



STRATEGY ON AGING

A proactive response to the challenges and opportunities associated with supporting adults with developmental disabilities who are growing older in our communities

July 2013

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This strategy has been developed by Community Living British Columbia (CLBC), in concert with the Advisory Committee on Aging, Community Councils, and the many individuals, family members, service providers, caregivers, professionals and staff who contributed through forums held across BC.

Thank you to everyone who attended meetings, told their stories and offered positive ideas.

1. Why a Strategy on Aging?

As a result of the de-institutionalization of people into community living environments over 25 years ago, we now have, for the first time, a growing population of individuals with developmental disabilities who are aging in community. Understanding and providing what they need to age with safety and dignity in community is not something we as an organization or a broader community have done before.

The richer quality of life offered by community living is resulting in longer lives for many people. Like the general population, these individuals are likely to become more vulnerable and develop more complex care needs as they get older. Some people with developmental disabilities may also experience the onset of age-related challenges earlier than the general population. People's needs, strengths, and concerns change as they get older. Many middle-aged individuals are living with family members or caregivers who may not be able to continue to care for them as they themselves age.

This produces challenges and opportunities for individuals, their families and service providers, as well as public agencies, and the broader community. The challenges are about the kinds of supports and services individuals and their families will need, and how best to plan for and develop them. The opportunities are about what individuals with developmental disabilities have to offer as they get older. And about the innovative, values-based and community-building strategies we can devise to meet the challenges.

"Family members are seeking peace of mind that others will care for their son, daughter or sibling with the same commitment they have shown.

They want love and happiness to be the hallmarks of the lives their loved ones lead as they age."

(Comment from a family member at an Aging Forum)

This *Strategy on Aging* is a collaborative and proactive response to both the challenge and the opportunity. Community Living British Columbia (CLBC) is prepared to play a leadership role in facilitating the changes and partnerships required to make it a reality.

2. What the Numbers tell us

The profile of the people who are looking for and using CLBC services is changing as they and their families, friends and extended families get older. Here are some key statistics that illustrate this trend. Unless otherwise noted, these figures come from the CLBC service system for September 30, 2012:

- About 23% of adults who are currently served by CLBC are aged 50 or over (3420 individuals).
- About 5% of adults who are currently served by CLBC are aged 65 or over (742 individuals).
- Individuals aged 50 or over are distributed around the province in roughly the same proportion as the overall population served by CLBC. They live in big urban areas, small towns and rural areas.
- 70% of the individuals aged 50 or over receive CLBC residential service (2399 individuals). This is a noticeable increase over the previous year when 60% were receiving residential service.
- 30% of the individuals aged 50 or over receive only non-residential CLBC services, such as respite or community inclusion (1021 individuals). This is a noticeable decrease over the previous year, when 40% were receiving only non-residential services. These people live with family members or other caregivers with no residential support from CLBC. The people they live with are themselves getting older and are likely finding it harder to manage with only non-residential support.
- 94 individuals over the age of 45, who have never received CLBC services, registered with CLBC for the first time in 2012-2013
- In the next five years, CLBC expects the size of the group of people aged 45-64 using funded services to increase by 14%.

"As parents grow older and experience increasing health care needs, they worry about who will provide support when they can no longer fulfill this role. They are requesting support when the system is already stretched to capacity."

(CLBC Strategic Plan 2012/13 – 2014/15; Page 5)

3. Engaging Community

Our work on aging began in community, rooted in a belief that the best solutions and responses are found by listening closely to the people most affected. A thoughtful community engagement process is an essential foundation upon which to build a strategy.

In partnership with Community Councils and with the active involvement of regional CLBC staff, we conducted aging forums around the province over an eight-month period ending in June 2011. Thirty-nine forums attracted over 1200 attendees. The forums were well-received and helped raise awareness of the issues affecting people with disabilities as they age. People who attended often extended their thanks for an opportunity to be listened to. A broad range of people participated, including families, self-advocates, health care providers, senior-serving organizations, academics, partner agencies, municipal representatives and staff from both CLBC and service providers.

The most recent stage of the community engagement process has been the work of the CLBC Advisory Committee on Aging. The committee has 23 members, representing a wide range of partners, perspectives and expertise (see Appendix A for list of members). Chaired by the CLBC Manager of Service Accountability and Safeguards, the committee reviewed in detail the material gathered through the aging forums and provided valuable advice on an initial draft of the strategy.

