

Report from the Roundtable On Aging



April 2022



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Introduction

Individuals with intellectual disabilities continue to live longer and longer lives. Happily, people living into their sixties and seventies is now much more commonplace; a testament to the success of established community based services and supports. In a milieu where most people who are eligible for CLBC services live with parents, and where there is a disproportionate number of individuals who are in the 19 – 30 years age group, there are numerous implications to consider with respect to services and supports for people as they age.

The Origins of CLBC's Strategy on Aging

Anticipating the need to determine what the needs of older adults would be, CLBC initiated a public consultation process to welcome input from diverse voices. Between the fall of 2010 and June of 2011, thirty-nine forums were conducted throughout the province. This first series of consultations attracted over 1200 participants: a broad range of individuals including families, self-advocates, health care providers, senior-serving community organizations, academics, partner agencies, municipal representatives, and staff from both CLBC and service providers.

Several overarching themes emerged from these initial aging forums which were further discussed and validated by an Advisory Committee. These themes represent the values-based commitments adopted by CLBC that have guided all the work since. 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 has embraced these as the foundations - the building blocks - of the *Strategy on Aging*. See [CLBC's Strategy on Aging](#).

CLBC and Ministry of Health Three-year Action Plan

Concurrently, CLBC activated a special focus with the Ministry of Health and collaboratively developed: *CLBC and Ministry of Health Three-year Action Plan: A Collaborative Approach to Supporting Aging Adults with Developmental Disabilities* in 2013/14.

Work to date

Work continued following the creation of the Strategy on Aging. Highlights of the work to date include:

- Community forums on best practices in aging: events with individuals, families, and service providers to shine a spotlight on and learn from local promising practices and from which subsequent resources were developed.
- Research and publication of the resource [*Looking Forward to the Future: Supporting Individuals with Developmental Disabilities as they Age*](#) - a book of stories about strategies and experiences people have created to promote positive outcomes for individuals with developmental disabilities as they age.
- The launch of the **Aware Share Care** website with resources for individuals, family members, and health care practitioners. The website www.AwareShareCare.ca provides

helpful tips and resources to assist in better planning for aging, with a section focused on supporting health care professionals.

- Publication of the resource [*Aging with a Developmental Disability: A planning guide for families, personal support networks and other supporters of adults with developmental disabilities who are getting older*](#)
- [*Aging Parents / Caregivers Pamphlet*](#) – a short introduction for aging parents and caregivers about planning with their family member.

A significant piece of planning to support people who are aging and the work of CLBC staff was completed in 2018. The guide, called ***Planning with Aging Adults: A Tool for CLBC Staff***, provides not only support to initiate conversations but addresses an important safeguard in planning with adults by establishing formal check-ins with individuals at age 55 and 63 to ensure thoughtful and proactive preparation is incorporated into the person centred plans.

In 2020, CLBC undertook a review and subsequent refinement of their forecasting model to enable more accurate projections of the future demographics of people that the CLBC serves. Appendix A To solicit feedback, the results of the forecasting completed was presented to a diverse audience including CLBC staff, service providers, family members, allied community organizations and advocates, and individuals with developmental disabilities. The Roundtable was originally scheduled for April 2020. Due to COVID restrictions, the event was delayed and conducted virtually in September 2020.

Unfortunately, efforts to ensure participation by self-advocates as part of the September Roundtable were not as successful as hoped. In order to ensure the experience and input of individuals from the various regions in the province was included, a second session specifically for self advocates, was convened in the winter of 2021.

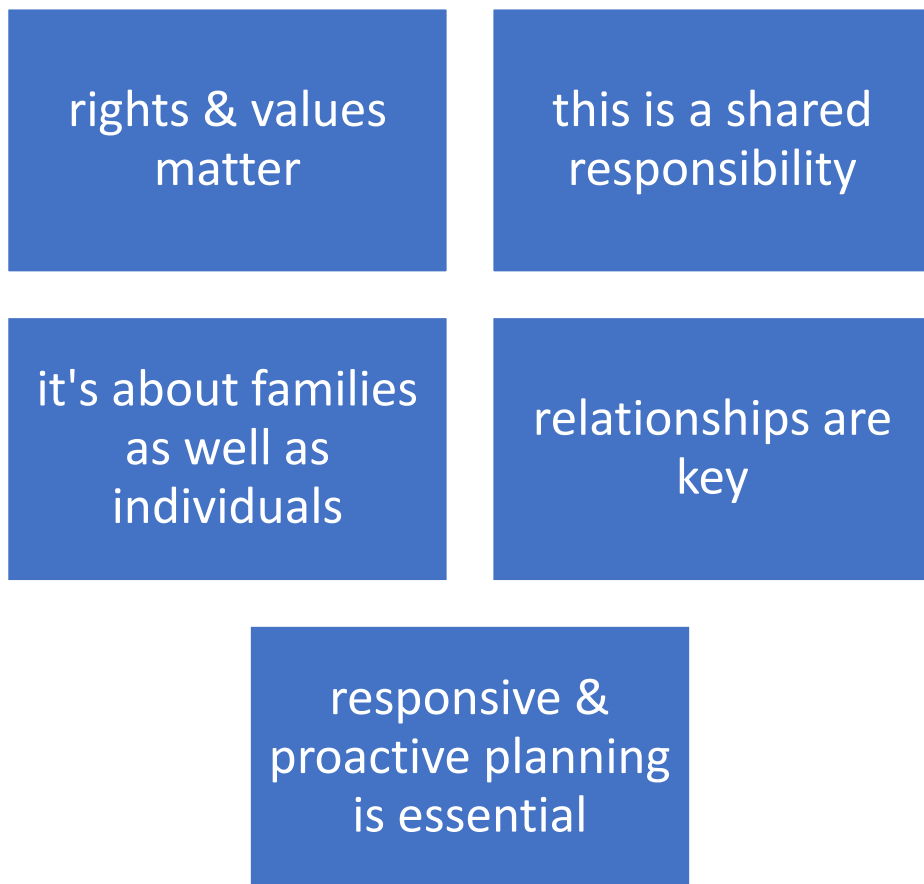
The purposes of the Roundtable consultation were:

- to present the forecasting information,
- solicit feedback on the data,
- apply the information to the analysis of issues impacting older adults with intellectual disabilities,
- explore collaborative opportunities to support people who are aging, both within and with allies outside the community living sector, and,
- receive recommendations for next steps.

The session with self advocates was co-designed and co-facilitated by three individuals with diversabilities. The input received from the participants provided the privilege of receiving more personal perspectives on the experience of those aging, what matters in terms of support, questions people have, and resources that have proven helpful or areas where additional information would be valued.

Foundational Values and Beliefs

CLBC's Aging Strategy is based on the following foundational **Values** and **Beliefs** which continue to guide the strategic directions for the future. The themes from the consultation aligned with these core beliefs and the strategies to promote and sustain an optimal quality of life for older adults.



What Supports Optimal Quality of Life for Individuals as they Age?

Themes from the Roundtable were analyzed to highlight the necessary conditions which must be in place to support optimal quality of life for individuals as they age. The themes fell into three broad areas:

- proactive, person centred planning
- system level planning and capacity building
- strengthening community alliances and partnerships

The suggestions, which were offered from the participants in both consultations, are grouped according to these themes.

1. Proactive, Person Centred Planning:

The feedback from the Roundtable emphasized the need to actively incorporate thoughtful conversations and intentional planning for later life to safeguard quality of life for individuals. These conversations, while often considered sensitive and perhaps uncomfortable to initiate, are regarded as necessary to fully understand and honour the wishes, needs, and plan for potential supports that might be required. The conversations must involve the individual, their family and support network, service provider, and community professionals. While some families and individuals have done thorough and proactive planning, all too often it has been delayed and/or avoided potentially leading to crises when dramatic health events occur, or a parent or caregiver dies suddenly.

