



LOOKING FORWARD TO THE FUTURE:

Supporting Individuals with
Developmental Disabilities as they Age



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**COMMUNITY LIVING
BRITISH COLUMBIA**

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Supporting Individuals with Developmental Disabilities as they Age

*We would like to dedicate this book to Elizabeth, Elinor and Martha
and thank them and their families for so generously sharing their stories with us*

Foreward

Tamara Kulusic

It is with pleasure that I provide an introduction for this resource. CLBC has been working together with partners to increase our knowledge and experience with providing the right kinds of support for people as they age. We have been creating opportunities to hear people's stories and learn from their experiences. This book is a compilation of stories to celebrate aging. It is also a way of reminding us of the ways we must come together to create opportunities, and honour people's aspirations to be full members of community while we stay committed to the right support, at the right time, for people as they age.

People have been generous with their stories, ideas about aging, and about how to plan for the future and make adjustments with supports to enable people to age with grace and with the support they need. We received many more contributions than we could bring to publication. These stories include perspectives from individuals and families who have been planning for their own and their son's or daughter's futures, other steadfast supporters who commit to this work through their role as friend or service provider, and partners from health who bring their own experiences related to health and aging. At the heart of each story is somebody who is or will be experiencing aging related changes.

Although a supporter, with the opportunity to influence changes through my role as a provincial manager with CLBC, I come to this work first and foremost as a mother. Throughout my life and my career, my most profound learning has been with other families and through the experiences of the individuals we serve. For families who are looking forward to the future when their sons and daughters have support needs, the future can feel quite daunting. The stories that were told at provincial forums, were filled with the difficulty and angst that I have been hearing from other families since my son was young.

When I was first asked to take on the aging portfolio at CLBC I did not know how I could bring myself to talk about aging at the front of rooms and in public spaces without my own fear for the future overshadowing the important topic at hand. As a mom, I have been worrying about my son's future since he was a little, blue eyed boy with blond curls wearing Osh-Kosh overalls, holding his lunch kit, and heading off for his first day of preschool. I knew that he would need an extensive amount of support forever and was not sure how I, as his mother, could feel assured that he would have access to the support he needs after I would no longer be here to assist him. These are the worries of families and the people who care deeply about somebody who is heading into new territory as they and everybody around them ages. These are the kinds of worries that have compelled people to take meaningful action to plan for security into the future and make changes to how support is provided to keep people well and safe as they age. The stories in the book are rich with ideas. As I learned about new strategies and new ideas for planning for the future through this work, I became more confident about talking about aging and changes to come. In fact, I became aware of how important it is to focus on aging both broadly and personally.

We hope these stories offer you inspiration and ideas. Enjoy!

Thank You

We are grateful for the generosity and enthusiasm of contributors and wish to express our thanks to the following groups and people for their support in making this work possible.

Individuals, their families and friends who so generously contributed ideas and experiences,

CLBC staff from all across the province,

Agencies providing community living services who graciously helped host the events,

All the speakers who contributed time and expertise,

Community Councils and their members,

Jule Hopkins – whose vision and passion for the conversation about aging inspired this work.

We are also reminded that time marches on. When we began this project, we included two posthumous entries ~ the stories about Louise and Esther ~ conscious of the reality that dying is an eventual end of the aging process and one that needs to be discussed and addressed for both the people we serve and also for their supporters. We are fortunate to also have contributions celebrate the lives of Elizabeth, Elinor and Martha who all sadly passed away during the completion of this resource.

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Dan and Elizabeth

With a Glad Heart



Elizabeth Hamilton was born on September 22, 1922 in Los Angeles, California. She came to Canada with her parents as a small child initially living in Courtenay, B.C.

She was 94 when she died on March 15th, 2017.



“She was a survivor; in her presence I sensed an elegant dignity and pride. Telling Elizabeth’s story is important; her life is part of the record of the history of our province’s institutionalization of people with intellectual disabilities. Her resiliency and long life is a testament to her remarkable spirit.”

I was privileged to spend an afternoon with Elizabeth the year before her death in the company of two of the members of her support team, and two friends from the community. During our visit, and with the help of her circle of admirers, I was able to learn more about her and her long life

Elizabeth spent over forty years in the institutions in BC, initially admitted to Essendale in 1938 when she was 16 years old. Although unable to recall the story behind her admission, she thought it was because she had what she referred to as a ‘nervous breakdown’. Her connection with her family was severed because of her institutionalization. She spent five years at Essendale, and then was sent to Woodlands in 1943. Eighteen years later, in 1961, Elizabeth was transferred to Tranquille, an institution in Kamloops and the last large facility she lived in before returning to community in the early 1980’s. Elizabeth’s departure from Tranquille was just prior to the beginning of the major thrust to downsize and eventually close these institutions in British Columbia. Over time, her memories of these places became less and less specific but when we talked, the dates she entered each new institution were precise and exact. Elizabeth recalled having to line up for everything and being ordered back if she stepped out of the queue. She remembered living with many other people and having very little that was hers and hers alone. She described working in the laundry as part of her weekly duties, earning only pocket change which she could use to purchase small items at the Tuck Shops (stores) on the grounds of the institutions.

After her release from Tranquille, Elizabeth lived in several different situations in Kamloops eventually being



Kim and Elizabeth at their visit

welcomed at the home where she resided until her death. The home located in a suburb of Kamloops, was, in Elizabeth’s words “the best home I’ve been in”. The staff are “helpful and in a good mood”. And, in this home, she experienced both the privacy she deeply valued, and the ability to organize her daily activities in ways which respected her energy and choices.

In her younger years, Elizabeth spent her days in community sheltered workshops. After retiring from those demands, she enjoyed attending and participating in activities at a local seniors’ program during the week for part of the year when the weather permitted. Winters can be treacherous in Kamloops, and slippery streets and sidewalks are tough to navigate so her activities changed accordingly. As she aged, Elizabeth navigated her home with a walker and used a wheelchair in the community to make travel easier and to safeguard her from falling.

Elizabeth liked to shop! She was also a movie fan, attending regularly a couple of times a month, took pleasure in hearing music at community concerts, enjoyed favourite treats at her local Dairy Queen, and relaxed by doing art, watching movies at home, and doing word puzzles. Her art was a source of special pride and

pleasure. The annual schedule of holidays, like Christmas, Easter, Valentine's Day and so on, were all important to Elizabeth as each provided an opportunity to decorate and celebrate with friends.

I was privileged to receive an invitation to see her room; a sanctuary with a comfortable chair, her movie collection, personal belongings neatly organized, and most importantly, a door that shut! She was a wonderful host - telling me that she especially enjoyed visitors. On the day we met, she was happy to have three of us sitting around her table with her.

When I asked for her advice, having lived 93 years, Elizabeth provided us with some of her wisdom. She recommended we all pay attention when out in traffic. Having been hit by a car many years ago, Elizabeth was very concerned that people use caution and learn about safety in traffic. She also placed a distinct emphasis on kindness, loving others, watching what you say and do, and staying young at heart. One of the adages she offered us was to "make a smile your umbrella on a rainy, rainy day". She also emphasized the importance of "sticking up for yourself", referencing occasions in her life when she had been unfairly maligned by other's accusations. Elizabeth



Photo from Elizabeth's Celebration of Life showing her art

seemed to place a priority on a sense of justice and fairness, and demonstrated enormous grace despite having lived a life that offered more than its share of hardship and isolation than it had provided safety and respect.

Two of Elizabeth's support team members were included in the conversation. Although her life at this home was comparatively brief (only 4 years), supporting elderly people with intellectual disabilities has become a hallmark of the service and culture of this home. The house has been gradually modified to accommodate changing mobility and care needs and each day's pace is highly respectful of the choices and energy of the people who live there. The staff team have consciously developed knowledge about aging, are committed and able to provide palliative care as needed, and have a deep commitment to the well-being of the people they serve.

Near the end of our visit, I asked Elizabeth if she had any thoughts in response to the question, "If you could live your life over...". She was quick to reply, "I'd keep trying to be a better person" - emphasizing again her belief in the importance of loving others, having people around who care about you, and staying connected. Her advice speaks to the ingredients for a long life; being known by others who help you and with whom you feel a sense of welcome and belonging.

Why a Focus on Aging?

We are privileged to have a growing population of individuals with developmental disabilities living well into their senior years as citizens in our province. Many factors have contributed to this, including: better health care and community supports, the committed advocacy of families, individuals with disabilities, and others, and the commitment to de-institutionalization in British Columbia. The richer quality of life living in community has meant that these men and women are among the first generation to survive beyond childhood and adulthood into older age. Understanding their aging process more fully, and providing what they need to age safely, with fulfillment, and dignity in community, offers new opportunities and challenges.

It is important to note that older people with developmental disabilities are a diverse group:

- many individuals now enjoy a life expectancy similar to the general population,
- some individuals are likely to become more vulnerable and develop more complex care needs as they get older,
- some people with developmental disabilities experience the onset of age-related challenges earlier than the general population.

People's needs, interests, and concerns are likely to change as they get older making it necessary to create responsive and thoughtful changes to their life plans. Many middle-aged individuals with developmental disabilities are still living with family members or caregivers who may struggle to continue to care for them as they themselves age.

All of these realities factor into the challenges and opportunities for individuals, their families and CLBC, service providers, as well as public agencies, and the broader community. Collectively we face challenges in anticipating the kinds of supports and services individuals and their families will need, and how best to plan for and develop them. We also have a responsibility to consider how we sustain the meaningful contributions individuals with developmental disabilities can continue to offer to our communities as they get older.