The Advisory Committee mandate also includes advising CLBC on the development of an implementation workplan. The workplan will set out detailed actions along with indicators we can use to measure progress. During implementation, we will draw on the breadth of experience of the Advisory Committee members and what current research tells us about successful initiatives, while remaining open to creative and innovative actions.

"Community engagement is the foundation upon which a strategy addressing the needs of vulnerable individuals who are aging will be developed.

(Dr. Brian Plain, Member, CLBC Advisory Committee on Aging)

4. Foundational Values and Beliefs

Several overarching themes emerged from the aging forums and were further discussed and developed by the Advisory Committee. We offer them as values-based commitments about how CLBC intends to proceed. While they are congruent with the values of CLBC and the general principles of the community living sector, we see them as particularly critical as individuals and their families age. CLBC embraces these as the foundations - the building blocks - of the *Strategy on Aging*.

We believe that:

1. Rights and values matter

Education, advocacy, and innovation are required to ensure that people with developmental disabilities continue to live in community as they age, with access to the same rights, choices and treatments as everyone else. Collective vigilance and leadership are needed to sustain the vision and values of community living and resist both discrimination and any movement back to institutions.

2. This is a shared responsibility

CLBC does not have the sole responsibility or capacity to provide all the supports and services individuals with developmental disabilities will need as a result of aging. Proactive partnerships and positive collaborations with families, other government agencies, service providers, community professionals and community senior-serving organizations are required to develop a shared and holistic community capacity to ensure that people age with safety and dignity, as contributing members of our communities.

3. It's as much about families as well as individuals

Families and extended families need to be supported in their long-term roles as caregivers and key emotional and financial supporters of their family members, as they all age. Their legitimate concerns, worries and needs deserve to be recognized and addressed. Families need to have peace-of-mind, trust and faith in a future where their loved ones will be safe and well-supported after they are no longer able to care for them or they themselves pass away.

4. Relationships are key

A sense of safety, emotional connection, and belonging becomes increasingly important as people age, and their families and friends reach the end of their lives. Supporting existing relationships among caregivers and extended families, and expanding personal support networks are both critical to ensuring that individuals have people in their lives who love them and who can safeguard their well-being as they get older.

5. Responsive and proactive planning is essential

Flexible and timely service responses and proactive age-appropriate planning are needed to ensure that people do not end up in crisis situations. Both planning and services need to be collaborative, values-based, and rooted in best practices. This applies at both the individual level, where a person-centred approach must honour the voice and dignity of each individual; and at the organizational level, where service responses need to be integrated, flexible and collaborative.

A Word about Language

Here is how we use some key words in this document:

We use the term **family** to refer to the whole range of how different cultures may think of their families. Family may include extended family members such as uncles or grandmothers. It may also include people who are not technically related, but who think of themselves as family to each other.

We use the term **individuals who are aging** to refer to people with developmental disabilities who are eligible for CLBC services and are aged 55 or over. On occasion, this may also include people under age 55 who experience early onset of aging-related challenges. In this case, this *Strategy on Aging* may help inform services and supports for them, even if they are under 55 years old.

See the Glossary (Appendix B) for more definitions.

5. Strategic Approach

This section sets out the differences we intend to see as a result of successful implementation of CLBC's *Strategy on Aging*. These are the broad brush strokes of how we intend to move forward – the details will come later in the workplan.

We analyzed the information collected through community engagement and organized it using the domains and outcomes from the *Quality of Life Framework*.¹ This essentially puts an aging lens onto the *Quality of Life Framework* – linking the eight domains to specific challenges related to aging. While there is necessarily some overlap among these domains as they affect aging, they serve as a useful way to organize our thinking – in terms of expected impacts on the quality of life of the individuals we support and their families.

The tables on the following pages set out the current situation and challenges under each domain, and then the key differences we intend to make.

Eight Domains of the Quality of Life Framework

Independence

- Personal Development
- Self-Determination

Social Participation

- Inter-personal Relations
- Social Inclusion
- Rights

Well-being

- Emotional Well-Being
- Physical Well-being
- Material Well-being

While some of these changes and improvements can be made directly by CLBC, many will require collaborative efforts with service providers, families, government ministries, community organizations and others. CLBC intends to play a leadership role – bringing people together, sharing information and resources, promoting research, raising awareness, building partnerships and modeling and facilitating change.