Recommendations:

With and for individuals and their families and supporters:

- Enhance knowledge of resources, planning, etc. for individuals - self advocates need and want to be part of the conversation as self determining participants in their life planning.
- Support knowledge and participation with resources (plain language, videos, infographics, etc.) that provide helpful information for individuals and their circle of support. Topics should include: grief, loss, aging, making your wishes known, supported decision making, etc.
- Create a focus on enhancing supported decision making opportunities and strategies as part of a continuum of planning options v. moving solely and/or immediately to Representation Agreements.
- Support peer mentorship initiatives to sustain the conversation and broaden the reach of peer to peer connections in a leadership role on late life planning and supports.
- Facilitate transition planning, from age to age, with a focus on examining vulnerabilities as people age, considering both formal and informal safeguards, and anticipating and accessing supports.

Among service providers:

- Continued investment in proactive conversations/training and sharing of ideas about person centred planning that honours and holds the person's story, reduces the potential for diagnostic overshadowing, prevents the premature intrusion of medical involvement, reflects their wishes and needs, their personal support network, and encompasses a whole life focus. Ensure the person served and their supporters are supported to fully participate in the important conversations about later life and end of life wishes during planning.
- Develop competencies of personnel in response to this new area of skills and competencies. Emphasize training on health needs, Advanced Planning, Personal Assistance Guidelines, later life planning and supports, end of life care, roles and responsibilities, and facilitation of safeguards including personal support networks.
- Share tools and planning resources among service providers to support best practices in planning for later life.
- Consider convening support groups for individuals and senior parents to encourage conversations about late life planning.
- Develop policy and procedures re: late life planning, supports, and service provider roles and responsibilities to guide personnel.
- Re-establish conversations about safeguards and vulnerability – mandatory, multi-level safeguards are needed to promote social networks, personal supports, prevent neglect and abuse.

Within CLBC:

- CLBC's ***Planning with Aging Adults: A Tool for CLBC Staff*** resource is currently maintained as an internal only document for personnel of CLBC. It would be helpful to roll it to the service provider community, families, and individuals to support their understanding of the intent and application of the resource and welcome their active participation in utilizing the tool.
- Case management approaches should be implemented to build wrap around supports in planning for older adults, when appropriate e.g. involving medical community, aligned professionals such as physio, OT, pharmacists, CLBC analysts, and others.
- CLBC analysts engaging with their service provides on the topic of aging adults, as it pertains to aging strategies and the direct needs of individuals.

2. System Level Planning and Capacity Building

The feedback from the Roundtable also emphasized the importance of broad system level planning and capacity building actions to augment and sustain optimal quality of life for individuals with developmental disabilities. For CLBC, this involves maintaining work in forecasting needs, cross ministerial protocols, and policy development.

Recommendations:

Among service providers:

- Activate internal forecasting regarding age cohorts that the provider is serving e.g. age cohorts, changes in health, housing, and support needs. Host conversations with younger cohorts of individuals to obtain their input on future needs and design creative options (the future won't necessarily look the like past), people are not going to demonstrate growing older in the same way nor have the same support needs.
- Incorporate supports needed by older adults into organizational strategic planning, accessibility planning, technology, etc. These will also align with accreditation planning requirements.
- Invest in community building work to build alliances with local organizations who are supporting seniors including: Alzheimer's Society, Caregivers Networks, Senior's Drop-In groups, etc. and enhance their awareness of the needs of seniors with developmental disabilities.
- Communicating strategies for people who are aging or similar plans with the involved CLBC analyst.

Within CLBC:

Data:

- Continue to enhance the depth and scope of forecasting work by the CLBC including: planning for those not currently receiving services, confirmation of the anticipated numbers, a regular schedule for updating, and consultation with younger individuals about their expectations as they age.
- Families need support as well as individuals – it is important to generate data on parents in the 70-85 age range who are primary carers for sons and daughters and/or siblings who are aging and caregiving. These individuals may not know about CLBC and where to get information.
- Analyze the alignment between CLBC and Health data to assess gaps, capacity issues, and highlight areas where further information is required.
- Work with BCANDS to ensure the data is inclusive of Indigenous persons, their age cohorts, and potential support needs.

Research:

- Support innovation in housing, services, and supports with targeted funding, pilot projects and research on creative options to maintain quality of life in community as individuals age. Conduct research into what other jurisdictions are doing to promote innovation and dignity in older years as part of capacity building in the sector.

Cross Ministry Collaboration and Re-Imagining Community Inclusion Table:

- Continue to critical work with Ministry of Health to plan alternatives and sustain advocacy for individuals with developmental disabilities and provide seamless services when needed including Primary Care Network Development. E.g. what is disability

related v. health related. Dr. Behn Smith has played a critical bridging role during the pandemic which should continue.

- Incorporate people who are aging within the Reimagining Community Inclusion work. Ensure a key role for service providers to enact the directions from this work – provide meaningful funding to enable success.
- Ensure that Black, Indigenous and People of Color (BIPOC) representation is included to facilitate cultural sensitivity and responsiveness.
- Explore if a provincial medical consulting program would assist with addressing complex health concerns.
- Ensure accountability by BC Housing in supporting long term housing options that sustain access, mobility, and increase the range of choices available e.g. cluster housing, coopers, supported living. Younger people are wanting different things in their future than perhaps their parents might.
- Inclusive Housing Task Force work should ensure that supports for individuals as they age is a focus of the planning.

Regional Leadership:

- Explore how the regional structure within CLBC can be leveraged to sustain a provincial focus – create champions within each Director of Regional Operations (DRO's) area of responsibility and then link with existing networks from other organizations e.g. FSI, PLAN, Vela, etc. to sustain conversations about aging adults and implement best practices.
- Planning has to factor in both rural and urban access and responses – nursing support, hospice, palliative care is not as available, if at all, in smaller communities and some rural areas of the province. Regional leadership encompasses both rural and urban centres.

Capacity, Policy, and Strategic Planning:

- Ensure that the topic of aging adults is sustained as a focus within CLBC by incorporating into the strategic plan and confirming a lead contact person who can continue outreach and maintain connections with allies.
- Develop policy re: people aging in the right place for individuals served by CLBC to prevent moves into long term care facilities. Past traumas must be taken into account – we cannot retraumatize people who have already survived institutions.
- Continue engagement with Indigenous communities to promote their leadership, guidance, and capacity with respect to supports to their elders with developmental disabilities.
- Re-establish conversations and leadership re: safeguards and vulnerability – multi-level safeguards are needed to promote social networks, personal supports, prevent neglect and abuse.
- Review Youth Transition Protocol and develop similar support to transition protocols for senior hood.
- Review the Welcome to CLBC workshops to incorporate the topic of aging.

- Examine how the Quality of Life (QOL) framework considers the needs of older adults. What are the metrics for this cohort and are there others which should be considered?

3. Strengthening Community Alliances and Partnerships

Feedback from the Roundtable emphasized the necessity of building a deeper understanding of the needs and interests of older adults with developmental disabilities among community organizations already aligned with seniors' causes. Strengthening alliances and partnerships can and should occur at the local, regional, and provincial level.

Recommendations:

- Broad, sector wide advocacy is needed to help ensure government funding decisions prioritize the needs of seniors with developmental disabilities – we must raise their profile and ensure that the voices of self advocates inform the advocacy process as additional supports are likely to be required and financial capacity to meet the need is not in place.
- Education for community professionals to encourage their awareness and ensure their services meaningfully include people with developmental disabilities e.g. legal community, doctors, notaries, palliative care, hospice organizations.
- Align with United Way Healthy Aging CORE work. They host webinars on a regular basis and are always looking for new organizations to partner with. Their HUB is a location to share resources.
- Caregivers of BC is receiving requests for information from a variety of caregivers, including families who have a loved with a developmental disabilities. Look for ways to align and support one another.
- Work with NIDUS and the PGT to determine opportunities for education and supported decision making.
- BC CEO Network hosts regular professional development days and brings up to 125 people to these sessions from around the province. Ideal opportunity to host panels, share information, and best practices.
- BC Community Response Networks provide leadership in preventing abuse, neglect and self neglect and are operating in communities around the province.
- Inclusion BC is providing leadership on an Inclusive Housing Plan where the topic of aging could be a focus. Also linked to Inclusion Canada and can bring information from across the country.
- Vela, FSI, PLAN are all interested in this conversation and can provide regional links and connections. PLAN establishing a peer mentoring program and has information and resources on planning as part of their advocacy role.
- Follow up with leaders in the self advocacy movement (BC Peoples First and other groups) to support their knowledge and advocacy.
- Is there a partnership possible with the Senior's Advocate to incorporate issue impacting seniors with developmental disabilities in her role? Does the Advocate for Service Quality provide advocacy in this area?