This will require that we renew our commitment to focus on creating the innovative, values-based, and community building strategies we need to meet the challenges.

What are the numbers telling us about the individuals who are aging in BC?

In BC many people with developmental disabilities are eligible to receive supports and services through CLBC. As of March 31, 2017 CLBC served 20,049 adults who range in age from 19 to over 90 years of age.

Of these adults:

- About 22.3% are aged 50 or over - 4,462 individuals
- About 5.6% are aged 65 or over - 1,127 individuals
- Approximately 69% of the individuals aged 50 or over receive CLBC residential services (3,086 individuals)
- Approximately 31% of the individuals aged 50 or over receive only non-residential CLBC services, such as respite or community inclusion (1,376 individuals). Many of these adults live with family members or other informal caregivers while some of these adults live independently with only non-residential support from CLBC
- 69 individuals over the age of 45, who have never received CLBC services, registered with CLBC for the first time in 2016-2017

Developing a framework to move forward

In 2013, CLBC released a **Strategy on Aging**¹ - a collaborative and proactive response to both forecasted opportunities and challenges. The **Strategy** emerged from phase one of a wide-ranging, facilitated, community consultation process involving 39 forums held throughout the province. Over 1,275 people attended representing diverse community roles and perspectives. The participants included:

- Individuals with developmental disabilities, parents, and other family members
- Health care providers
- Seniors' groups and centres
- Staff from university gerontology departments
- CLBC staff and non-CLBC service providers
- Provincial partners such as VELA, FSI, Inclusion BC, and PLAN
- Municipal recreation department staff
- Community based groups and clubs that provide services and supports to seniors (e.g. Alzheimer's Society, Heart and Stroke, and Diabetes organizations)
- First responders including police officers and fire department personnel

The discussions at these initial forums focused on three broad areas of inquiry:

1. **What would a safe and dignified future look like for you or your family member?** We sought to understand what safeguards would provide respect for personhood and honour family hopes and dreams.
2. **What challenges do you perceive you or your family will experience as you age?** We wanted to define the concerns and potential resources needed.

¹ The Strategy on Aging can be found on CLBC's website at www.communitylivingbc.ca

3. *What has worked well for you thus far?* We sought to identify the strategies that should be explored and expanded upon to support aging.

Participants at the forums also explored where partnerships and joint responses could better address the needs of people who are aging, specifically in the areas of services, capacity building, and information sharing. The importance of addressing how best to support aging individuals and their families was consistently highlighted as an increasingly significant issue for everyone who participated.

Establishing foundational values and beliefs

Feedback received from this first phase of extensive community consultation generated consistent themes which shaped the **Strategy on Aging**. Five foundational values and beliefs emerged which can guide our actions.

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 and aren't at risk of a return to institutions. Individuals must be afforded access to the same rights, choices and medical treatments as everyone else. Collective vigilance and leadership remains vital to sustain the vision and values of community living and safeguard people from experiencing the double jeopardy of discrimination due to age and disability.

Shared responsibility

No one group or entity has 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, CLBC and other government agencies, service providers, community professionals, and community based senior-serving organizations, will be required to develop a shared and holistic community capacity to ensure that people age with safety, dignity, and as contributing members of our communities.

It is as much about families 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 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 if they are no longer able to care for them or they themselves have passed away.

Relationships are key

A sense of safety, belonging, and authentic emotional connections are important at any age,² however, they are vital as people age, and their friends and families reach the end of their lives. Supporting existing relationships among caregivers and extended families, and expanding personal support networks, are 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

Proactive, age appropriate planning and flexible and timely service responses are needed to ensure that people do not end up in crisis situations. Both the process and the services provided 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. Capturing the conversation about strategies and successful practices



Jan and Diana

One of the things the **Strategy on Aging** highlighted was the need to work with key stakeholders to identify the varied approaches already being used to support people to live safely and with dignity in their communities across B.C. It was hoped that understanding and sharing these successful practices would provide examples and stimulate new ideas, and thereby support individuals, families, staff, service providers, and community partners to collectively improve and safeguard the experience of aging for individuals with developmental disabilities.

Building on the original consultation process, CLBC in partnership with service providers, co-hosted nine more community forums in the spring of 2015. These forums were designed to host a collaborative conversation that could:

- Highlight successful practices in providing respectful supports for aging individuals and their families and/or caregivers in both residential and community inclusion services, **AND**,
- Feature stories about local community-based services and projects which are responding to the needs, and

² We use the term family to refer to the whole range of how different cultures and groups 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.

creating opportunities, for aging individuals with developmental disabilities.

As with the first set of community forums, interest in the topic of aging was high, and these events were also well attended. Approximately 800 people attended the 9 events, including: individuals with developmental disabilities, family members, CLBC staff, service providers, community organizations, and health care providers. Many family members and caregivers offered powerful testimonies on the impact of aging on their lives and the lives of their loved ones. Each event featured local presenters, including: individuals with developmental disabilities, family members, service providers, and health care professionals. These presenters offered examples of successful practices from their experience, as well as their particular perspective on the challenges and opportunities for people as they age.

What people said at the forums aligned well with the foundations set out in the **Strategy on Aging**. Their feedback validated both the common experiences across the province, and the general direction set out in the **Strategy**. The findings offer insight about what success looks like. We have organized these findings under three broad headings below – however they are complementary and overlap in their applicability and usefulness going forward.

- Protect personhood
- Focus on safeguards
- Work and plan together to enhance capacity

Each of these broad categories of successful practices are a reflection of the stories of challenges and successes provided by the participants. This compilation is intended to provide a summary overview of each of the broad theme areas which emerged. They are illuminated by vignettes gathered from around the province which help personalize and provide illustrations of the practices in action.

Both sets of community forums emphasized the importance of continuing to network to expand the scope the dialogue about aging and issues affecting people with disabilities. The stories included are examples of thoughtful, person-centred thinking and are intended to help continue the conversation.

It is important to note that while there are some unique challenges that face people with disabilities as they age, in fact, many of the strategies and successful practices which were suggested are consistent with a global framework developed by the World Health Organization (WHO)³ in support of active aging for all members of our communities and countries. The WHO describes active aging as a “process of optimizing opportunities for health, participation, and security in order to enhance quality of life as people age. The word “active” refers to continuing participation in social, economic, cultural, spiritual, and civic affairs.” Perhaps most importantly, the framework specifically notes that active aging takes place “within the context of friends, work associates, neighbours, and family members”. The emphasis is on interdependence, and intergenerational solidarity as vital tenets of active aging – an alignment with deep resonance among members of the community living sector.

³ World Health Organization, 2002. More information can found on the WHO website at www.who.int

Everybody deserves a good life: Roni's Story



Roni lives in Penticton, BC. Her active life and healthy aging is testament to the importance of sustaining community participation and contribution.

Roni's friend Kim, interviewed her to learn about her life story and her thoughts about getting older.



Roni warmly welcomed me into her tidy home, offering a tour of her new apartment and proudly showing me her needlepoint pictures and other decor. Born in 1956, Roni was raised in and remains a resident of Penticton, BC. She is one of three children. Her father passed away a few years ago; she is especially close to her mother who moved to Chilliwack 12 years ago. According to Roni, her mom's move to the lower mainland was in order "to give me my independence", adding with a grin, "it's worked hasn't it?" While Roni has been living on her own since she was 21, she feels these more recent years have increased her confidence and fortified her self determined nature.

"I feel more confidence in myself, I save money to do things for myself, and I am more mature. I want a quieter life now. I am committed to my health and have my regular walking route and swim at the community centre. The only thing I don't do now is listen to music while I am walking - that way I can hear the traffic. It's safer."

Roni felt it was important to talk about her disability with me and how it has impacted her life. At the age of 9 months, Roni contracted chicken pox and experienced very high fevers from the illness. Serious complications ensued including paralysis on her right side and debilitating seizures. Roni was taken to Vancouver at the age of 8 and radical brain surgery was done which resulted in further developmental disabilities. Her parents were, according to Roni, told by the doctors that, "I would not amount to anything...put her into an institution and forget about her..." Roni offers, "I'd like to show that doctor how wrong he was!"

Roni's mother Joyce also provided her thoughts. "Community services to support families with children with disabilities were very limited at that time. Roni's health was worrisome, and we were given very little information to help us care for her, both before and after her surgery." In spite of these challenges, Roni's parents persevered and she returned home, eventually returning to school. Roni completed grade 8 at one of the local high schools, later achieving her grade 10 equivalency through her local college's adult basic education program. Joyce is proud of



Roni

Roni's successes and independence while acknowledging the many challenges she has had to manage.

Joyce went on to say, "There have been many difficult times over the years. As a result of Roni's paralysis, she has not had the use of her right arm and hand. She has also walked with a significant limp all her life until the doctors provided her with a build up on her right shoe which helped. Roni's dad and I are very proud of the way she lives her life, planning her days and activities. She is very much like her dad - she plans ahead and she's thoughtful and capable. I am very happy about her recent move - and how she's managing her life."

Roni's schedule is busy and full. She is a hard working, committed community volunteer and has amassed a closet full of t-shirts to prove it! Her reasons for volunteering are like those of many community boosters. Roni offered, "I have done many volunteer jobs over the years...the Children's Festival, Elvis Festival, Beach Cruise, and the Challenge. I like to be around people, I like to be needed, and I love meeting so many varieties of people. I mostly do the information table although at the Beach Cruise, they have me do the gate control which means I make sure everyone has their right bracelets on for the event." Her collection of t-shirts from volunteer events grew so large a friend made her a quilt as a way of featuring the array of memories they provide.