One particular focus for collaboration will be with the Ministry of Health, with regard to the health-related needs of aging individuals with developmental disabilities, as required by both the *Deputy Ministers Review of CLBC (2011)* and the *CLBC Strategic Plan 2012/13 – 2014/15*.

¹ Quality of Life is an internationally validated framework adopted by CLBC as a tool to measure and improve service quality. It has expected outcomes in eight domains that affect an individual's life, and uses individual surveys to collect data that can be used to monitor and improve services.

Domain #1: Personal Development

Quality of Life Outcomes:

- Individuals pursue their interests
- Individuals have opportunities for personal growth and skill development
- Individuals have access to necessary information and support

Current Situation/Challenge	Difference We Want to Make
<p>Many individuals are not aware of or prepared for the personal challenges and opportunities for learning and growth related to aging that they will face. For instance:</p> <ul style="list-style-type: none"> • Retirement activities and lifestyle choices • Role as an elder • Opportunities for life-long learning • Grief and loss • Death and dying 	<ul style="list-style-type: none"> ■ Individuals who are aging and their families/caregivers have access to information and resources about the personal challenges and opportunities that accompany aging. ■ Individuals who are aging have age-appropriate opportunities to grow, learn and make contributions throughout their lives.

"I'm ready to retire from my job. I'd like to stay active and involved in my community. How do I find out about volunteer activities? "

(Comment from an adult with a developmental disability at an Aging Forum)

Domain #2: Self-Determination

Quality of Life Outcome:

- Individuals make decisions in their lives about things that matter to them

Current Situation/Challenge	Difference We Want to Make
<p>The current individual support planning process is not specific to aging individuals and does not explicitly contemplate or anticipate many of the life decisions they will face. For example:</p> <ul style="list-style-type: none"> • Health care decisions • Financial planning • Retirement planning • Estate planning • End-of-life care planning <p>The planning process is not set up specifically to anticipate or facilitate active participation by aging individuals, or the skills or accommodations they may need to continue to be self-determining to the full extent of their capacity.</p> <p>Many aging individuals and their families/caregivers are not aware of the impact that aging will have on their planning and decision-making. Others are concerned that assumptions and decisions that affect them are being made without their active participation or knowledge.</p> <p>Unanticipated/unplanned changes in individuals' lives often result in crisis-driven responses that are not optimal.</p>	<ul style="list-style-type: none"> ■ Individuals who are aging and their families/caregivers have access to planning tools and practices that: <ul style="list-style-type: none"> <input type="checkbox"/> Support proactive, person-centred planning <input type="checkbox"/> Are specific to aging <input type="checkbox"/> Are in clear, plain language <input type="checkbox"/> Help people navigate the changes that aging brings <input type="checkbox"/> Are appropriate to an individual's Aboriginal or cultural heritage <p>They are supported in an age-appropriate way to learn about and use these tools in ways that are meaningful to them and their own self-determination.</p> <ul style="list-style-type: none"> ■ There are flexible and innovative funding options in place that can respond to changing life circumstances and service demands, and offer alternatives to emergency crisis responses. ■ Service responses are sensitive to the Aboriginal or cultural heritage and values of aging individuals.

Domain #3: Interpersonal Relations

Quality of Life Outcome:

- Individuals have meaningful relationships with family and friends

Current Situation/Challenge	Difference We Want to Make
<p>Individuals may experience loss of a sense of belonging, connection, safeguards, and dignity as a result of age-related changes. They lose consistency and continuity of relationships when their family/caregivers and/or friends die or become unable to care for them, or when they have to move or change long-established routines.</p> <p>Both seniors and people with developmental disabilities are already vulnerable to social isolation and marginalization. They often have trouble dealing with loss of family and friends, transition to a new place to live, and forming new relationships. For seniors with developmental disabilities, this vulnerability is multiplied. People living with multiple disabilities or challenges with behavior or communication often face especially enhanced vulnerability.</p> <p>Families/caregivers also become vulnerable as they age. Their capacity and needs change. Especially where the family/caregiver is the sole or main support network of the individual. This can result in complex and changing roles and relationships – when for example, a middle-aged individual with developmental disabilities becomes a caregiver for her aging parents.</p> <p>Support networks can become fragile and vulnerable if a key person gets ill, moves away or dies. The network becomes less able to support the person with developmental disabilities – at precisely the time when he likely really needs that support.</p>	<ul style="list-style-type: none"> ■ Individuals who are aging and their families/caregivers have natural and personal support networks that are: <ul style="list-style-type: none"> <input type="checkbox"/> Wide <input type="checkbox"/> Strong <input type="checkbox"/> Adaptable <input type="checkbox"/> Resilient <input type="checkbox"/> Diverse <input type="checkbox"/> Appropriate to their age and stage of life <input type="checkbox"/> Inclusive of people experiencing similar challenges <input type="checkbox"/> Appropriate to an individual's Aboriginal or cultural heritage <p>These networks reflect a wide diversity of family, extended family, friends and community members.</p>

