

'Better for You - Better for Us'

Supported Living in Community



Executive Directors and Chairs Network
July 2013

ACKNOWLEDGEMENTS

This document, *Better for You – Better for Us*, was prepared by and represents a collaborative and consensus effort of the Executive Directors and Chairs Network. This Network, comprising of representatives from the provincial community organizations, working with and on behalf of people with disabilities and their families, meets on a regular basis to critically discuss issues of common interest in order to provide a more powerful and united voice within the disability community. Collectively, the organizations within the Executive Directors and Chairs Network in one way or another represent the vast majority of the approximately 75,000 citizens within this province who report as having a disability.

Appreciation is extended to all Network members for their invaluable contribution to the development of this document, and for ensuring that the voice of their organization was fully and accurately reflected in the final version. In particular gratitude is extended to the Coalition of Persons with Disabilities (COD-NL) for its ongoing leadership and facilitative role within the Network.

The Network would also acknowledge and extend appreciation to the Newfoundland and Labrador Association for Community Living (NLACL) and its Community Inclusion project for providing the means for the preparation of this document.

Finally, appreciation is extended to Don Gallant, *Don Gallant and Associates*, for his assistance in the writing of this document.

FOREWORD

Society's response to the housing needs of people with disabilities has historically been juxtaposed with their disability or label. For generations the prevailing societal view was that people with disabilities could not be supported in community and required specialized residential facilities. This led to the development of large institutions as a primary response to the residential needs of people with disabilities (e.g. in 1967 in Canada, 194,650 persons with intellectual disabilities were living in public institutions). With our changing attitudes toward people with disabilities and an increased understanding of disability we have learned that large congregate settings serve no function other than to isolate and separate people with disabilities from the mainstream of society, and deny opportunity for an inclusive life in community. In accord with this reconceptualization of disability, significant efforts were focused on deinstitutionalization both nationally and internationally beginning in the early 1980s. Within this province, both policies and practices were established that enabled people with disabilities to live within community. Our large institutions were closed, we moved

away from a reliance on group homes as a preferred option, and instead placed focus on the provision of individual planning which extended maximum choice to individuals (and families) as to life in community.

However based on ongoing dialogue with people with disabilities (and their families) throughout this province, it is apparent that the capacity to support people to live in community, in meaningful and inclusive ways, has decreased significantly within the past decade and is now reaching crisis proportions.

One of the emerging demographics as related to people with disabilities is that they are, quite simply, living longer, and for the first time now generally outliving their parents. This demographic shift places increased pressure on the community (and its associated service system) to respond to this changing service demand. With increased life expectancy, many parents are by default expected to maintain a primary 'caregiving' role for their adult sons and daughters for a much longer period of time than ever before. There are now many more instances of aged parents providing care to their adult sons and daughters, sometimes with but often times without adequate supports. With the aging of the 'baby boomers' the percentage of people in the province over the age of 65 years has increased and is expected to increase considerably within the next 10 years. These seniors, many of whom are parents of adults with disabilities, will as they age often acquire age related disabilities, and thus themselves require supportive services.

People with disabilities and their families have repeatedly indicated that there is now an undeniable crisis within the area of community living. These individuals and families tell us that:

- Factors such as imposed ceilings on home supports, lack of available accessible and affordable housing, and inadequate levels of home supports have contributed to this crisis situation.
- Increasingly adults with disabilities are forced to live with their parents due to the lack of available and acceptable alternatives.
- Aged parents are caring for aging adults without any plan (either individual or systemic) in place to respond when these families can no longer provide the needed support.
- Young adults with disabilities are being placed in seniors' facilities, long term care, and/or nursing homes because no other options exist and because a 'bed' is available in one of these facilities.
- In both crisis and planned situations individuals and their families are given little or no choice in the options offered, with choice being replaced by 'placement'.

While the current provincial system of supports and services to people with disabilities and their families has many strengths and at a policy level, we believe, is firmly committed to inclusive community living, it is equally apparent that delivery on these

policies has not kept pace with the changing demographic within the disability community, or indeed with changing expectations of people with disabilities and their families. What is needed is a systems transformation that would extend and enable, in a financially viable and sustainable manner, greater choice, flexibility, innovation and self-determination, which in turn will facilitate more inclusive and participatory lives both within and outside the family unit.

Issues of Concern

Within the province today there are several stark realities that face people with disabilities (and their families) in pursuing supported living within community. These include:

Housing stock – insufficient availability of affordable, accessible, adequate and safe housing to meet current demand.

Disability Supports – where affordable, accessible housing is available, many people with disabilities cannot exercise their choice to live in community due to an inability to secure the necessary disability supports (i.e. home support).

Aging Caregivers – a growing number of adults with disabilities are continuing to reside in the family home, where the primary caregivers are the aging parents. These parents report as receiving less than needed outside support with caring responsibilities and as they age, these situations are not sustainable.