Of particular note among her community volunteer activities, is the 28-year commitment Roni has made as a regular volunteer at a local seniors' assisted living facility. Andrea, the volunteer coordinator at the centre offered these commendations:

"Roni is a delight. She is faithful in her attendance and is always friendly and upbeat. Everybody knows her and likes her. She has really found her niche in the jobs that she takes on here, and is a valuable addition to our team."

When asked about the future, Roni admitted she is worried about her mother who is 89. "I'm worried about her now - I

don't know how much longer I will have her around. We talk every day - often several times. I wonder who I will turn to for that support when she's gone."

Roni has made some thoughtful decisions that support her healthy aging including a recent move to a new apartment which provides better security, no stairs, and a friendly, reliable building manager she knows will respond to any concerns she has about her home. The complex she lives in also coordinates some planned social activities, including regular bingo games, which she has started attending. Despite her pride in her self sufficiency, Roni is aware that she needs support and advice to navigate the next few years. Like others, she wonders about how to apply for Old Age Security, whether or not she needs a will, and other aspects of managing her aging process.

When asked for advice about how to live and age well, Roni offered her motto, "I want to be treated as others want to be treated; with respect, with kindness, and with a smile once in a while. Everybody deserves a good life, to live in their community as they age, and to make a contribution each day."

Roni's story, and her energetic focus on sustaining a very active volunteering schedule, provides an illustration of how one woman is maintaining a good life in her community as she ages.

Protecting Personhood

Although enlightened and progressive attitudes towards the rights of aging persons are more prevalent now than ever in our society, ageism can still permeate decisions regarding expectations and services for people as they get older. This is particularly worrisome with respect to people with developmental disabilities who may experience not only stigmatization and marginalization due to their disability, but may have these discriminatory attitudes and actions further compounded by their aging and the societal attitudes associated with this status.

Protecting personhood is therefore, of particular significance when considering the needs and wishes of people with disabilities. Personhood is the quality of being recognized as an individual human being. Thomas Kitwood (1997)⁴ advocates that personhood is “sacred and unique” and that every person should be treated with deep respect. He places an emphasis on the relational aspects of personhood; noting how it arises from simply being, with others, able to participate in social experiences which offer mutual respect and opportunities for engagement.

Feedback from participants at the community forums highlighted the following ways in which personhood can be protected and the aging process honoured.

Re-frame our perspective on aging - host different conversations

Conversations and attitudes about the aging process can be approached from either a positive perspective, which promotes the value and worth of older people with developmental disabilities, or as a wholly negative and forbidding challenge. The perspective that is chosen then either emphasizes opportunities and natural changes as people age or begins to see their aging process as a problem. Placing an emphasis on the wisdom and experience people have acquired, which can then afford them the opportunity to maintain their contributions and add value to their communities as they age, is part of maintaining each person’s dignity, presence, and rights.

A shift in how we frame the conversations we hold about the aging process, helps ensure we place a priority on active aging. This can be supported by appropriate opportunities to maintain good health, enjoy regular exercise, volunteering and sustaining access to supportive services and environments that honour the person as they age, and respect their unique needs and interest.

⁴ Kitwood, T. (1997) Dementia reconsidered: the person comes first. Open University Press.

The Odyssey of Aging



Aging well in our communities involves supporting people with developmental disabilities to connect with their peers in meaningful ways. A proactive approach to aging involves multiple strategies, at an individual level and organizationally.

Monique Nelson and Pam Balog from posAbilities offer this contribution which highlights key values, methods for promoting choice and opportunity, capacity building initiatives, and support to families. We also meet Cathy and learn about her community connections.



At *posAbilities*, the topic of aging is becoming more and more important. Approximately 25 percent of the adult persons whom we serve are between the ages of 50 and 80. Their changing needs require continued reconsideration of how we tailor the supports we provide to respond to health care issues and other changes arising from aging. It has been our experience that aging for the persons we support can either be quite typical or occur much earlier in life. As a result, we are also needing to thoughtfully plan the supports required for a significant number of individuals who are in their forties.

A core value for us is that the supports we provide, at any time in an individual's life, must be person centred. This remains an essential covenant as people age. Although there are many strategies we have employed to respond to



Cathy

the support needs of aging individuals and their families, areas where we have had success include:

- Fostering belonging and contribution
- Actively empowering families
- Specialized team training and support
- Working to support aging in the right place

Fostering Belonging and Contribution

Some of the more senior persons we support, who have been part of our day programs for many years, are challenging us to rethink how best to address an important inquiry: "When do I get to retire from the program?" It's a good question; most of us will have to plan for retirement as we mark the phases from one time in our lives to another. For anyone who is aging, retirement may involve thinking about changing care needs, accessible housing, and other things. As service providers, we believe we need to focus on community building and supporting people to transition to new opportunities that fulfill their interests and continue their contributions to community. To do this, we know we need to make our focus about discovering our neighbourhoods, exploring people's interests and talents, and very intentionally accessing opportunities to link up individuals with others.

For one woman we support named Cathy, her active life after her retirement is a helpful story about the value of honouring neighbourhood connections. Cathy was interested in participating in regular gatherings across the street from her home in New Westminster, as a participant of the Sapperton Pensioners Club. Cathy is able to easily access this community group, enjoys a regular coffee house gathering at the hall, and has been welcomed to join in other activities too. Cathy accesses her community using her electric wheelchair. Maintaining her active involvement is all about ensuring access is not restricted and that she can safely move about her neighbourhood. Through the

Pensioners Club, Cathy got involved in the group's pedestrian safety initiative. The pensioners funded \$150 worth of LED lights and reflective surfaces to outfit Cathy's power chair so that she could wheel about more safely and independently. Cathy was also invited to speak at a Community Safety Forum in a room filled with first responders, others who attend the Club, and the general public. The entire experience, while new and a little terrifying initially, proved quite exhilarating for her in the long run. Her relationship with seniors with common interests, concerns, and challenges has proven to be a powerful connection to sustain her sense of belonging in the Pensioners Club.

We regularly review the strategies and opportunities which help individuals we support contribute to community. One of the initiatives that we now host, called Can You Dig It!, promotes inclusive community gardening and welcomes individuals of all abilities and backgrounds to participate. It's an initiative that reduces social isolation and increases food security, while also promoting the therapeutic benefits of working with soil to grow food. We realized that several of our residential homes have large yards that were perfect for hosting a few garden beds - an available and natural resource that we felt could stimulate health and wellbeing as well as build community connectivity. Many of the individuals we support have produced bumper crops in their own home-based community gardens, or in gardening hubs that they have joined in their neighbourhoods. The principles in both these examples are the same; intentionally fostering belonging, building connections with others, and finding ways to help people make contributions.

Empowering Families

We know that parents/families of people with developmental disabilities are busy. As they themselves age, often dual concerns emerge about their own health and mobility changes as well as those of their aging family member. A critical and poignant question they are seeking answers to is front and centre for them, (if not always

spoken out loud), namely "Who is going to love them like I do when I am gone?" Every family situation is different as well: some aging parents are also caring for grandchildren, some are wanting to pursue their own retirement and 'bucket list' interests like travel. We have learned that it is important to actively support families in the transitional processes of shifting the responsibility of overseeing their relative's care to the next generation of siblings, extended family members, or friends.

In response to this, *posAbilities* has been hosting a Senior Parents Support Network for the past five years, in recognition of our belief that senior families likely have similar lived experiences and face similar challenges. We also wanted to honour and celebrate their amazing contributions as the pioneers of the community living movement which has heralded so many positive changes. Our director of community engagement is responsible for supporting the network by hosting regular meetings.

As host, we provide a forum for parents and/or family members to support each other and to share their experiences and expertise. We also arrange for speakers on a wide variety of topics in response to their expressed needs and interests. This has included the important topics of supported decision making and legal representation; both critical to helping think forward into the future. Group members have shared that they value meeting in person to learn about sector news and to consider how new ideas, service changes, and resources may impact their family member.

Supports to senior families have proven to be a powerful and successful practice. Two, single parent participants in the group have expressed how much they value having someone to bounce ideas and challenges off of. The work we do is aimed at assisting with planning for the future - we have seen the benefits this is having for families and we also recognize that after five years, it is time to begin engaging the next generation in our support network.

Specialized Team Training and Support

At *posAbilities* we have learned that we need to provide educational opportunities for agency staff, family members, and for caregivers to learn about the aging process. Providing specific information related to the unique challenges of aging and conditions such as dementia, has been vital. For individuals who have dementia, their carers need to be able to recognize and adapt to their rapidly changing needs and abilities. Changes in physical care needs also require a focus on building capacity. In order to maintain confidence and competence to respond to the unique and intimate needs of the person, an emphasis on assisting people to maintain their health, wellbeing, and dignity is key. Our staff teams also have access to training in senior and dementia care from community partners like the Alzheimer Society of BC, Down Syndrome Research Foundation as well as resources like on-call access to community professionals such as Vinge Nursing. Our capacity to respond to the needs of the individuals we support who are aging has been very intentionally built with an emphasis on the quality of their life complemented by a focus on sustaining the quality of our supports.

Aging in the Right Place

We believe that aging, safely and with dignity, requires the opportunity to age in the right place. Homes that feature thoughtful design modifications are important. Having the proper equipment such as lifts, adapted baths, widened hallways and doors, and accessible indoor and outdoor spaces to gather, are all important particularly as people experience changes in their mobility as they age. In addition, wheelchair accessible transportation to facilitate community outings and medical appointments is essential.