"I always thought that my son would join me in the retirement home when we cannot live in our house anymore. Now I'm not so sure that is the best choice for him. I don't want to lose our relationship if we are living separately."

(Comment from a parent at an Aging Forum)

Domain #4: Social Inclusion

Quality of Life Outcome:

- Individuals participate in community life in roles they and society value

Current Situation/Challenge	Difference We Want to Make
<p>Individuals with developmental disabilities who are aging have difficulty accessing community services – including transportation, social activities and recreation.</p> <p>Community senior-serving agencies (seniors' centres, activity clubs etc) currently have limited interaction and experience with people with developmental disabilities. There are attitudinal and physical barriers to accessibility for individuals with developmental disabilities.</p> <p>Individuals who are aging may also face barriers in their existing homes and/or community living services, such as:</p> <ul style="list-style-type: none"> • Physical accessibility • Limited staff/caregiver skills and knowledge related to aging • Lack of access to medical supports or aids • Lack of sensitivity to cultural needs related to aging <p>Activity and employment patterns change, as people retire, work less, stop participating in their usual daily activities, switch to volunteering, or stop working or volunteering entirely. This changes their social visibility and roles.</p>	<ul style="list-style-type: none"> ■ Community senior-serving agencies have the capacity and support they need to welcome and include aging individuals with developmental disabilities, and respond to both their specific needs and the gifts they have to offer. ■ Community services such as recreation, transportation etc are knowledgeable about and able to respond to the specific needs of aging individuals with developmental disabilities. ■ Individuals who are aging make useful contributions and play valued roles as elders, role models and mentors in their communities and for younger people with developmental disabilities. ■ Community living services and families/caregivers have tools and resources to support the appropriate continued participation of individuals who are aging in community life.

Domain #5: Rights

Quality of Life Outcomes:

- Individuals have autonomy
- Individuals' decisions are respected

Current Situation/Challenge	Difference We Want to Make
<p>Individuals with developmental disabilities who are aging, like others with 'labels', face discrimination, accessibility or attitudinal barriers, and ageism, when accessing services of all kinds. They often do not have the knowledge or support they need to recognize and address such violations of their rights.</p> <p>Individuals and families may not be aware of legal and personal rights issues they will face as they age. Existing generic tools and resources to support aging safely and with dignity are not always fully or appropriately used. For example:</p> <ul style="list-style-type: none"> • Advanced care planning tools including representation agreements and advanced directives • Estate planning tools such as wills and trusts • Abuse prevention • Information on palliative care/hospice services • Registered disability savings plan (RDSP) <p>Many family members are not aware that they don't have the legal authority to speak for or provide consent on behalf of their adult child/sibling. This may become problematic as parents themselves age, or a sibling takes over the main support role from a parent. Some agency staff are also not aware of the boundaries of their role in regards to the rights of the people they support. These issues can be particularly challenging where communication styles or cultural/ethnic backgrounds are different.</p>	<ul style="list-style-type: none"> ■ Individuals who are aging are aware of their rights. They have access to the tools they need to navigate the system and to understand and exercise their rights. ■ Families/caregivers and service providers supporting aging individuals understand their role and limitations with regard to the rights of the individuals, and have access to information and resources. ■ There is broad awareness in the community living sector about the existing tools to promote and support the exercise of individual rights. New and unique tools and resources are developed as needed. ■ Community and health service providers respect and honour the right of aging individuals to have the same access to programs and facilities as all citizens.

Domain #6: Emotional Well-Being

Quality of Life Outcomes:

- Individuals feel safe in their home and community
- Individuals have a positive sense of self and trust the people in their lives.