Limited / Inappropriate Choice – where adults with disabilities seek to establish a life outside the nuclear family the choices offered are either inappropriate or in fact represent no choice. For example, current practice in many regions throughout the province has ‘alternate family care’ being offered as the first (and only) choice. More individualized and appropriate choices (and associated supports) are not being made available.

Institutionalization – in the absence of adequate home supports to either remain in the family home or to establish supported living in the community, young adults with disabilities are being placed in nursing homes, seniors’ residences, and personal care homes.

Residential Options - where ‘residential options’ are currently being developed such are being completed primarily within a congregate care model. Facilities and/or housing complexes are being built to serve certain population based on disability type rather than placing a focus (and financial investment) on development of adequate dispersed housing and the provision of necessary disability supports to the person so that they may use available housing stock. Such supports should include resources to alter the physical environment to accommodate any specific disability-related requirements. Adults with disabilities should have access to living arrangements that resemble the rest of society including the choice to live alone, with one’s family, or in small groups with peers/friends/roommates, in an ordinary home, in a regular neighborhood.

A Common Understanding of Supported Living

People with disabilities have a right to live and to be included in the community. This right extends to everyone regardless of age, ability or nature of disability. It means that everyone should have the opportunity to live and participate in the community they choose; be involved in decisions about the support they receive and have maximum control over their lives. The realization of this right should be at the heart of any community-based system of supports and services to people with disabilities. In order to exercise this right of citizenship, people with disabilities must be afforded the opportunity, and necessary supports, to live in typical houses and communities. Public policy must facilitate, accommodate and enable the free and full exercise of this right.

The UN Convention on the Rights of Persons with Disabilities (UNCRPD), which Canada has both signed and ratified, explicitly recognizes the right to live in the community.

Article 19 - Living independently and being included in the community – states:

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; and
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

The term '*supported living*' is used in this document to define the outcome being sought by people with disabilities. We use this term as an alternative to the other often used terms of 'independent living' and 'community living', which have become incorrectly associated with meaning 'living alone', being 'completely self-sufficient', or requiring '24 hour / 7 day a week paid support'.

For our purposes, the term supported living can perhaps be best described as having a safe and decent home of your own, choice, and personalized assistance and support from others who care about and respect you. It is the outcome achieved when people

have access to needed personal supports and to the environmental supports and accommodations that enable people with disabilities to live good lives in communities. It reflects the fact that to live inclusive lives in community, all people require, to lesser or greater degrees, some form of support.

It also includes the need to value and support families, including the need to help maintain or improve their quality of life. The term supported living draws on and reflects directly the principles and aspirations of the CRPD.

It is equally important to understand what supported living is not. It is not:

- A program to fix or change people
- Isolation or loneliness
- Segregation by disability
- Another stop on the service continuum
- Another name for downsizing facilities into smaller units or otherwise renaming existing services
- Being assigned roommates
- A house with rules on the wall
- Living in an agency controlled apartment
- Signing a lease on a house/apartment that staff control
- A fixed amount of support forever
- Expecting that the amount of assistance necessarily will always decrease
- Compatible with services that control and congregate people
- A funding stream for use to do more of the same kinds of services

Supported living is not exclusively a housing issue. Simply building more disability specific housing units into which people are 'placed' cannot lead to inclusive lives in community. People with disabilities need and have a right to choice and mobility, not to be told by government that in order to have their disability needs met, they must live in a particular housing unit.

To enable inclusive lives in community, there must be an investment in people rather than buildings. What people with disabilities need is an availability of generic housing stock (which is accessible, affordable and non-congregate) and access to the disability supports that will enable them to avail of this housing stock in a manner appropriate to their particular needs and preferences.



The majority of people with disabilities do not want ‘residential options’ or ‘specialized residential facilities’. They want a safe and decent home of their own, where they can exercise choice and control, choice of where and with whom they live, where they have tenure as tenants or homeowners, and have access to needed personalized support/assistance. In short they want what all other Canadians want – a home in community.

The provincial government, in 2012, released ‘*Access. Inclusion. Equality. Provincial Strategy for the Inclusion of Persons with Disabilities in Newfoundland and Labrador.*’ The strategy is a broad framework intended to guide actions to remove and prevent barriers, resulting in the improved status of persons with disabilities. The strategy is intended to enable access by people with disabilities to economic, cultural and social opportunities on an equal basis with other citizens. It speaks of supporting individuals with disabilities to contribute to all aspects of society. We believe this strategy could provide a roadmap for system transformation, and if paired with specific actions in accord with known best practices could, over time, result in a system that is much more responsive to and reflective of the needs and aspirations of people with disabilities and their families.