We currently have a few fully accessible homes and specially trained teams that are supporting people who have early onset dementia or other physical health challenges. We recognize that we need to add more accessible homes so that the persons we serve can remain in community for as long as possible. We collaborate with funders and government agencies like BC Housing to make renovations to our existing homes. The quality of individual's home environment is fundamental to ensuring people are thriving and able to enjoy living long lives with the appropriate supports at home and in the community.

We are continuing to examine how we can deepen our experience and appreciation about the opportunities and challenges that supporting people who are aging, and their families, will bring. As an organization, we are engaged in actively thinking about the future with and for those we serve - all in alignment with our vision of inclusive communities and enriched lives.

The person must be at the centre of the conversation

“Person centred planning begins when people decide to listen carefully and in ways that can strengthen the voice of people who have been or are at risk of being silenced.”⁵

Person centred planning is the active heart of values based support. As people age, the responsibility to maintain this focus and practice remains paramount. Successful support emphasizes a holistic approach including considerations of health and wellness, cultural, psychological, and emotional needs. Fundamental to the planning process is continued deep listening, learning, and meaningful actions which focus not only on what is important now, but what will enable dignified transitions throughout the aging process. Key questions that support transition planning, include:

- Who are you, and who are we in your life?
- What can we do together to achieve a better life for you now, and in the future?
- What is important to you? What support might we need to develop to achieve your goals?
- What are important safeguards for your health, friendships, contributions, and home?
- Who else can help?

Successful conversations about aging are rooted in values. Successful supports and services are those that consistently and authentically value individuals’ rights and needs. Values-based planning means that the voice and choice of the individual is privileged and participation of their family and friends is honoured and safeguarded.

I'm ready to retire



Supporting people with developmental disabilities to age successfully involves considerations of how we demonstrate respect for their life choices and facilitate transitions like retirement.

Glen McClughan provides this story of his friend Ryan, whose self-advocacy, helped his supporters remember the heart of their work.





Ryan

The Sunshine Coast Association for Community Living, like many other organizations across our province, is working hard to be responsive to individuals we support who are aging. One of the men, we have had a long relationship with, has been a powerful teacher for us. Ryan has helped us deepen our understanding and live even more fully into our commitment to ensure that people with developmental disabilities and their families who we serve are listened to and heard.

Ryan is a 46-year-old man who lives on the Sunshine Coast, the youngest in a family of 5 siblings. Ryan has lived with

housemates in a staffed residence in his community for many years. He has an incredibly diverse set of attributes, not the least of which are his natural athleticism and rhythm which have allowed him to participate at a very high level in all kinds of sports. Swimming is a particular area of expertise as well as dancing and performing. Ryan has had a busy life. In addition to his athletic pursuits, he was also employed in several jobs including, but not limited to, working at the Fire Department rolling hoses, landscaping and stocking shelves.

We believed that Ryan's abilities and interests were well

supported by our agency and we took pride in providing him with assistance to participate in a variety of activities through our Community Inclusion services. As well, Ryan was an active member of his local Special Olympics group. Both his work and his recreational pursuits contributed to a healthy lifestyle which Ryan seemed to revel in and find fulfilling. When Ryan turned 40 he announced to his family, as well as those who work in support of him, that he was "retiring". Given his level of activity, achievements, and the pleasure he took in his recreational life, we found his announcement surprising to say the least. Everyone in his life tried to change his mind, pointing out how "good he was" at sport and dancing and expressing concern that his health might be compromised if he didn't maintain his regimen of activities. Ryan remained (and remains) undeterred - he was ready to retire. Full stop. Our role, as his supporters, was to help him do so - to listen to him and hear his desires to navigate a new stage in his life.

After a host of meetings with Ryan and his family, managers, staff, and one to one conversations with Ryan, we finally came to the realization that we needed to serve him in the ways that appealed to him and honour his commitment to his "retirement."

We focussed on listening to him, and worked to create a balance; thus a plan was made. Another passion of Ryan's is his art. As a result, he wanted to invest in as many coloured Sharpie pens as he could and spend as much time as possible on drawing. He has amassed what maybe the world's largest collection of Sharpie's! Another activity that he chose was to work at the office. He now has a regular set of janitorial jobs which he does with skill and attention to detail.

In supporting Ryan's desire to retire, we also wanted to emphasize healthy aging for him as well as his peers. Ryan

has had some health issues which were important to help him manage. Through conversations with him, he agreed he should maintain his activity through daily walks as long as there was a "reason", shopping for groceries being an example of a favourite destination. At first we all felt that he would eventually relent, at least in part, and return to some of the more strenuous exercise that he excelled in, but he has not. He is truly retired from that part of his life and enjoying this new phase. The bottom line... after 5 years or so of enacting these changes, Ryan reports that he is happy having designed his own daily routines and we can attest that his health has been for the most part maintained.

Lessons we've learned from Ryan...

As much as we hoped we truly listened to the people we serve, Ryan taught us that we needed to reaffirm our person centred focus by engaging in deep listening in support of his retirement goals and interests.

Healthy aging is optimal. Ryan's health and wellbeing are essential commitments and assisting him to maintain activities that he enjoyed and which would support his overall health, were important to emphasize in our planning with him.

Retirement should be an available choice we are prepared to support. Our lifelong commitments to the folks we serve must now include considerations of changing interests, shifting schedules, and the opportunity to retire.

A key part of our values and philosophy at SCACL, is to ensure that people with developmental disabilities will be "*looking forward to what the next day will bring*". In helping our friend Ryan, and others plan for their retirement, we are offered an important opportunity to realize and honour this commitment.

Hold people's stories

“A sad and all too common truth for people who experience developmental disabilities is that little, if anything, is known of their stories. Reams and reams of paperwork are generated each year, but only a fraction of what is generated describes the person's connection to the world. The file is instead a collection of things that the service system wants — a chronicling of interventions, evaluations, signatures, data points. There is no unfolding of things in these files, no character development, no plot.”⁶

When people's stories are lost, misplaced, or interrupted, they are at greater risk of being misunderstood and misrepresented, particularly as they age. It is equally vital that people's stories are held by people who authentically know them. This makes it more likely that their preferences, choices, cultural traditions, and life history will be reflected in planning and decisions, and that continuity in their lives will be honoured. Stories are best held in relationships. To enhance and help retain people's stories, some organizations and family members are also creating memory books, and using technology such as iPads, in innovative ways, installing videos and photos on them.

We hold each other's stories



Sustaining our presence in community is reliant on people who know us, love us, and who safeguard our memories and our story.

Brenda Gillette offers this story of her friend Bruce and their long friendship.





Bruce and Brenda

I feel privileged to tell you about my friend Bruce - we have known one another for a very long time and I consider him one of my very best and oldest friends. As such, we hold each other's stories - we carry each other's hearts and memories. Bruce has always lived in the community and is one of the individuals around whom the Chilliwack Society for Community Living was initially formed. He has participated in CSCL services for his entire life and his family has also described his services as "being his life".

Bruce always lived at home with his family and enjoyed summer visits with his aunts in Sechelt. Other than these occasions, he had never stayed away from home

overnight. This family circle was small, intimate, and satisfying for everyone. Following his father's death, Bruce and his mother relocated to a new home, closer to his brother, where they continued to live together. When Bruce was 67, and his mother 97, it became clear that her health was failing and that alternatives had to be found. Our society's long standing relationship with Bruce and his family, and my friendship with he and his mother provided a safe group of people to help facilitate these sensitive and critical conversations. Working closely with the family, CSCL began to provide structured overnight respite supports for Bruce hoping that this would provide a safe and supportive transition for him from living at home to

another successful option. While the family's stated preference was a group home, this was not the best option for Bruce.

In May 2013, Bruce's mother, perhaps sensing her impending death, asked me the poignant question "What are you going to do for my boy?" Shortly thereafter she was hospitalized and was unable to return home. His circle of supporters spent time considering possible options, including long-term care, but rapidly rejected this. Bruce was still an active senior, enjoying all that life had to offer and anticipating more adventures ahead! After many conversations and deliberations, we introduced Bruce and his family to a caregiver whose property (a small acreage) was similar to Bruce's family home. The caregiver was already providing support for Bruce's long-time friend who is also aging. From the first few minutes it was evident that we found the perfect place. It met all of the family's expectations in terms of the home, the property, the care, and the availability of a friend in the home.

Bruce's mother passed away in August 2013 but died knowing that Bruce was happy and repeatedly expressed her gratitude for the loving care and opportunities he was being provided. The team at CSCL ensured that Bruce's care providers met his mother in the hospital. That meeting enabled these two very important people in Bruce's life to meet and for the caregiver to hear firsthand

how happy Bruce's mother was with the match for her son.

Bruce has now been in his new home for 3 ½ years. He mourns the loss of his mother quite openly but is very happy with where he lives. His brother visits often and Bruce goes to his home for holidays. His caregiver is able to share, support, and honour his emotions. On his first Mother's Day without his Mom, in recognition of his loss, she arranged for a bouquet of "flower balloons" that he let go in the back field so that he could send flowers to his mother in heaven. When I visited him at his home last Christmas he spent quite a lot of the time reminiscing with me about who's "gone". He wanted me to put it into order for him ... first Grandma, then Dad, then Auntie Sylvia, etc. His caregiver was surprised; she had been aware of his feelings about his Mom but had never heard him talk about the others and the things he did with them at all. As his long-time friend, I was privileged and able to help act as a memory board.