- Centre for Elder Law at UBC is providing leadership on a variety of issues impacting seniors, supported decision making, and the law.

LOOKING FORWARD TO THE FUTURE

A Paper Exploring the Future Supports of Older Adults
with Intellectual Disabilities in BC

March 10, 2020

Vision from CLBC's Aging Plan...

“Older adults with intellectual disabilities are provided with appropriate supports and services to enable them to live healthy and meaningful lives as participating members of their communities.”

Background

Individuals with intellectual disabilities continue to live longer and longer lives; people living into their sixties and seventies is now common place. In a milieu where most people who are eligible for CLBC services live with parents and where there is a disproportionate number of individuals who are in the 19 – 30 years age group, there are numerous implications.

The Successes and Challenges of our Current Context:

The history of formal supports and services for people with intellectual disabilities in BC, has navigated from an era of institutionalization to the development of our current array of community-based services. This shift was accomplished through the sustained advocacy efforts of families, individuals with intellectual disabilities, federated groups, service providers, and other allies. In the period from 1985 to 1996, the four major institutions housing individuals were closed: Tranquille in 1985, Endicott Centre in 1993, Glendale in 1994, and Woodlands in 1996.

The closure of these facilities was concurrent with and stimulated by the evolution of attitudes about people with intellectual disabilities via concepts such as normalization and social role valorization. Continued advocacy has supported improvements in health care resources, living conditions, and access to employment opportunities, all of which have enhanced both the quality of and life span of individuals. Self advocacy by people with intellectual disabilities, as part of broader disability rights activism, has further supported societal shifts and social change.

Despite the progress noted, we are at the beginning of our leadership in responding to the needs of individuals with intellectual disabilities as they age. The World Health Organization (WHO) has noted that these individuals are still regarded as a devalued class and experience disadvantages in accessing health and social supports.¹ While the WHO acknowledges that the experience of aging varies depending upon the location, funding, and policy frameworks in place, they also emphasize that work remains, at all levels, to ensure that the continuum of services and supports is available to safeguard people with intellectual disabilities as they age. Further the services and supports provided should confirm that their older years are synonymous with dignity, contribution, good health, and sustained quality of life.

Just as CLBC has developed proactive planning processes to support the transitions youth entering adulthood must navigate, intentional and anticipatory planning must support the transitions associated with the aging process.

Aging as a Person with an Intellectual Disability:

Chronological Definition of Aging: Although 65 years of age is generally accepted as the typical criteria for identifying an individual as an older adult (retirement, OAS, etc.), this is often not appropriate for persons with intellectual disabilities. While many people will age in a manner not unlike their non-disabled peers, several mitigating factors can be present for individuals with intellectual disabilities that impact on the aging process.

Research indicates that, as a group, older individuals with intellectual disabilities have an increased frequency of thyroid and heart disorders, gastrointestinal and respiratory conditions, and sensory

¹ World Health Organization (2000). *Ageing and Intellectual Disabilities – Improving Longevity and Promoting Healthy Ageing: Summative Report*. Geneva, Switzerland: World Health Organization.

impairments.^{2 3} Further, studies in Ontario identified higher rates of poor health outcomes for this population, including premature mortality, which increase with age and stem from ongoing challenges in health care access, treatment, planning.⁴

As a result, and due to pre-existing neurological issues, co-morbid medical conditions, long term medication use, and barriers in accessing appropriate services and supports, individuals with intellectual disabilities may evidence signs of aging earlier than the general population. This is particularly noteworthy for adults with Down syndrome who are more likely to experience precocious aging from about 40 years of age.

Given these factors, it is increasingly recommended by researchers, medical practitioners, and advocates, that the age of 50 should be used to define individuals with intellectual disabilities as an older adult.⁵ While CLBC has not formally adopted this definition in policy, CLBC has been operating in accordance with this practice in recognition of the distinctions between the experience of aging for people with intellectual disabilities, the general population, and the observations of service experience in BC. Establishing and operating from an adjusted chronological age will also assist with proactive planning for CLBC with respect to policy and funding, as well as for families, individuals and service providers who are concerned with accessing and delivering services.

Functional Definition of Aging

While a chronological age of 50 years assists with defining cohorts for planning purposes, assessments of functional abilities provide complementary information that can assist with determining personalized support needs as the person ages. The purpose of the functional assessment is to document the person's current abilities and/or levels of supports in relation to those they have demonstrated throughout their lifetime. This comparative analysis assists with defining support needs, changes associated with aging, potential medical issues that might not be age related, and allow for appropriate safeguards to be put in place. To be of most benefit, a functional assessment combines observation, self-report (wherever possible), and third party input from family, friends, and service providers. It is generally agreed that monitoring changes at a functional level begins with establishing a baseline and then establishing a frequency of review appropriate to the person's unique characteristics.⁶ The Early Detection Screen⁷, developed by the National Task Group on Intellectual Disabilities and Dementia Practices, has been proactively implemented to record this information by several service providers in BC, and tested in a pilot project in the Upper Fraser region by the CLBC team there.

² Calgary Region Community Board: Persons with Developmental Disabilities (2012). *Supports and Services for Older Adults with Developmental Disabilities Study*. Calgary, Alberta. p.29.

³ Stemp, S. (2014). *The Compelling Data on Aging in Residential Resources*. Retrieved from <https://connectability.ca/2013/04/03/aging-and-developmental-disabilities-are-we-prepared/>

⁴ Health Care Access Research and Developmental Disabilities Program (2019). *Addressing Gaps in the health Care Services Used by Adults with Developmental Disabilities in Ontario*. Toronto, Ontario.

⁵ Calgary Region Community Board: Persons with Developmental Disabilities (2012). *Supports and Services for Older Adults with Developmental Disabilities Study*. Calgary, Alberta. p.30.

⁶ Calgary Region Community Board: Persons with Developmental Disabilities (2012). *Supports and Services for Older Adults with Developmental Disabilities Study*. Calgary, Alberta. p.30.

⁷ National Task Group on Intellectual Disabilities and Dementia Practices (2013). *Early Detection Screen For Dementia*. Retrieved from <http://aadmd.org/sites/default/files/NTG-EDSD-Final.pdf>

Life Span and Demographic Projections

By 2021, seniors will form 18% of Canada's population, compared to 12.5% in 2000.⁸ The overall health and wellbeing of Canadian seniors has improved steadily, and life span according to data collated in 2013, puts the average life expectancy at 81.5 years of age.

The rate of developmental disability among Canadians aged 15 years and over in 2001, was 0.5 percent or 120,140 persons. Of these, an estimated 44,770 persons were aged 45-64 and 11,080 are aged 65-74.⁹ Compare this with census data from 2017 and the rate of developmental disability among this same demographic had risen to 5.1% or 315,470 persons.¹⁰ Although information regarding the estimates of persons in the 45-64 and 65-74 age groups is not available in the census data, a reasonable extrapolation from the earlier figures would suggest that the numbers of older adults with developmental disabilities is growing proportionately.

