended impact of privacy legislation has made it difficult for individuals to navigate the community. There is legal reform process underway which aims to empower individuals to control, with supports and accommodations, if required, their own financial and medical affairs.
- The introduction of individualized funding greatly enhances flexibility and self-determination, supported by the legal reforms underway, but can be made more powerful if the safety and security of having a home can be made more secure. Long term planning can be part of the action plan.

- While there have been measures supported by community and government to encourage private savings and investment there is no formal mechanism to have a long term planning conversation with government through Health and Community Services or through the Health Authorities.
- Failing to embrace collaborative planning will ensure significant numbers of individuals with disabilities will come under state responsibility and control, create a stampede to costly and invasive guardianship orders, and increase homelessness or other devastating outcomes.
- The early concerns around cost and the inability to commit for future governments seem to be premature, without discussion or analysis.

**Conclusion:**

There is a need to embrace serious discussion leading to consideration of the implications of constructing a long term planning framework.

Without this framework we would be endorsing a future where government would seek to retain sole responsibility for the cost and well-being of thousands of people who would otherwise live, with supports, in the community.

To dismiss the potential of a multi-billion dollar wealth transfer from private savings and investments from individuals, family and extended family supported by personal support networks would be unthinkable.

**Recommendations:**

- Inclusion Canada NL (ICNL, formerly known as NLACL) will establish an initial meeting with the Deputy Minister of Health and Community Services and the Deputy Minister of Department of Children, Seniors and Social Development with appropriate governmental staff together with community representatives engaged in future planning to discuss and clarify the issues.
- Identify the potential benefits to developing a framework and put in place the measures and participants to oversee the design.
- Community participation in the design, implementation and evaluation process would be absolutely essential.

**Contact Information:**

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