In March 2015, approximately 100 friends, family and community members helped Bruce celebrate his 70th birthday. That the circle of people who love him, and wanted to help him celebrate, was as large as this is not a surprise. Bruce is a bit of a local celebrity and continues to surprise us all with his zeal for life. Moreover, I am lucky to call him my friend and to be one of the people who hold his story and his memories.

Loneliness is perhaps the greatest disability

Vulnerability and loneliness should not be heightened or considered inevitable as people age. However, without an emphasis on maintaining the continuity of relationships, people with developmental disabilities may be at heightened risk of experiencing isolation and having only limited social connections. Supporting meaningful and continuing relationships as people retire, or change their interests, is a successful practice to support healthy aging. Intentionally focusing on developing and maintaining extended personal support networks, which help preserve and safeguard individual's histories and community presence, was consistently recommended as an important responsibility in our service to individuals.

We miss her



The aging process is sometimes fraught with challenges for people with developmental disabilities, especially if other issues emerge such as critical health concerns or dementia.

Cathy Alpaugh offers this powerful reflection of Louise whom she was privileged to have known and help support for many years. Her story highlights the importance of grace, compassion, and respect.





Louise

Louise died in June of 2014. As the people who supported her, we miss her. We miss the woman we knew for over a decade, when she was not struggling with dementia, and we miss the woman she was during the challenges the illness presented. While dementia caused her some emotional and physical pain, and that troubled all of us, we maintained our steadfast commitment to continue to honour her personhood. We can truly say that we have many fond memories of those times too.

Aging can have physical and mental impacts that make it more difficult for us to cope. However, with the right supports and environment to live in, as we age we are also capable of adaptations and perspective that allows us to manage a wide range of things. Physical changes, mobility challenges and cognitive shifts may create some limitations, but what the person has done in their past provides memories, experience, a way to connect and share with others, a capacity for empathy, a sense of

humour, and wisdom; these are touchstones which enhance their ability to cope and our ability to engage with them.

There is a difference between typical aging and the dramatic neurological decline Louise experienced. While we had confirmed she had dementia, a diagnosis of Alzheimer's was never received, though all of her symptoms and her death indicated as much. Louise's decline was the extreme version of aging we tend to fear: a loss of memory and executive functions, even understanding of reality, with a decline in physical health that is eventually incapacitating. It can be hard to find a silver lining in that... but, we did.

Louise taught us that it is the changes, and yes, the needs a person has, that help us develop the strengths, the perspective... that deepen our compassion and caring. Every smile becomes a diamond (it takes practice to see it

at the time!).

Louise taught us that sometimes you cannot have the good without the not-so-good. Louise was a woman who had a developmental disability and a mental illness. She had experienced abuse, and required the support of full time staff after July 2000. These later years provided her with many wonderful experiences and milestones! Louise appreciated nice clothes, nice furniture, meals in a restaurant, parties, staying in a hotel, and most of all, people she could trust, who cared about her, and she let us know it.

And because our agency provided her with services, we met at least annually to discuss with her and her supporters what she wanted from us. Because of our long relationship with her, we had years of recorded plans, goals, likes and dislikes, memories, her story; each of these helped with the assessment of her dementia diagnosis and provided a gold mine of connection when her illness made that harder to find. We knew the music she liked, her favourite colour, her favourite flower, and her favourite foods. Holding these seemingly small and insignificant pieces of knowledge is invaluable when someone is disoriented or anxious or limited by changes in their mobility.

Louise taught us that you already know what you need to know. Those of us in this field hopefully know that a developmental disability is not an illness to be cured, though we always support learning and the development of capacity and potential. Our job is not to fix people but rather to support the person we meet each day. That perspective is essential when supporting older adults.

Louise could be uncooperative, slow, resistant, argumentative and violent, and in ways that were, to those supporting her, inexplicable. We advise people to “not take it personally”, but we were challenged to really learn and practice this perspective. We learned that in supporting people who have dementia, sometimes you are not even “the person” she is talking about or to! Despite the challenges of her disease, Louise was also generous with a teary “thank you” or “I love you”. Those kept us all

going. There was nothing polite or obligatory about her declarations; she said what she felt in the moment. And even if our name was not attached, or we weren’t sure if she was talking about us, these words of gratitude and love meant we had contributed to someone’s happiness.

Louise taught us that she would not be who we wanted her to be. Of course we knew that but as she aged, she forced us to accept it. We all live in our own world, a little. Responding to that, not challenging it, is often the best way to cooperate with someone who needs your help. I might have been in the middle of helping Louise dress or moving her toward the car and she would call me names. If I were wise, I would stop what I was doing, and start a conversation about topics she enjoyed, as in “did your mother used to help you with this?” or “these clothes remind me of [favourite place/occasion].” And then listen to and encourage her stories for a few minutes. She would often smile and relax, and an opportunity to help her get to the next step might then arise. Wherever it was she needed to be (and sometimes I would forget that she did not need to be anywhere at all, so who cared how long it took?), I would not have as much success if I could not get her cooperation. If I could just help her focus on a positive memory, I might find I could attend to the tasks on the calendar. And if I could not, in the end, chatting about her mother, which made Louise smile, would often turn out to be the best part of her day and mine.

She got me a card for Mother’s Day. A member of her support staff helped her to do that. Of course they both knew I was not her mother. Louise loved her mother, and I took it as the compliment it was. And besides, being older means you can make up the rules!

The dementia meant Louise was sometimes sad or afraid or angry, and often not cognitively in the same place or time as those around her. Once we learned not to argue, but to respond to what she felt, and guide the discussion to topics and memories she loved, we had some great conversations which helped manage her anxiety and distress. She liked to talk about Montreal, and weddings and funerals, and fancy clothes. We had some great

laughs. Sometimes her language got pretty blue, but when you are older, and not feeling well, and it is just your friends around...oh well. She could make you feel special by promising to take you on a holiday, and then you would discover she was secretly inviting half her support team! It was such fun talking about what we might do, where we would go, not worrying about whether it would happen; the pleasure was in the moment.

Even on a good day, it demanded patience to support Louise. It could be slow... she was unpredictable. And yet, she continued to gain friends when she was ill... new staff bonded with her quickly. They smiled when they talked about her - they accepted her. Their openness reminded those of us, who had known her longer, to do the same.

I wish Louise had not experienced pain. I wish no one was hurt by her words or actions. But I cannot regret the time I had with her, whatever her condition. And how is that different from what we would say about anyone? We wish those we care about to be pain free and happy, but accept them and enjoy them as they are, and hope they will do the same for us.

Advocacy is essential

It is important to remember that the heart of the work is the person, regardless of age, increased vulnerability, or changes they are experiencing. Protecting and supporting personhood requires a sustained commitment to advocacy. Vigilance and personal advocacy – through the collective efforts of members of support networks, service providers, individuals with disabilities, families, and others is vital.

A Testament of Friendship



The power and necessity of individual advocacy to safeguard people's health, dignity, and rights was reinforced repeatedly throughout the conversations on aging.

In this story, Lorna Dittmar, a long-time advocate for people with developmental disabilities, offers us the story of her friend Esther and provides lessons about aging and community.





Esther

It is with pleasure that I tell you about my friend Esther. I first knew her through my sister Florence, who also has a developmental disability, when they both attended the same school. Later I got to know Esther better when I was hired by the local association for community living. At that time we operated a sheltered workshop where she made plastic wedding flowers. She was so good, so competent and productive in her job, that we quickly negotiated a contract with a local bank for her to run their coin rolling machine. Esther capably worked at this position for many years until the bank closed that operation. Later Esther worked as part of the team running the canteen at the provincial jail in Prince George. Once again, she was a star employee - reliable, competent, and a hard worker much admired by her colleagues.

Esther and I kept in touch over the years. After my retirement, she often came to play cards with many of the people who lived in an Assisted Living Home for seniors that I ran in our community. At one point in her life, Esther had rented a basement suite in our home - she was close to both my husband and I. When she was diagnosed with lung cancer, she called me and of course I was there for her - after all we had been friends for more than 30 years!

Together with her family, whom I knew well, we formed a circle of support for Esther. She was in the hospital for more than 200 days - it was not a good experience for her. The nurses on staff had little experience with people with developmental disabilities. Esther did not ask for help or complain if she was in pain and they were not attuned to her body language. It was only through committed

advocacy by her family and friends, in partnership with a young medical student I had taught, that we managed to help them become more attentive to her signals of distress. We also had to coach Esther to use her call button as she was concerned about being a 'burden' to nursing staff. Sadly, many members of the health care community have not had specific training or very much experience supporting people with developmental disabilities. Our advocacy was critical to ensuring that Esther had the care and attention she needed; we helped the hospital team learn more about her unique needs and perhaps more about people with disabilities.

Esther stoically endured rounds of chemotherapy and radiation for her cancer. These had a positive benefit and she perked up such that we started to think about her returning home with some support. Accessing supports proved to be a long and frustrating process. She had never been registered with CLBC, despite her disability, and the process of getting assessed to confirm eligibility took longer much than we had hoped. Esther's health worsened in the interim and we were advised that her cancer had spread and going home was no longer an option. Happily, in a journey that had so many disheartening aspects, the referral to our local hospice was a positive outcome. Esther's care in the hospice was wonderful - all the staff displayed incredible compassion and her friends and family were welcome at all times. My dear friend Esther died in March last year - I will always miss her... till we meet again.

These are the lessons we learned from her story

We learned that everyone needs a circle of support: family and friends play a very important role in ensuring that the wishes of the person you care about will be kept front and centre in managing aging, changing health, and emergencies. Family and friends help to hold the story of who the person is, what their likes and dislikes are, where they would like to live and with whom, along with their fears and wants. This circle of support offers essential

advocacy and helps to remember and honour the large and small details of a person's life.