Estimated Prevalence in BC

In 2019, CLBC asked Dr. Hans Krueger, Ph.D. to review its forecasting model. As part of the work, Dr. Krueger also reviewed the literature to attempt to estimate the incidence of individuals with developmental disabilities in BC:

Based on the 2012 Canadian Survey on Disability, there are an estimated 23,440 individuals ages 15 and over living with intellectual disabilities in BC, a prevalence rate of 0.60%. In this survey, an individual is identified as having a “developmental disorder” if the person had been diagnosed with this condition, “regardless of the level of difficulty or the frequency of the activity limitation reported.” At the end of the fiscal year 2012/13, CLBC had 15,568 individuals ages 19 and over eligible for or receiving services, a prevalence rate of 0.42%.

While it is challenging to come up with any level of precision in estimating the prevalence of individuals with DD in BC, the evidence suggests that it may be between 0.4% and 0.6%, but could also be as high as 0.8%. The often quoted estimate of 1.05% likely comes from the 2011 meta-analysis by Maulik and colleagues which is an average figure including DD in children and adults from low-, middle- and high-income countries. The same analysis estimated an overall prevalence of 0.49% when excluding children (i.e. in adults only).

As noted previously, the prevalence rate of individuals ages 19 and over registered for service from CLBC has increased over time, from 0.31% in 2006/07 to 0.54% in 2017/18 (see Table in Appendix A).

For the three year period between April 1, 2016 and March 31, 2019, the average annual prevalence rate of individuals ages 19 and over registered for service from CLBC was 0.53% (see Table 2). The rate is highest in the 19-24 year old age group at 1.54%, decreasing to 1.10% in the 25-29 year old age group and steadily declining with each older age cohort. As noted earlier, mortality rates are higher in the population registered for service from CLBC compared with the general BC population. In the 19-24 year old age group, mortality rates are 3.5 times as high (0.21% in the population registered for service from CLBC vs. 0.06% in the general BC population).

⁸ National Advisory Council on Aging: Public Health Agency of Canada (2004). *Seniors on the Margins: Aging with a Developmental Disability*. Ottawa, Ontario. p. 1.

⁹ Ibid. p. 3.

¹⁰ Statistics Canada. Table 13-10-0376-01 (2017). Type of Disability for persons with disabilities aged 15 years and over, by age group and sex, Canada, provinces and territories.

Caseload Growth and Demographic Trends

It is projected by March 31, 2020 that over 23,000 adults will be registered for CLBC services, an increase of 5.24 percent over the previous year, and 32.2 percent over five years. CLBC expects this growth rate to continue to increase by about 5 percent annually in the short and medium term.

CLBC recently created a long-term forecasting model to predict total caseload and caseload changes over the next 20 years. Longer term forecasting is imperative due to rapid historical caseload growth. The number of BC adults registered for Community Living Services has increased from 6,928 in March 1997 to 22,224 in March 2019. An external review of the model concluded that it is technically accurate, reasonable and defensible, and CLBC has implemented recommendations to enhance its efficacy.

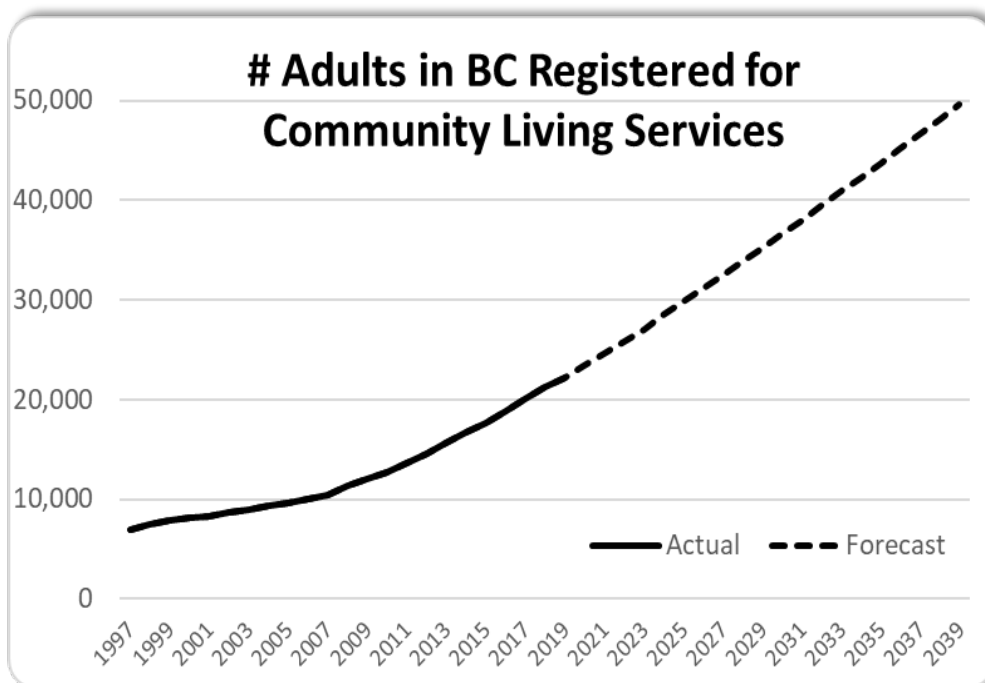


Figure 1. CLBC caseload projected to 2039.

The results of the forecasting model predict ongoing growth in CLBC's caseload over the next 20 years, essentially pushing recent trends into the future, culminating with a predicted caseload of 49,651 eligible individuals by March 2039, an increase of 123% (27,427 individuals).

CLBC's total caseload is impacted by three primary drivers; youth transitioning to adulthood and becoming eligible for CLBC services, older adults registering for service for the first time and discharges due to deaths or moves out of the Province. Over the past five years CLBC has experienced, each year, on average, an increase of 1,114 eligible individuals: 937 transitioning youth; 369 older adults; and 192 discharges. This increased demand for CLBC services is due to several factors including: general population growth; advances in health care and extended life expectancy; increased identification and referral rates of youth to CLBC by the school system; and aging family members who need greater assistance in caring for their adult sons and daughters at home.

While individuals turning 19 are a primary driver of caseload growth, the increasing service requirements that come as individuals age also plays a key role with understanding the service demands. The number of adults registered for CLBC services aged 50 and above is expected to increase from 4,754 at March 2019 to 5,558 at March 2024, 6,522 at March 2029, 7,983 at March 2034 and 10,483 at March 2039.

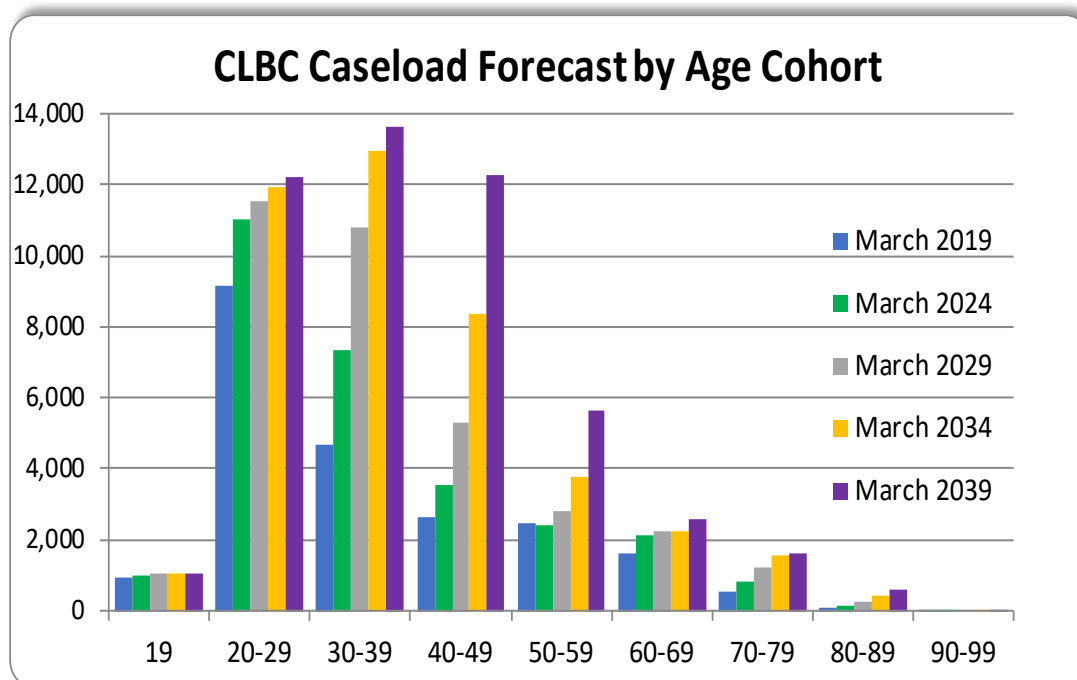


Figure 2. CLBC caseload projected to 2039, by age cohort.