The strategy is comprised of five strategic directions: attitudes, engagement, accessibility, support, and services, and can be summarized as follows:

Creating a Positive Image of Disability - changing society’s focus to what people can do rather than on limitations associated with disability by promoting positive attitudes, helping communities understand barriers as experienced by people with disabilities and promoting the benefits of including people in all aspects of society.

Moving Forward Together: ‘Nothing About Us Without Us’ - meaning that it is essential for people with disabilities to be involved in the decisions that most intimately affect them. The strategy acknowledges that individuals know what is best for them and that when individuals are supported to identify their own needs and best ways to meet those needs, solutions tend to be more successful.

Accessibility for All in the Built Environment - access to community activities, employment, transportation, housing and education is often times limited because of inaccessible buildings and facilities. The intent is to create a community in which people, regardless of a disability, can use buildings, programs and products on an equal basis with others.

Strengthening Disability Related Supports - disability related supports are essential to inclusion and represent a key link to participating in education, employment, recreational and community opportunities.

Delivering Services with Dignity, Fairness and Respect - by increasing choice and control for individuals; and delivering services in ways that are respectful of the principles of consumer control, choice, inclusiveness and removal of barriers.

The concepts and principles set forward in this paper with specific relevance to living in community are in full accord with and complementary to the strategic directions as set forward in the Provincial Strategy. They are described here not to duplicate or replace but rather to draw attention to emerging needs within this area and the imperative to ensure that people with disabilities and their families have access to the supports required to exercise the fundamental right of community living.

Delivered within a comprehensive disability framework and compatible with the directions set within the Provincial Strategy, a concept of supported living would be best advanced in accord with the following vision, principles and service elements.

VISION

People with disabilities are afforded the opportunity to live in typical houses and communities where they exercise their full rights and responsibilities as citizens. People with disabilities are able to choose where and with whom to live, and have access to the necessary level of disability supports in order to realize this choice. Public policy facilitates, accommodates and enables the free and full exercise of the right to life in community.

Principles

In supporting people with disabilities to live inclusive lives within community, the following principles are applicable:

Full participation in the community

Supports and services should enable individuals to participate in the community on an equal basis with others, to the fullest extent desired. A wide range of services should be developed which will remove barriers to participation and ensure access to mainstream services, thus contributing to full community inclusion. Assistance with housing (i.e. disability supports) should reduce restrictions and foster capacity to live a fulfilling lifestyle as a contributing member of the community.

Choice and control

Individuals have a right to make decisions about their lives and to have control over the support they receive. Access to information, advice and advocacy should be provided so people are able to make informed choices about the support they want. People with disabilities should have control over personal disability related funding. Funding for disability related supports should be linked to the person and not to services or programs.

Fairness and Equity

People with disabilities have the same rights as all other members of the community. It must also be recognized that people with similar disabilities and similar supports needs may have quite different housing needs or preferences. Disability supports must be provided in a manner that enables individual choices to be realized. To ensure equality of opportunity and the best possible housing outcomes for people with disabilities, individual needs and circumstances must be taken into consideration.

Equality under the Law

People with disabilities have the equal right of all persons to legal capacity, without discrimination on the basis of disability. People have a right to exercise control over financial/property, health care, and personal care and life decisions. The concept of legal capacity is inclusive of those who may not act entirely independently in their decision-making. Article 12 of the UN Convention states that because a person may not be able by him or herself to understand, appreciate and communicate a decision, such cannot trigger the removal of the right to legal capacity. Rather, support and accommodation must be provided to assist the person in making decisions (i.e. Supported Decision Making).

Elements

To ensure equality of opportunity and to facilitate the attainment of supported living in community, the following elements must be present:

Person-centred Planning

Traditionally, support has been provided in a service-centred way; that is, trying to fit the person into existing service options. Instead, the needs and preferences of the person should be at the center and support should be tailored to their individual situation and should offer personal choices. This means that people with disabilities (and their families) should be actively and centrally involved in the decision making process. In a person-centred planning approach, each person has the authority to define and pursue his or her own vision, the concept of self-determination is fully respected, and personal relationships and community membership are valued.

Person-Centred Planning is a process through which all aspects of an individual's life are considered. The key feature is that the individual determines (sometimes via a supported decision-making process) what is meaningful to them. Decisions may range from daily issues to more meaningful and impacting decisions such as where to live and with whom. The individual at all points in the process makes all major decisions and directs the process.

Separation of housing and disability support

The type and level of support individuals receive should not be determined by where they live, but by their needs and requirements. Support should follow the person wherever they live; even high levels of support can be provided in ordinary housing. Separating the provision of housing from disability support will ensure that individuals will not lose their support should they decide to change their living arrangements, for whatever reason.

Access to personal disability supports

To be most effective, disability supports must be attached to people, not programs, services or physical structures. Accessing needed disability supports should not be contingent upon entry into a particular service or living in a particular type of residential option. Disability supports need to be identified and used by the individual and/or family to achieve their goals and aspirations in ways that make sense to them. Disability supports are tools to be used to enable and facilitate full and inclusive participation in community and all its associated activities.