We learned to plan ahead: A planning session should be a priority for anyone over 50, and earlier if changes are evident. In my family, my sister and I were raised to look after our sister who has a disability and we do...but we are also aging and she is much younger than we are! We always have to consider whether or not our children will take up the responsibilities we have accepted and plan accordingly.

Consider having a baseline assessment completed so you can watch for changes and then change your plan accordingly. Make sure others are aware of your plan.

We learned to have the important conversations early: Representation Agreements can be a vital process to engage in the important discussions that help define end of life wishes, funeral plans, will and estate terms, key decision makers, and the like. Circumstances during hospitalization can change rapidly and knowing what your family member or friend wants helps ensure their dignity, safety, and wishes are honoured.

We learned we needed to enlist other supports: Talk to your GP about aging. If your relatives or friends have not registered with CLBC, please do so asap. Talk to your local service provider(s) about your wants and needs and the supports they can offer. Access the resources of other community resources for support and care including hospice, dieticians, the local chapter of the Alzheimer's Society, etc. Talk to a lawyer about a will to ensure these important details are not overlooked.

Help build community capacity: Consider joining your local society for community living, Council of Seniors, or Community Response Network and assist them to incorporate issues impacting people with developmental disabilities who are aging into their planning and advocacy.

Grief and loss

While death is inevitable, it can often be an uncomfortable topic to discuss and plan for. Despite this discomfort, in conversations with individuals with disabilities, their support staff, and family members the importance of honouring the experiences of grief and loss was consistently highlighted as an important area to expand skills and knowledge. At many of the community forums on aging hosted throughout the province, people with developmental disabilities were especially eloquent about their frustration that so few of their supporters would recognize and respond to their need to talk about death; both their own death and the deaths of others who were important to them. They also expressed frustration that supporters either would not or did not know how to respond to their grief when they experienced a loss. People with developmental disabilities were clear they want to exercise their right to participate in respectful conversations about death and end of life care, and about how they wish their lives to be celebrated after death. They also want the opportunity to have their grief honoured and respected. However, for many individuals, systemic and attitudinal barriers prevent them accessing timely and appropriate supports to be able to do so.

Providing support to people with developmental disabilities throughout their lives will offer opportunities to experience both the practical and emotional dimensions of attending to the dying process as well as the hard work of honouring the grief that results. Changes in people's lives due to declining health, the deaths of friends or family, and their own mortality, may provoke challenging and sensitive conversations. These changes also offer an important and essential opportunity to build a circle of responsive and compassionate support, to consider appropriate safeguards, and live fully into the vision of community living.

According to Ms. Lepage, many factors impact on our ability to provide respectful and responsive supports to people with developmental disabilities. As a result, individuals may be at heightened risk for “cumulative and unresolved loss”.⁷ She believes that the reasons for this heightened risk can be attributed to some of the circumstances associated with their personal, life stories and the systems of supports and services which have historically been in place for people. These circumstances converge to create multiple and unintended barriers to accessing timely and appropriate supports.

Lepage points out that the research and literature around grievers with intellectual disabilities remains limited. Despite this limitation, she identifies that “there is growing agreement that individuals are at risk of *disenfranchised grief* (i.e., unrecognized multiple losses; disregard for an individual’s need and/or capacity to grieve), or by our misattributions of grief responses as behavioural or mental health issues.⁸ This latter factor she labels as *diagnostic overshadowing* (i.e., behavioural “problems” or emotional distress attributed exclusively to the disability itself).

Both disenfranchised grief and diagnostic overshadowing can be compounded by other factors, including: unique communication styles which make interpreting people’s expression of grief more difficult, grief reactions that are delayed or displayed behaviourally rather than verbally (and therefore open to misinterpretations), and a lack of experience or comfort on the part of supporters to identify or address these as symptoms of grief and loss. Further, the historic infantilizing of people has led to a diminished belief in their capacity to experience grief and loss. As a result, a corresponding protective stance emerges that supposes that denial or deflection of the emotions associated with death and loss, will be ‘*in the person’s best interests*’. Opportunities to grieve in healthful ways are often not pursued.

Rather, Lepage argues, the responsible presumption should be that people will and do experience grief and loss and that education to build capacity among support staff and community partners regarding the signs and symptoms of grief, is vitally necessary. Lepage emphasizes the importance of pursuing opportunities for, and promoting the benefits of meaningful collaboration between those providing bereavement care and the mental health clinicians, support workers, and caregivers for grievers identified as having an developmental disability.

In truth, the experience of loss for people with developmental disabilities is as diverse as it is within the non-disabled community. Notwithstanding the need to respect each person’s unique communication styles, language, and individual emotional vulnerabilities, it is essential that service providers and others, intentionally address these systemic and attitudinal barriers in order to authentically and compassionately provide the support individuals need and deserve.

7 Lepage, M. Grief Support for Adults with Intellectual Disabilities: A Guidebook for Residential Caregivers. (2012) <http://www.mylepage.ca/>. Whitehorse, Yukon. p. 9. Author can be reached at: yvette.lepage@gmail.com

8 Lepage, M. Ibid. p.9

We made a commitment



Lynn Roberts, a member of the Leadership Team at inclusion Powell River, provides this story about Martha, her life in community, and the values that guided their supports to her as she aged.

inclusion Powell River, has been providing supports to people with developmental disabilities and their families for over 60 years. Like other agencies with deep roots in community, we have often served individuals and their families for their entire lives. As a result, we are now providing support to many aging individuals. Values inform our practice and have always been at the heart of inclusion Powell River's services. Key to providing respectful supports to people as they age is our steadfast belief that a good life should also include a good death. As an organization, we maintain a lifelong commitment to individuals, and have worked hard to adapt our highly personalized supports in order to honour and accommodate the aging processes of the people we serve. Martha's story is illustrative of some of the strategies we were able to employ to support this woman's changing needs thereby ensuring she not only aged in the right place, but also that her death exemplified this same care and concern.

Throughout much of her early years, Martha was a very active, healthy woman whose daily walks took her all over her community. She had been married as a young woman and had become a parent. When the marriage broke down, she was able to raise her daughter with the assistance of her mother. Later in life, Martha successfully lived in a companion model home with roommates, and regularly attended and enjoyed, a community based day program. She continued to be active in the community, and was an enthusiastic member of her church. Martha was an assertive woman, clear about her preferences, and loved to be the first at everything from bowling to eating a meal. This character trait sometimes meant that sharing space proved difficult and Martha was far happier when her home life provided the opportunity for her to be the number one priority!

Later in life, Martha moved into a shared living situation and happily resided in this home for almost 10 years. As she aged, her health began to decline signalling that different kinds of supports would be needed to support her quality of life and aging. Through conversations with her family and friends, Martha choose to move into a



Martha

residence where she had a staff team available around the clock. Her health continued to shift quite dramatically and she was diagnosed with bowel cancer which resulted in surgery and a colostomy. Additional, complicating health issues continued to develop. After a lengthy stay in the hospital, Martha was able to return home with additional supports and the understanding that she might need to be admitted to ECU. Although some consideration was given to admitting her to a long term care facility, Martha's circle of support could not imagine that this option would be successful. Knowing her as they did, they envisioned the stress that waiting for assistance, and the realities of coping

with a large group setting, would create for Martha. Although bringing Martha home would require some creative solutions, everyone in her circle was convinced that her quality of life could only be maintained by finding a way to do so.

Vancouver Coastal Health, along with Martha and her family, and the leadership at inclusion Powell River, agreed that personalized care was vital. Together, with some financial support provided by VCH, they determined that an extra allocation of four hours per day, and some adjustments in the schedule, would keep Martha at home for as long as possible. These discussions also included thoughtful considerations of how to monitor Martha's changing health, schedule adjustments that would be supportive, and which safeguards were needed. The emphasis was on her quality of life, maintaining her relationships with family, her peers, and familiar members of her staff team, and sustaining her involvement in events and activities in the community. Her staff team focused on helping her regain her strength and recover her feisty spirit. Martha's family was intimately involved in the planning and decision making. Sensitive and emotional conversations had to occur as planning regarding end of life care had to be on the table. inclusion Powell River worked with their staff team to be creative about scheduling to ensure that Martha's house mates maintained their active lives in the community, while at the same time honouring their interest and desire to spend time with their friend. As ever, the focus remained on what each person wanted and needed, while maintaining the intended goal of Martha being at home.

By the end of the summer of 2016, Martha's health was showing marked decline. She had little appetite and was losing weight. and she became increasingly ill. A visit to the local emergency department confirmed that she was palliative and had very little time left. Her support team knew that getting Martha home was a priority. Two days

later, Martha died in her own bed, in her room, holding her daughter's hand. Her bedroom was a special place; painted exactly the colour she wanted, the walls adorned with pictures of her daughter, her grandchildren, and her brother. Her roommates and support staff were able to spend time with her to say goodbye in her final hours and days.

Both before Martha's death and afterwards, inclusion Powell River leadership team members focused on providing support to Martha's housemates and staff team. We hosted conversations with the members of her household about anticipating Martha's death and provided easy access and welcome to her family. The family was responsible for the funeral arrangements and welcomed the involvement of her support team.

Providing end of life care to individuals has led to changes within inclusion Powell River. We offer extra training for staff, encourage team members to access their employee assistance plan, and consciously work to attend to the bereavement needs of the people we serve, and those we employ, by hosting meetings and bringing in resources and supports as needed. We are deeply aware that a focus on relationships will necessarily require attending to grief and loss; we have made a lifelong commitment to those we serve and diligently work to live into that commitment.