Over the next 20 years the number of individuals aged 20-29 years is expected to increase from 9,162 to 12,189, the number of individuals aged 30-39 years is expected to increase from 4,700 to 13,611 and the number of individuals aged 40-49 years is expected to increase from 2,648 to 12,291.

These changing demographics are noteworthy and, when combined with the lack of research on the topic of aging (particularly in the Canadian context), speak to the necessity of proactivity on the part of CLBC. The importance of forecasting and planning is reinforced by the research of members of the Centre for Inclusion and Citizenship who emphasize that planning is vital to assist with the support issues which will be faced by family caregivers, aging parents whose son or daughter may be living with them, and indeed, the concerns of individuals with intellectual disabilities themselves.¹¹

Improvements in extending the life span of people with intellectual disabilities have been most dramatic in the period since the closure of institutions. At the same time as health care was improving for the general population, people with intellectual disabilities were also experiencing enhanced access to health care and social supports which extended their longevity. The scope of medical interventions for children born with complex disabilities have enabled them to live into adulthood and the design and delivery of community based social services have significantly improved people's quality of life and living conditions.

Although there is no current Canadian data on the life expectancy of persons with an intellectual disability, United States data show that many of those with milder disabilities are living as long as the general population.¹² The happy reality of extended lives will mean that many adults with intellectual

¹¹ Hole, R., Stainton, T. & Wilson, L. (2013) Ageing Adults with Intellectual Disabilities: Self-advocates' and Family Members' Perspectives about the Future, *Australian Social Work*, 66:4, pp. 571-589.

¹² National Advisory Council on Aging: Public Health Agency of Canada (2004). *Seniors on the Margins: Aging with a Developmental Disability*. Ottawa, Ontario. p. 3.

disabilities will now outlive their parents. Planning is of significant concern to these parents as a result and must be a priority in order to honour our societal responsibility to these citizens.

Concurrent challenges and support needs that may exist:

It is important to emphasize that individuals with intellectual disabilities are a heterogeneous community of people. There are, however, some common additional support needs which are present for many people and which may impact on their aging process and support needs. These challenges may include:

- Medical conditions that increase frailty (epilepsy, dysphagia, osteoporosis)
- Mental health concerns (both chronic and emergent)
- Physical disabilities which require monitoring and mobility aids (pre-existing and acquired)
- Unique sensory or communication challenges
- Genetic conditions which increase the potential for dementia (Down Syndrome)

When some or all of these additional personal challenges are present, the importance of anticipatory planning is even more vital. Understanding the prevalence of these conditions and the medical care that will be required in the future is a current gap in our knowledge.

CLBC's Strategy on Aging

Between the fall of 2010 and June of 2011, thirty-nine forums were conducted throughout the province. This initial consultation process attracted over 1200 participants; a broad range of individuals including families, self-advocates, health care providers, senior-serving community organizations, academics, partner agencies, municipal representatives, and staff from both CLBC and service providers.

Several overarching themes emerged from these initial aging forums which were further discussed and validated by an Advisory Committee. These themes represent the values-based commitments adopted by CLBC that have guided all the work since. 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 has embraced these as the foundations - the building blocks - of the *Strategy on Aging*. See [CLBC's Strategy on Aging](#) or Appendix C for more detail.

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Concurrently, CLBC activated a special focus with the Ministry of Health and collaboratively developed: *CLBC and Ministry of Health Three-year Action Plan: A Collaborative Approach to Supporting Aging Adults with Developmental Disabilities* in 2013/14. See Appendix D for more detail.

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Work continued following the creation of the Strategy on Aging. Highlights of our work to date include:

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- Research and publication of the resource [Looking Forward to the Future: Supporting Individuals with Developmental Disabilities as they Age](#) - a book of stories about strategies and experiences people have created positive outcomes for individuals with developmental disabilities as they age.
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- Publication of the resource [*Aging with a Developmental Disability: A planning guide for families, personal support networks and other supporters of adults with developmental disabilities who are getting older*](#)
- [*Aging Parents / Caregivers Pamphlet*](#) - informs aging parents and caregivers about planning with their family member.

A significant piece of planning to support aging and the work of CLBC staff was completed in 2018. The guide called *Planning with Aging Adults: A Tool for CLBC Staff* provides not only support to initiate conversations but addresses an important safeguard in planning with adults by establishing formal check-ins with individuals at age 55 and 63 to ensure thoughtful and proactive preparation is incorporated into the person centred plans.

Most recently, CLBC undertook a review and subsequent refinement of CLBC's fore-casting model to enable more accurate prediction of future demographics of people that CLBC serves.

APPENDIX A. DEMOGRAPHIC PROJECTIONS FOR CLBC ELIGIBLE INDIVIDUALS

1. CLBC Caseload, by those eligible for PSI and Developmental Disability eligibility streams, as of December 31, 2019.

AGE COHORT	DD	% OF TTL	PSI	% OF TTL	TOTAL	% OF TTL
19	811	3.9%	201	9.3%	1,012	4.4%
20-29	7,902	37.8%	1,585	73.4%	9,487	41.1%
30-39	4,721	22.6%	263	12.2%	4,984	21.6%
40-49	2,656	12.7%	71	3.3%	2,727	11.8%
50-59	2,397	11.5%	29	1.3%	2,426	10.5%
60-69	1,726	8.3%	7	0.3%	1,733	7.5%
70-79	568	2.7%	2	0.1%	570	2.5%
80-89	123	0.6%	0	0.0%	123	0.5%
90-99	14	0.1%	0	0.0%	14	0.1%
TOTAL	20,918	100%	2,158	100%	23,076	100%