Disability supports are any good, service or environmental adaptation which assists people with disabilities to overcome limitations in carrying out activities of daily living, and to participating in the social, economic, political and cultural life of the community. Personal disability supports include animal assistance; a wide range of human supports (e.g. attendants, interpreters, home support workers, etc. for assistance with activities of daily living, learning, community access, work, transportation, and communication); pharmacological supports; and technical aids and devices for communication, mobility, agility and learning. For many individuals, the primary personal disability support comes in the form of 'people support'. Disability supports enable access and inclusion by people with disabilities in all aspects of daily and community life. These goods, services and supports are essential for participation at home, school and community and are key to maximizing personal and economic independence, and inclusion and access in the community.

To achieve these outcomes, disability supports must be designed and delivered such that:

- Eligibility for the support is delinked from a particular placement (i.e. residential option);
- Access to needed support is not contingent upon income; and
- Funding for disability supports is linked to and controlled by the person.

Aging in Place

Many people with disabilities are forced to leave their home and go to some type of residential setting; either because their home is not accessible, is dangerous or is not suitably adapted to their needs. Research has shown that the majority of people prefer to remain in their own homes instead of going to a nursing home or other type of residential setting. Provision of housing adaptations and repairs to improve the accessibility, comfort and safety of the house or apartment has an important and cost effective role to play in allowing people to remain in their own homes and thus avoid the need for alternate housing and/or avoid institutionalization.

Accessible housing

For many people with disabilities, the availability of affordable, accessible, non-isolating and safe housing is crucial. Therefore, policies should be adopted to ensure access to social housing and to increase the number of universally designed houses and apartments in the community. The term 'universal design' means "design of products, environments, programs and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design".

Independent Facilitation

Appropriate person-centred planning is best accomplished when there is access to independent planning (and necessary planning assistance) and facilitation. Many adults (and families) require support in accessing and understanding the myriad of information on programs and services and arranging these supports and services in ways that best meet their individual needs. To ensure accountability to the individual, this planning function needs to maintain sufficient independence and minimize any conflicts of interest. The planning function should therefore be directed by the individual and be separate from eligibility, service delivery and funding allocation decisions. This can be best achieved if assistance with planning is provided by an independent community based agency (ies), via the use of trained independent planners who are available and accessible to people with disabilities and their families.

Individualized Funding Model

Individualized funding is generally recognized as a key and essential mechanism to the full actualization of such concepts as citizenship, self-determination and community participation, with an anticipated outcome of providing people with genuine choice and control of their lives. Provision of individualized funding creates a support system that moves away from 'menu selection' and the exclusive use of pre-existing services, and transfers control over required resources to individuals and families. This can be best accomplished via an allocation of public money, directly to an individual to meet their disability-related needs. An individualized funding option has been proven to be a means by which much greater innovation and flexibility can be introduced. Individuals and families will, when given control over resources, develop solutions that are much better suited to their particular needs, generally in a more cost effective manner than selection from a predefined menu of residential options.

Individualized funding (IF) has two fundamental characteristics:

- The funding amount is determined by direct reference to the individual and/or family's specific needs; and
- The individual (or family), supported by their personal network, determines how funds are spent.

Conclusion/Summary

Many people with disabilities are simply unable to exercise their right to establish a life in community, in ways that reflect their needs and aspirations. What is needed and indeed what individuals with disabilities and their families are demanding is a fundamental rethinking of how supports and services are provided within this province so that people with disabilities are better able to take or retain their rightful place within community. What is needed is a commitment to changing current practice within the area of community living so that the day to day reality of individuals with disabilities and their families is in accord with the principles and vision as set out in the Provincial Disability Strategy, and indeed guaranteed by the UN Convention.

The Executive Directors and Chairs Network is uniquely well positioned, given our direct relationship with individuals and families, to assist government transform its policies and practices to better meet the needs of individuals with disabilities and their families. We are more than ready and willing to engage in a collaborative process to achieve such a transformation.

Respectfully submitted by;

Michelle Murdoch, Coalition of Persons with Disabilities – NL, on behalf of the Executive Directors and Chairs Network and endorsed by the following organizations:



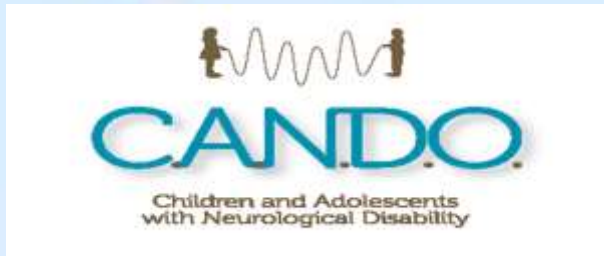
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