Martha's brother helped to craft this story and when we talked about the things that were important to include, Bruce offered his heartfelt response:

"Martha felt loved, needed, and wanted by the people at her home. On behalf of Martha's family, I would like to express how grateful Martha was to spend her last years and days loved and care for by inclusion Powell River and the team at Golden House."

Focus on Intentional Safeguards

Safeguards are actions that help a person to be safe in community, to take advantage of opportunities, and which help to prevent harmful things from happening. Safeguards may be specific to the individual and their family, or apply to everyone in community. They may be formal or informal in nature. Safeguards which are identified through person centred planning are intentional and individualized. They are designed to address the unique situation of each person and critical to successfully supporting individuals throughout their aging process.⁹

Feedback from participants at the community forums highlighted the following ways in which safeguards play an essential role in our thinking about aging.

There's no place like home

Aging in the right place is key to maintaining quality of life; a stable, safe home is critical to successful aging. This looks different for different people, depending on their preferences and changing health or mobility needs. Sometimes it means staying in the same home and making physical modifications such as widening doorways and adding ramps, or adding assistive or adaptive devices such as ceiling tracking. Sometimes it means moving – where thoughtful planning that honours people's needs and preferences makes all the difference to the outcome. In addition to thoughtful considerations about where a person lives, long term relationships, including those with caregivers and support staff, are key to having good lives as people get older.

Service providers and family members described the necessity of actively planning for the future with aging in mind. Community living service providers who attended the forums, recommended leveraging their existing housing assets, where possible, to help purchase or remodel homes to ensure accessibility and design features can accommodate people's changing needs as they age. Anticipating aging is vitally important.

⁹ CLBC has developed a collection of resources on safeguards including: Responding to Vulnerability and Addressing Personal Vulnerability through Planning. www.communitylivingbc.ca



Creating a Home for Life



On March 30th, 2016, Elinor Mary Valeriotte passed away from complications associated with surgery. Elinor was deeply loved by her family and by her community. Her celebration of life welcomed almost 200 people to join with her intimate circle in honour of her passion for a life well lived. At the time of her death, Elinor's parents, Gene and Mary, had contributed this story for publication.

It chronicles their efforts to create a long-term and stable home for Elinor... her "home for life", as they planned for their eventual deaths and their daughter's future needs. Gene and Mary have generously agreed to have their story included in this resource in the hopes that it offers ideas for other families and in memory of their beautiful daughter Elinor.



Elinor and her parents, Gene and Mary Valeriotte

Our daughter, Elinor, had Rett syndrome, a neurological disability that requires round-the-clock care. Until April 2014, she lived full time at home with me and my husband, Gene.

We moved from Ontario to Victoria over a decade ago, were both retired, and thoroughly enjoyed having Elinor at home. We were in no hurry for her to move out. Elinor's care was still a manageable team task, we were comfortable with her day program, and she travelled everywhere with us and loved it.

However, as we aged, caring for her became more difficult and we recognized that we needed to ensure that Elinor would be cared for by others, especially when we were no longer around. Her brother and his family live on the Sunshine Coast. Although we anticipated that Jeremy would always be involved in Elinor's life, in our estimation it would have been unfair to expect him to undertake the full time care of her.

We had been active in the community living movement in Ontario, so once in Victoria, we again became involved

with the service system network including local agencies. We knew what we wanted for Elinor: a secure, genuine, home for life. We were able to participate in a Family Support Group, hosted by Community Living Victoria, where we met other parents. These conversations allowed all of us to consider how future needs could be addressed. Through this group, we met another family with the same hopes, values, and aspirations for their daughter - the symmetry between our two families enabled us to begin working together towards achieving our common aims. By sharing our resources and ideas we felt we could produce a creative and thoughtful plan with which to approach CLBC whom we knew would need to be a partner in our process.

We registered Elinor with CLBC for future residential care but were not yet in crisis so we included no concrete plan. In 2008, our two families began to get serious. Strategic planning, facilitated with the support of Community Living Victoria, helped us to focus on what, when, and how to proceed. We agreed to aim for our own home 4-5 years hence.

We attended many meetings with CLBC staff and considered various scenarios.

Although Home Sharing¹⁰ was suggested as a possible option, we rejected that for our daughter. Permanency was always our priority and we had concerns that down the road even the most well meaning caregivers would not be able to sustain her care and she would be moved on to different arrangements. We visited several group homes, some of which were excellent but had no vacancies. Our ultimate preference, and the path we ultimately pursued, was to build a home for Elinor and secure caregivers who would support this option.

Cooperation and negotiation, rather than confrontation, were our guiding principles. The challenge was finding the best fit where a reasonable budget could be presented to CLBC for their consideration. At times we felt optimistic... at times we felt like giving up. We returned to the conversation with CLBC several times trying to fine tune different versions of our proposals. After much deliberation, and through consulting with the Advocate for Service Quality,¹¹ we worked through the complaint

¹⁰ Home Sharing is a residential option in which an adult with a developmental disability shares a home with someone who is contracted to provide ongoing support. The home is the primary residence of both the individual being supported and the person offering support. Shared living includes home sharing and live-in support. Within home sharing, the contractor controls the home through ownership, lease, or rental. Within live-in support, the individual controls the home.

resolution process with CLBC. We were fortunate to have kept good records of all our meetings and so could make a solid case. Our family was successful at reaching a resolution with CLBC that we were pleased with; individualized funding to support our daughter's care and her home for life.

The search for a house, and an agency to administer the funds, followed. Shekinah Homes Society agreed to be the Host Agency. We bought, renovated and adapted a house and our daughters gradually moved in early 2014. My message to other parents is that early planning for the future is definitely necessary. In our case I wonder if we were perhaps guilty of not wanting to face the future soon enough.

Shekinah uses live-in caregivers (following their previous affiliation with L'Arche), thus, as we proceeded with renovations, we extended the home to include a suite for the live-in-caregivers who became an intimate part of the circle of support for our daughters. We were delighted with the result. The house coordinator and caregivers proved to be excellent, the neighbours were welcoming, we developed an open and friendly relationship with staff, and most importantly, always felt welcome and free to visit at any time. Elinor loved to walk on the local streets and her personality and ready smile encouraged relative strangers to respond. She became a member of her neighbourhood, valued and recognized by others who lived in the same part of her city.

In order to maintain aspects of the formal relationship between our two families, we constructed a detailed legal agreement which defined finances and responsibilities for utilities and maintenance of the home, with rental income substantially offsetting costs. We were always acutely aware that funding is not infinite, and so made innovation, cooperation, and family leadership (without a sense of entitlement) hallmarks of our process and interactions. We will always be grateful to CLBC for accepting and supporting our unique model and also to the agencies (particularly Community Living Victoria and Shekinah Homes Society) who advised and encouraged us along the way.

These are the facts; the feelings and emotions are less easy to describe. Emotionally, it was a long, sometimes difficult journey. There were many times when, as Elinor's mother, I said that my head knew that we had chosen the right path, but my heart was not always in sync. The process of our daughter's adjustment to her new home was gradual. Upon reflection, I can now say that we are confident that Elinor was very happy and really enjoyed her own "home for life".

The family with whom we partnered in this project is fully committed to maintaining the "home for life" for their daughter. They are now working with us, two other families, and CLBC to ensure the legacy of our work and vision meets the needs of all involved.

You gotta have friends

An intentional focus on the developmental and maintenance of resilient personal support networks can be a critical safeguard throughout people's lives. A strong network can help provide vital advocacy, contribute to authentic planning, facilitate community contribution, honour choice and voice, and lessen the potential for social isolation as people age. Building and maintaining strong networks requires intentional and sustained effort.

What protects the future... a family's reflections



While the safeguard of a stable home was considered a critical asset to successful aging, so was a strong personal support network that promotes and sustains authentic membership in community.

Donalda Madsen talks about her family's partnership with their local community living society and the emphasis they have placed on relationship building for their son's future.



The experience of parenting, when your son or daughter has a developmental disability, more often than not differs from the typical trajectory of life's milestones other families know. Our responsibilities as parents carry on - well into our son's and daughter's adulthood, and, into our retirement years. As parents, one of the things that has nagged at our hearts since the time our son entered school was what the future would bring for him; specifically, what would happen to him, how to protect and safeguard his wellness, his comfort, and his safety in the event we were not in his life. Shane is now 50 years old and it is many years since he entered and finished school. These same worries have not diminished; they wash over my husband and I daily.

It is in the past few years, that more urgency in addressing these concerns has developed. As a family, we allowed ourselves the privilege of believing that because we had many things looked after, other things could and would just fall into place. We have been well supported by the Langley Association for Community Living; we have enormous trust and confidence in the organization and a secure and trusting relationship with the Executive Director, Dan Collins. Shane is alive and well in community, and yet we know this is not enough to protect his future.

Many things have changed our perspective and planning for Shane's future. We had begun our initial thinking about options as far back as 1987. The choices we made were centred around his brother, Shannon, who we believed was the obvious candidate for advocate and champion when we were gone. Shane's brother was his best friend. Shannon also challenged us, as parents, to exercise more bravery and to consider more possibilities, as we thought about Shane. As a family we determined that a safe and secure future would need to ensure that Shane would have a home that was accessible and meet all of his needs in the future. We began to plan and actually build that home.