2. Number of CLBC Eligible Individuals by Age

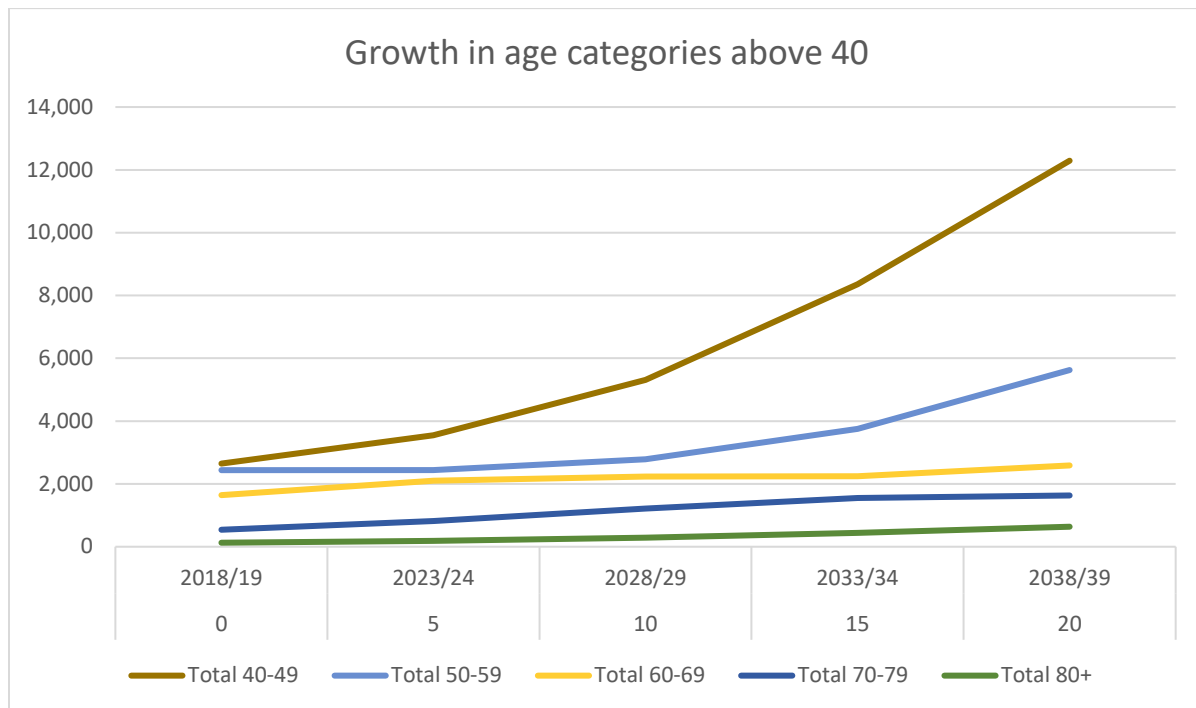
AGE COHORT	FY 2018/19	FY 2023/24	FY 2028/29	FY 2033/34	FY 2038/39
19	960	1,011	1,039	1,060	1,077
20-29	9,162	11,028	11,559	11,930	12,189
30-39	4,700	7,361	10,799	12,974	13,611
40-49	2,648	3,546	5,313	8,362	12,291
50-59	2,442	2,441	2,789	3,748	5,625
60-69	1,643	2,104	2,233	2,247	2,588
70-79	541	823	1,214	1,547	1,632
80-89	114	174	266	408	592
90-99	14	16	19	33	45
Grand Total	22,224	28,503	35,232	42,310	49,651

The number of individuals in the 20-29 age group is nearly twice that in any of the other age groups. This bulge, obviously moves forward over time and begins to impact the number of people in the 30-39 age group in five years and the 40-49 age group in ten years. Although people might be expected to remain with families until they are 30, certainly in the following years they will be preparing for, if not moving away from the family home. This has the implication of triggering more expensive residential costs and options. The average annual growth rate of individuals 40 years and older is 6% over the next ten years and 10.4 over the next 20 years.

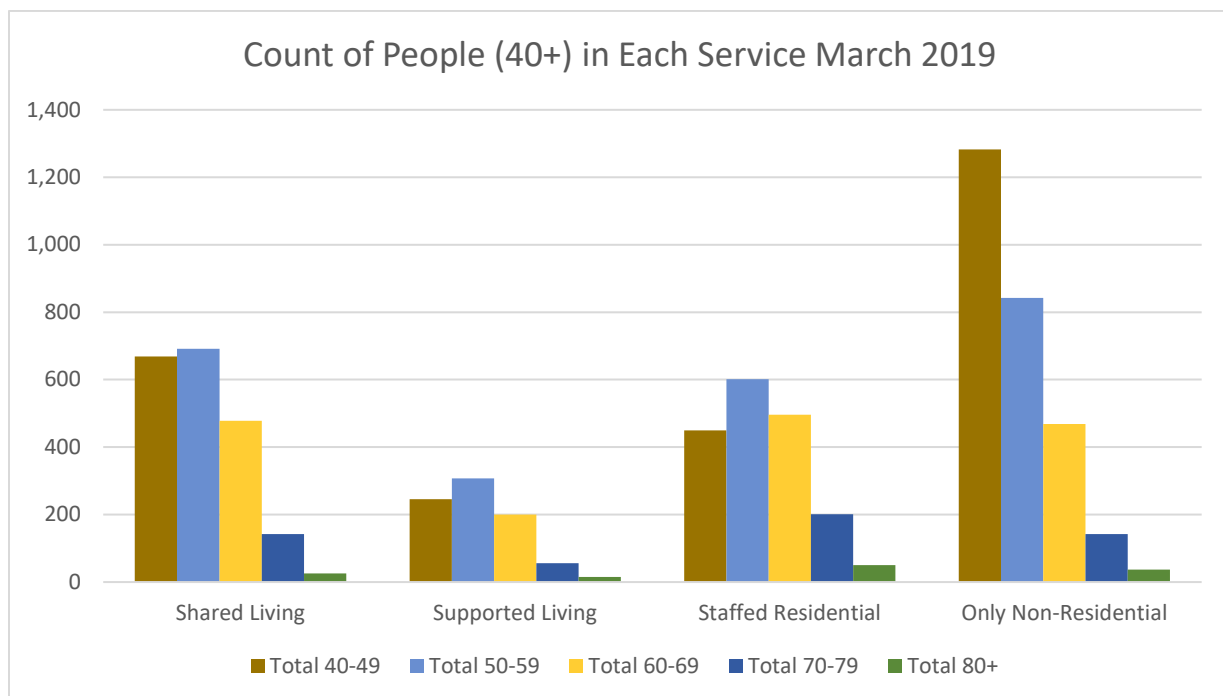
Many people's support needs begin to change in their 50's. The average growth rate of those 60 years and older over the next 5 years is 7%. This has implications for planning, service delivery and budgeting.

CLBC's revised forecasting model enables us to project future demographics with greater certainty. The following set of graphs outline various aspects of the situation facing older adults now and in the future.

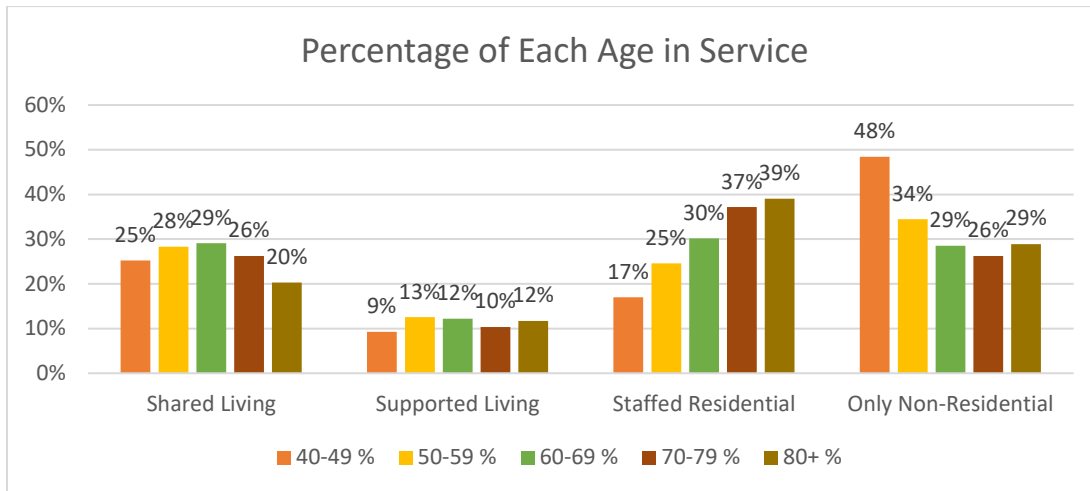
3. Growth in numbers of 40, 50, 60, 70 and 80+ year olds over the next 20 years.



4. Current composition by 10-year age group of each key residential service area as well as those not in residential services.



5..Percent distribution of each age group across residential services as well as those not in residential services.