Current Situation/Challenge	Difference We Want to Make
<p>Many individuals who are aging and their families/caregivers have fears and worries, and may not know how to get emotional help and support. This makes them more vulnerable to abuse and neglect. They may even be afraid to report abuse for fear that they will get in trouble.</p> <p>Some families who have been primary caregivers their whole lives are finding it harder as their own needs for respite and other supports change. They are worried about what will happen when they can no longer provide care. They wonder if anyone else will love and care for their family member as they do. Families want peace of mind and a sense of comfort and trust. They want access to supports to enable them to provide care for as long as possible. They need to know there is a safe plan for when they are no longer able to provide care.</p> <p>Families may not trust that service commitments will be honoured. Or that services will respond quickly to sudden age-related changes. Especially as resource allocation decisions are based on current disability-related needs of an individual. Future and aging-related needs are not factored into today's decision-making.</p> <p>Individuals may have their own worries:</p> <ul style="list-style-type: none"> • What will it be like to be old? • Will I have to move? • Will I be a burden on my aging family members? • What will I do after I stop going to my job or day program? • What will happen when my parents pass away? <p>Daily routines and structures that have been in place for a long time start to come apart, and it may not be clear what will replace them.</p>	<ul style="list-style-type: none"> ■ Aging individuals and their families/caregivers trust the service system to support their needs as they age. ■ People working with aging individuals and their families recognize emotional needs related to aging and respond proactively, appropriately and in a way that reduces stigma about seeking help. ■ Planning and resource allocation processes proactively anticipate future needs through an aging transition plan; and can respond in specific, clear, collaborative, creative and timely ways. ■ Individuals who are aging have access to supports to address their fear, worries, loss, isolation or grief, and help them adapt to life changes. ■ Aging individuals are supported to age in the most appropriate and inclusive environments and to maintain emotional relationships/connections. Residential and non-residential services are designed to adapt to age-related changing needs.

Domain #7: Physical Well-Being

Quality of Life Outcomes:

- Individuals are physically healthy and active
- Individuals have access to the health care they need

Current Situation/Challenge	Difference We Want to Make
<p>Individuals who are aging often face challenges related to physical safety, health and mobility. Changes in physical health and function may be sudden or gradual. Sudden changes may result in someone having to change where they live and their entire routine. Or requiring daily personal care that they did not need before. Hearing or vision loss can drastically affect someone’s activities and functioning.</p> <p>Community services for seniors, such as assisted living and residential care, have not planned for supporting individuals with developmental disabilities to date. Consequently, the programs, services and group sizes in these facilities may not be appropriate for the needs of this population. The staff may have no training or experience working with individuals with developmental disabilities. In addition, such service models are reminiscent of earlier institutions for people with developmental disabilities – many individuals may resist being ‘institutionalized’.</p> <p>Individuals are developing more complex care needs and/or dementias as they age. In some cases, individuals with developmental disabilities may develop age-related dementias or other conditions considerably earlier than the general population. Neither the individuals themselves, nor their families/caregivers, may know what to look for – what is ‘typical’ aging for a person with a developmental disability and what is a warning of something unusual.</p> <p>Increasingly, individuals with developmental disabilities under 55 years old are being placed in residential care facilities, due to the early onset of age-related conditions.</p> <p>Respite needs of families/caregivers increase as they themselves get older. Respite is about emotional support and relief as well as a break from the physical duties of care-giving. Some aging parents may not be taking good care of their own physical and emotional needs related to</p>	<ul style="list-style-type: none"> ■ Health care professionals and community resource people, including first responders, have the awareness, capacity and comfort level to support aging individuals and their families in a holistic, values-based and appropriate way. Their training and education prepares them to do this. ■ Health care professionals and community resource people, including first responders, have an understanding of community living and an awareness of the functions, strengths and limitations of community based support systems, and the resources available through Health Services for Community Living (HSL) and Developmental Disabilities Mental Health Services (DDMHS). ■ Flexible service models, including respite, are available to enable families to continue as primary caregivers for individuals as long as possible.

Current Situation/Challenge	Difference We Want to Make
<p>aging. This can lead to burn-out and health issues.</p> <p>Families may not know how palliative care can be appropriately used by aging individuals. Palliative care facilities and staff may not have much experience working with individuals with developmental disabilities and their families.</p> <p>Individuals and families report negative experiences in accessing medical and dental services both in the community and hospitals. For example, reluctance to implant a pacemaker; difficulties getting dental work done with sedation; or discomfort with someone's physical appearance. This can result in reduced access to health care and a lower quality of physical health. It is important that individuals with developmental disabilities have an identified primary care provider attached to them which will promote access to an integrated health care system.</p> <p>As individuals age, they may find themselves in an emergency room more often. Some emergency room doctors and staff may have little experience with individuals with developmental disabilities and may be unaware of an individual's communication style or behavioral challenges. They may not understand the kinds of community living environments that people live in, or the role of HSCL in the assessment, training and monitoring required to support an individual with more complex health care needs. Physicians may discharge people with prescribed medication or treatments that paid caregivers may need support to manage.</p>	<ul style="list-style-type: none"> ■ Individuals with early onset of age-related mental and physical health needs have access to early and appropriate planning and services including attachment to a primary care physician. ■ Individuals who are aging have access to preventative and educational services designed to maintain physical well-being as they get older and to empower them to access the services they need including typical community based services that other citizens may access. ■ Staff and caregivers in CLBC funded services have the awareness, knowledge and skills to successfully support aging individuals with deteriorating physical health and mobility.

"As a firefighter, I am a first responder in many situations. Police, fire and ambulance attendants all need to know about the community resources and services that support people with developmental disabilities because we will meet them, and often in emergency situations."

(Comment from firefighter at an Aging Forum)

Domain #8: Material Well-Being

Quality of Life Outcome:

- Individuals have the financial resources to do the things that are important to them

Current Situation/Challenge	Difference We Want to Make
<p>Many individuals who are aging are not aware of the financial impacts of changes that come with aging and retirement, such as:</p> <ul style="list-style-type: none"> • Loss of employment income • Change from PWD Benefits to OAS/GIS • Receiving an inheritance <p>They may not know who to talk to about this, how to get sound financial planning advice, or what their rights are around financial decisions. Even if they have thought about their wishes and choices for retirement, they likely do not know how to successfully make them happen financially.</p> <p>Families and individuals may not have adequate personal resources to finance home modifications or equipment needs relating to aging. They may not be aware of grants or funding sources to help address such needs. They may not know what they need to do to plan for their loved one's financial needs after they are gone. They may not know about or use tools such as registered disability savings plans (RDSPs); or have sought advice about vehicles such as trusts.</p>	<ul style="list-style-type: none"> ■ Individuals who are aging and their families/caregivers have ready access to support, information and resources to facilitate financial planning for aging, retirement and estate planning.

"My parents have already written their wills, set up a trust for me and told me about the plans they have in place for my support after they die. I feel so relieved to know what is going to happen. I'm glad they talked to me and were really honest about these things. It helped so much to know."

(Comment from an adult with a developmental disability at an Aging Forum)

Appendix A: Members of CLBC Advisory Committee on Aging

Current Members

Lorie & Dave Sherrit	Self-advocates	Individuals who are aging
Mary Valeriote	Family member	Parent and past member, CLBC South Island Community Council
Marie Sabine	Family member	Parent and member, CLBC Provincial Advisory Committee
Karen DeLong	Community	BC Association for Community Living
Kim Lyster	Community	Consultant and community member
Jane Holland	Community	Advocate for Service Quality (MSD)
Cynthia Roling	Service provider	Milieu Family Services
Helen Stovell	Service provider	Community Ventures Society
Mitchell Temkin	Service provider	Garth Homer Society
Dr. Brian Plain	Health sector	Retired Physician. and Medical Health Consultant
Elisabeth Antifeau	Health sector	Home Health Practice Lead, Populations Community Integration Health Services, Interior Health
Lynn Turner	Health sector	BC Hospice and Palliative Care Association
Sally Martin	Health sector & service provider	Richmond Society for Community Living Board member and retired Health Branch Manager
Marilyn Pawson	Health sector	Health Service for Community Living Nurse - Vancouver Coastal Health
Nancy Jokinen	Academia	Assistant Professor, UNBC School of Social Work
Nina Magee	CLBC	Manager of Quality Services - Vancouver Coastal
Meaghen Taylor-Reid	CLBC	Facilitator – Simon Fraser
Jessica Humphrey	CLBC	Self Advocate Advisor – Provincial
Lynn Davies	CLBC	Director of Regional Operations – Interior
Soheila Ghodsieh	CLBC	Manager of Community Planning & Development – Simon Fraser
Sylvie Zebroff	CLBC	Family Partnership Advisor - Provincial
Tracey Michell	CLBC	Aboriginal Advisor – Provincial
Jule Hopkins (Chair)	CLBC	Manager of Service Accountability and Safeguards

Past Members

Kay Johnson	Health Sector	BC Hospice and Palliative Care Association
Jenny Lau	CLBC	Facilitator – Simon Fraser
Bonnie Wilson	Health sector	Vancouver Coastal Health

Appendix B: Glossary

Ageism

Discrimination towards persons of a certain age group.