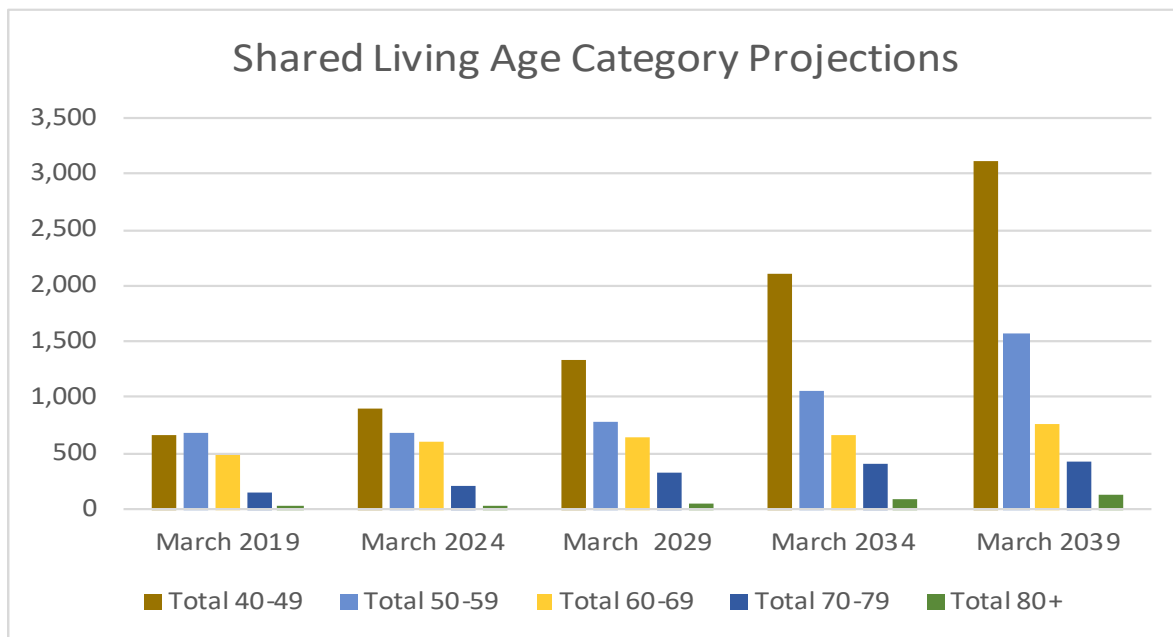


6. Shared Living

Total number of individuals projected in shared living

	March 31, 2019	March 31, 2024	March 31, 2029	March 31, 2034	March 31, 2039
Total number	4,143	5,340	6,752	8,393	10,228

Projected distributions by age group of those in shared living: current, 5, 10, 15, and 20 years from now based on current trajectories.

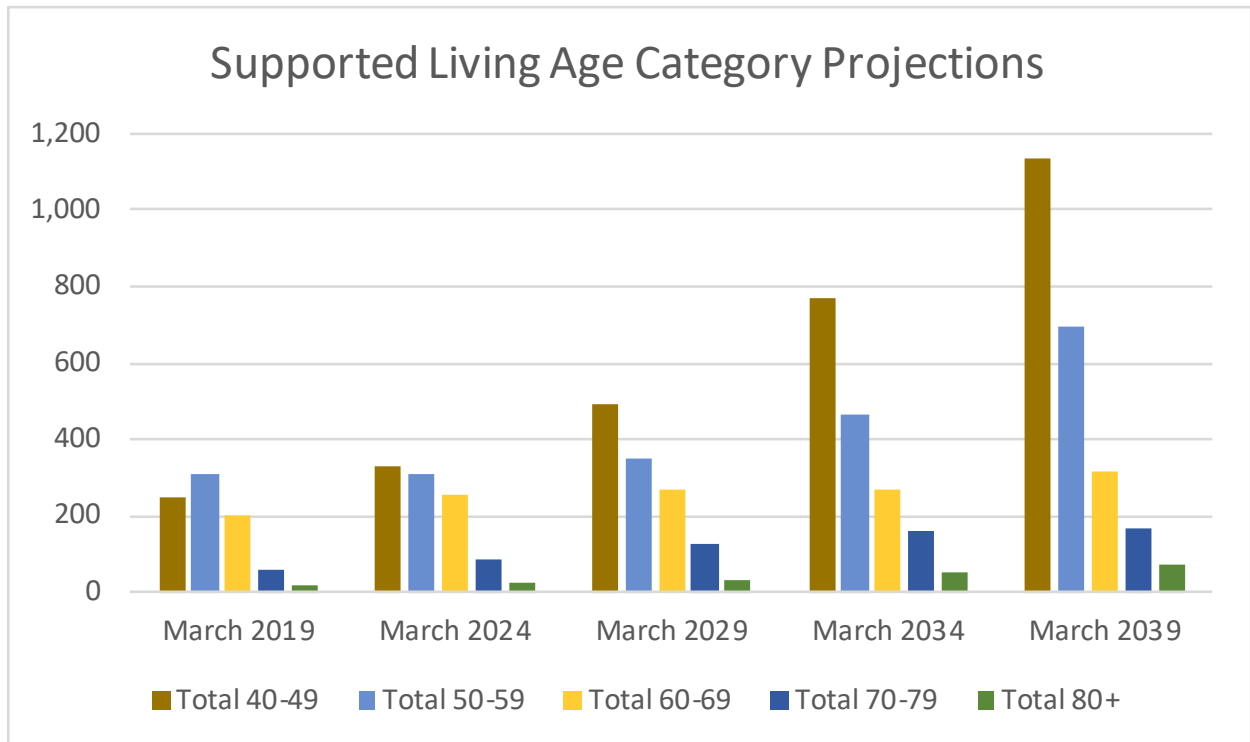


7. Supported Living

Total number of individuals projected in supported living

	March 31, 2019	March 31, 2024	March 31, 2029	March 31, 2034	March 31, 2039
Total number	1,920	2,466	3,080	3,769	4,519

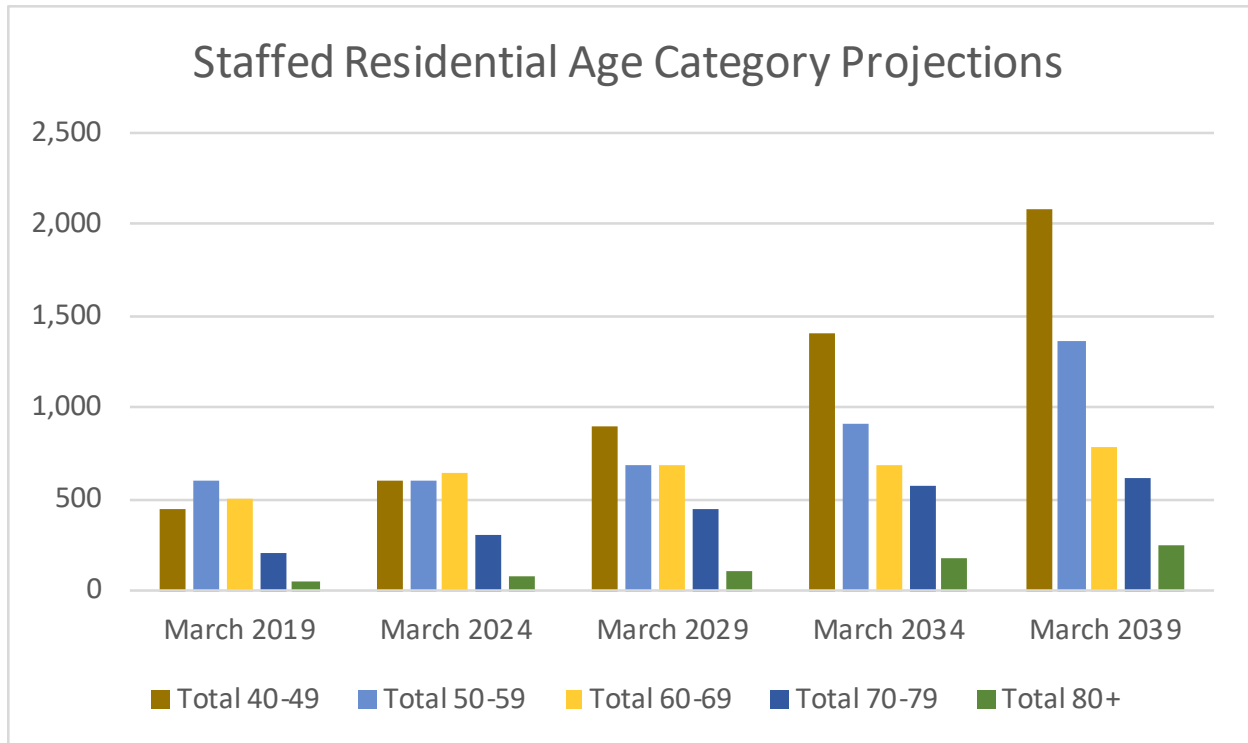
Projected distributions by age group of those in supported living: current, 5, 10, 15, and 20 years from now based on current trajectories.