Attitudinal Barriers

Attitudes, fears, and assumptions that prevent people with developmental disabilities from meaningfully interacting and participating within their community.

Caregiver

A person, paid or unpaid, who has accepted responsibility in providing care and support for someone with a developmental disability.

Community Engagement

The process of individuals and organizations building on-going relationships for the purpose of applying a collective vision, usually involving change, for the benefit of a community.

Community Living British Columbia (CLBC)

A provincial crown agency mandated under the *Community Living Authority Act* that delivers supports and services to adults with developmental disabilities and their families in British Columbia.

De-institutionalization

The process of closing down large institutions that provided care for people with developmental disabilities based on a medical model, and replacing them with community-based services that focus on inclusion and participation in community.

Dementia

Deterioration of intellectual functioning, such as memory, concentration, and judgment, resulting from a natural disease or a disorder of the brain, and often accompanied by emotional disturbance and personality changes.

Developmental Disabilities Mental Health Services (DDMHS)

A service provided by health regions for adults with developmental disabilities who have complex mental health needs. DDMHS provides psychiatric and behavioural assessments, as well as treatment, therapies, education and support for families/caregivers.

End-of-Life Care

Clinical and support services appropriate for dying people and their families. The goal of end-of-life care is to provide the best quality of life for dying people and their families.

Estate Planning

The process of making a will and other legal arrangements for what will happen to your money, possessions and dependents after you die, or if you become incapacitated.

Guaranteed Income Supplement (GIS)

A monthly payment, on top of the Old Age Security pension, paid by the federal government to low-income seniors living in Canada.

Health Services for Community Living (HSCL)

A service provided by health regions for adults with developmental disabilities who have complex health care needs and are living in community. HSCL staff help develop care plans and provide training and support for families and caregivers to provide certain types of nursing care tasks for a particular individual.

Holistic

An approach where all aspects of people's needs (psychological, physical, emotional, spiritual and social) are seen as a whole.

Inclusion

A sense of being welcomed, accepted and recognized, of belonging to a diverse group or community, in economic, social, and cultural aspects.

Marginalization

A situation where someone is treated as insignificant, or as of less importance than others, and has less influence or power as a result.

Old Age Security (OAS) Pension

A monthly allowance paid by the federal government to Canadians who are over the age of 65 and have lived in Canada for at least ten years.

Palliative Care/Hospice

Holistic physical, emotional, social and spiritual care provided in order to improve comfort and quality of life for a person who is dying or is living with an advanced illness.

Person-Centred Planning

The process of defining and exploring an individual's unique goals, dreams, strengths, abilities, gifts and needs, as a basis for setting goals and making decisions about their life. The process and result of person-centred planning is owned and controlled by the individual, and sometimes their family and/or support network. The format used and the range of people involved may vary widely, depending on the wishes of the individual. Person-centred planning is an important part of supporting individuals with developmental disabilities to live good lives in welcoming communities.

Persons with Disabilities (PWD) Benefits

A provincial government program that provides a monthly allowance, and other benefits (e.g. bus passes, extended medical and dental coverage, prescription glasses and medications, and medical service plan (MSP) coverage) for adults living with physical or mental disabilities. Depending on specific conditions, individuals may also be eligible for additional benefits such as nutritional or diet allowances, medical supplies or equipment.

Registered Disability Savings Plan (RDSP)

A savings plan that helps parents or individuals save for the long-term financial security of an individual with a disability.

Representation Agreement

A legal plan that states who an individual gives authority to if he/she needs assistance managing his/her affairs. A representation agreement can cover financial and legal matters and health and personal care matters.

Respite

A support to provide relief to a caregiver, family member or home sharing provider, so they can get a break from their care-giving responsibilities for an adult with a developmental disability.

Safeguards

Deliberate actions that help an individual to be safe in the community, to take advantage of opportunities and to prevent bad things from happening. Safeguards help reduce an individual's vulnerability while ensuring they can reach their goals.

Self-advocate

A term commonly used to describe the individuals CLBC supports.

Social Isolation

A situation where an individual or a group has little or no contact, communication, relationship or interactions with others in a community.

Stigma

A sense of disgrace, shame or social disapproval associated with particular personal characteristics or needs.