Projected distributions by age group of those in staffed residential: current, 5, 10, 15, and 20 years from now based on current trajectories.

Total number of individuals projected in staffed residential

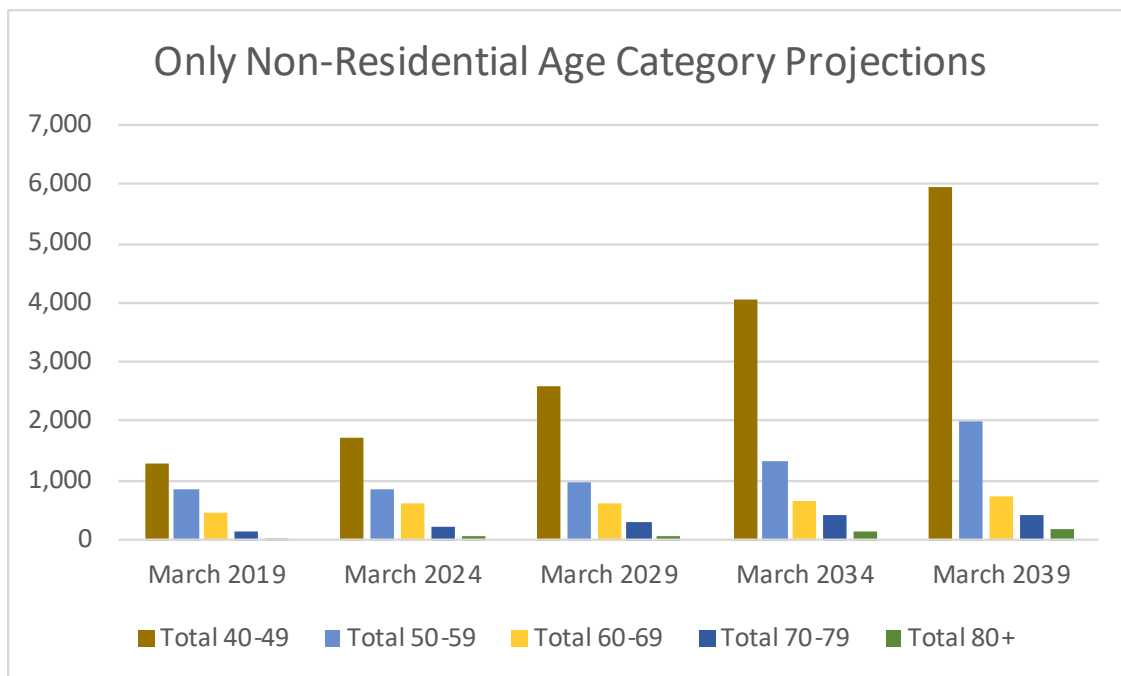
	March 31, 2019	March 31, 2024	March 31, 2029	March 31, 2034	March 31, 2039
Total number	2,656	3,399	4,333	5,500	6,910



8. Projected distributions by age group of those not in residential services: current, 5, 10, 15, and 20 years from now based on current trajectories.

Total number of individuals projected not in residential services

	March 31, 2019	March 31, 2024	March 31, 2029	March 31, 2034	March 31, 2039
Total number	13,505	17,299	21,067	24,648	27,995



APPENDIX B: CORE ELEMENTS OF CLBC’S STRATEGY ON AGING

We believe that:

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.

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.

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. CLBC

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.

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.

Since the earliest work on aging, CLBC has continued to expand and explore resources, cross-ministerial protocols and projects, and reviewed planning processes specifically to address responsibilities associated with aging.

APPENDIX C: AGING PLAN OBJECTIVES BY DOMAIN

Objective	
Domain #1: Personal Development	
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.	
Domain #2: Self-Determination	
Individuals who are aging and their families/caregivers have access to planning tools and practices that: <ul style="list-style-type: none"> - Support proactive, person-centred planning - Are specific to aging - Are in clear, plain language - Help people navigate the changes that aging brings - Are appropriate to an individual's Aboriginal or cultural heritage 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.	
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	
Individuals who are aging and their families/caregivers have natural and personal support networks that are: <ul style="list-style-type: none"> - Wide - Strong 	

<ul style="list-style-type: none"> - Adaptable - Resilient - Diverse - Appropriate to their age and stage of life - Inclusive of people experiencing similar challenges - 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>	
Domain #4: Social Inclusion	
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.	
CLBC.	
Domain #5: Rights	
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	
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	
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 (HSCL) 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.	
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.“	
Domain #8: Material Well-Being	
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.	

APPENDIX D: CLBC AND MINISTRY OF HEALTH THREE-YEAR ACTION PLAN

The action plan includes three major priorities, with goals and actions for each:

1. Focus on Access to Information and Early Planning

Goal: Raise awareness among aging adults with developmental disabilities their families, caregivers, health professionals and communities about the personal challenges and opportunities that accompany aging, and the availability of tools and resources to support early planning for healthy aging.

Key Actions

- Provide information about how to access and use tools and resources to support early planning for healthy aging for people with developmental disabilities.
- Review and assess materials to determine if there is a need to adapt CLBC and the MoH information resources to reflect aging challenges and issues and also to ensure these materials are accessible.
- Plan an initiative to promote inclusion and build awareness of the needs of aging adults with developmental disabilities and among individuals, families, support networks, community living service providers, health professionals, and the general public.
- Develop an Aging Transition Guide for Caregivers, in simple English, that will assist families, individuals, service providers, CLBC and health authorities with transition planning for people with developmental disabilities as they age.
- Plan educational opportunities and resources for health care providers to heighten their understanding and awareness of the needs of aging adults with developmental disabilities.

2. Assess and Redesign Health Services And Supports

Goal: Establish a joint planning approach that supports the provision of collaborative services that will meet the needs of adults with developmental disabilities as they move through the transitions associated with aging.

Key Actions

- Review health service utilization and conduct a gap analysis of current costs for existing health services and supports provided to aging adults with developmental disabilities and their families to determine the most appropriate way to ensure an integrated and standardized approach to meet the needs of aging adults with developmental disabilities.
- Begin the planning process to develop a provincial Aging Transition Protocol agreement by considering a joint planning approach to better meet the changing service and support needs of aging adults with developmental disabilities and their families.
- Explore the creation of customized technologies and services for use by CLBC eligible individuals and their families.
- Leverage work done by STADD in year one with respect to the development of a collaborative service delivery model to address service and support needs of aging adults with developmental disabilities.
- Support STADD in implementing the prototype for the collaborative service delivery model and evaluate outcomes.
- Explore how to meet needs of aging caregivers (family, friends and support networks).

3. Forecast Future Demand For Services And Supports

Goal: Ensure CLBC and MoH have access to the information required to plan for and meet the current and emerging service needs of aging adults with developmental disabilities.

Key Actions

- Based on information system and business process requirements that will capture current and future service needs of aging adults with developmental disabilities, develop a forecasting approach to predict future service needs.

- Consider formalizing an ongoing partnership agreement for information sharing of data based on the results of the prototype for the early implementation site.
- Align available resource and budget allocations with the requirements for services and supports of aging adults with developmental disabilities.

APPENDIX E. QUALITY OF LIFE RESULTS

The include Me! quality of life project has been collecting data on individuals' perceptions of their quality of life since 2012 and has a database of approximately 5,000 individuals surveyed. Based on this data, the following table shows the quality of life scores in each of eight domains comparing individuals 55 and over with younger demographics.