Our plans, and this version of the future, were shattered when three weeks before we moved into our new accessible home, Shane's brother died tragically in a car accident. We not only lost our son; we had to learn how to

¹² More information on Representation Agreements can be found at www.nidus.ca



Shane

navigate the complicated aftermath of our grief. Shannon's death also triggered new and critical issues for our family, leaving us with a more profound sense of distress in asking the question: "What will happen now after we are gone?"

It took many years, but we were finally at a place where we were strong enough to form a Friendship Circle for Shane. This circle was an intentional process on our part to build a network of individuals who we could count on to help support Shane, fulfill his wishes, and help him live his life well into the future. Through that circle, he now has a Representation Agreement¹² in place. We are also now in the process of adopting some strategies that we believe are vital in order to safeguard these measures. Regardless of the faith we have in our local association for community living, and its leaders, at a deep level we understand that

paid services won't keep our son safe. We truly believe that his future is more secure if Shane has deep and authentic involvement in his community and breadth and depth in his relationships; as a neighbour, a friend, as a volunteer, as a customer of businesses, as a citizen of his town. No amount of service can offer the power of having your story known and honoured by others. Our focus is promoting Shane's connections - having him known and valued all over town. These relationships offer natural safeguards. Shane is known, he is valued and his friends notice if he's not around.

We currently share our home with a young woman. She and Shane are quite compatible and we are planning for them to remain living together in our family home. With appropriate supports, we believe that we can achieve our vision that they continue to enjoy the quality of life that they currently have and are able to age in the right place for them.

A key factor in our family's planning process, and one we wish to emphasize, is that we are proceeding in a deep partnership with the community living agency we have been associated with for so many years. This relationship is one characterized by a long history of trust and dependable support which has been invaluable to our family all throughout our journey. Our family has been served by an organization that is deeply committed to hearing and honouring the voices of the people they serve and their family members - they emphasize relationships and community as the centre of where solutions for the future are to be found. We believe that Shane will be able to continue to live in his home as he does now; and we are also aware that fulfilling this dream will require the ongoing commitment and support of both CLBC and LACL to sustain it.

Plan with aging in mind

Aging offers an opportunity to look forward to the future. Whole life planning works best in anticipating and preparing for aging - including consideration of health supports, legal and financial needs, accessing appropriate technology and mobility adaptations, and anticipating crisis management and response. Successful planning is pro-active and person-centred. For some people with developmental disabilities, who may also have concurrent and/or complex health challenges, the aging process may begin at a younger chronological age. The need to host pro-active conversations about anticipated changes thus may need to start sooner. A planning focus, which considers transitions and progressive aging, reflects and respects these important life shifts.

Building Faith in the Future



Terry and Gord Robertson live in Prince George. Their experience as parents highlights the importance of thoughtful planning from very early on.

They also discuss the unique circumstances for the whole family and describe their micro-board as an example of one strategy for anticipating the future.





Bree-Anna and her brother, Drew

Our daughter Bree-Anna is an adult now, but our family started thinking about and searching for a way to support her future needs when she was very young. In our experience, planning, when a family member has unique and specialized support needs has to start early. The future has to be much more deliberately navigated; aging sometimes has to be anticipated at a much earlier point in life.

Bree-Anna needs care for every aspect of daily living, and while she doesn't talk like most of us, she clearly tells us what she does and does not like. We think Bree lives a life very rich in opportunity and contribution. She loves to travel and it is her real passion. She has been to many

places in the United States but her favourites are Disneyland and Las Vegas. She is a bright lights and action kind of girl! She has traveled in BC and Alberta, where she loves to visit her brother Drew and his wife Krysta. Bree spent 7 years at the College of New Caledonia and has volunteered at the Salvation Army and the Canada Games here in Prince George. She spends a lot of time with her 6 little cousins who live in town and are often at our home for a little babysitting and sleepovers. Bree loves to babysit. She is the watchful supervisor while Mom and Dad do all the running, which entertains her greatly. Those little children love spending time with her, watching movies and camping out in her bedroom. While she loves all that activity, life for Bree can be fragile and we juggle her wants

and desires with the reality of her physical and mental health needs.

Her brother Drew, a fierce and loving sibling and her champion, was expressing his concern for her needs by the time he was 5 years old. He was asking family members to never marry, have children, or move away so they would remain in our community and help him care for his sister when Gord and I had passed away. By the time he was 8, he was asking if then Prime Minister Kim Campbell had changed the law so he could marry his sister so no one could take her away and hurt her. His passionate commitment to her started young and will continue forever.

It was clear very early in both our kids' lives that we needed a way to support each of them to live lives that allowed them to reach their potential and not have Drew be solely responsible for his sister when we were gone. We did not presume or assume that her brother Drew would automatically accept a caregiving role. Our searching led us to Vela Micro-board Association in 2000. We knew we had found the answer to our questions about Bree-Anna's future with a strategy that would support both children and allow family and friends to be part of the solution.

We have been fortunate that our family have been very supportive and committed to the micro-board we have created for Bree-Anna. We deliberately chose to create a micro-board that was multi-generational and reflects a wide circle of people who love and have a deep connection with our daughter. At the point of our initial incorporation as a micro-board, our society consisted of Bree and Drew's Grandma, her dad Gord and I, Aunties Nicole, Kim, and Sandi, cousins Rob and Randy, and family friend Carmen. Since then we have added 2 more people; niece Jessie who is the same age as Bree, and daughter-in-law Krysta, bringing the total to 11 members.

Our reasoning for a multi-generational board was to mentor and train younger family members to navigate the service world and negotiate contracts with CLBC and the

Ministry of Health. We wanted everyone on the board to fully understand Bree's day-to-day care requirements and the supports which she would need for her to fully realize a quality life. They have learned to hire staff and run the business aspects of the micro-board so when we get too old to do these things, or if something happened to us, there would be a number of people who know what kind of life we dream of Bree living. They would work together to safeguard Bree's life in the absence of her parents being here to direct things in person.

We have two members of the micro-board who can do payroll. Two of the members have been involved in our Human Resources responsibilities, including hiring, evaluation, and dismissal process for Bree's staff. We typically meet every couple of months but will meet more frequently if the need arises. We usually meet for a meal so we are together and as many of the board are present as possible to discuss what is happening now, what isn't, and how these things inform future planning for Bree-Anna. We include Drew and his wife Krysta in our meetings from their home in Edmonton. They use their Wii U video game console to connect with our Wii and show up on our living room TV large as life. Bree-Anna loves this part of the meeting when her big brother is live on the living room wall! We have actively used technology as part of maintaining our circle.

Having said all of that, our micro-board is most importantly about safeguarding the future through intentional connections of the heart. Everyone involved has made a very personal commitment to Bree-Anna and her future, a commitment for the long term. The long term includes good times and tough times, supporting her to have rich life experiences including travel, parties, baby showers, being a maid of honours at a wedding, and much more. The commitment is for surgeries and seizures, disappointments, and days that are too nasty to go out in the cold. The people who are in Bree-Anna's circle cheer her up and spend time with her. The relationships are reciprocal - we are in awe of her joy, strength and resilience.

The micro-board has played a role in creating a future for both Bree and Drew. So much so that Drew felt he could leave our hometown 6 years ago and move to Edmonton with his girlfriend Krysta. He has confidence in the circle of support that has been created and is no longer constantly worried about his sister. He knows there is a caring group of people around her here at home who will move heaven and earth to make sure Bree is happy. Drew is only a phone call away. The family members he made promise to help him care for Bree continue to support Drew and Bree-Anna all these years later after he asked them for their help when he was a small boy.

It would be an understatement to say that we didn't get a set of instructions on how to raise a child like Bree-Anna. Parenting is a tough job with typical kids, throw in a child who literally can't move or speak and it takes you into a whole other world. The hands on personal care we provide has taken a physical toll on our bodies likely accelerating some aspects of our own aging. In Bree's lifetime, we estimate we have dealt with about 120 medical

professionals, dozens of teachers, dozens of social service workers, and politicians. It's not what typical families are doing on a daily basis - we aren't complaining...life is just different. We spend hours helping our 30-year-old child pick clothing, pick movies, arrange outings - most parents aren't doing those things after 30 years. This reality means that conversations about our aging and Bree-Anna's have had to happen earlier and have happened differently than in some families.

We have done the best we can and have taken what some might think are risks to enhance Bree's quality of life but we wouldn't change any of it. We have prepared the micro-board and shared our hopes and dreams, created a P.A.T.H.¹³ with input from Bree-Anna and everyone around her. We are as ready as we can be for whatever life deals us. We have peace of mind, faith, and confidence in the abilities and commitment of the fabulous people on Bree's board to continue providing her with the amazing life she wants and deserves.

¹³ A P.A.T.H. is a planning process which helps picture and direct future hopes and dreams. For more information and training tools regarding P.A.T.H., including videos, refer to the website for Inclusion Press at: www.inclusion.com/vdpathtraining

Aging in the right place



In this story about Jim, Charles Fox provides an important example of the necessity of a holistic approach to supporting individuals and the vital role that experience and training play in maintaining quality of life and dignity for individuals as they age.

In my experience, I see little difference between aging with a disability and aging without a disability. We all start with an array of abilities that change as we age. Abilities that we take for granted when we are young become less acute as we get older, and may even disappear entirely. For all of us, there will be shifts in our abilities, which some might then label as a disability.

Some of my perspectives on aging have been reinforced through my relationship with a man named Jim. Jim lived with his parents when he was young, moved out of the family home as a young adult, and had been through several different living situations over the years. Jim was born with a moderate intellectual disability, and mild physical disability; with the right supports he was successful in achieving a certain level of independence which he enjoyed. When I first met Jim, his health was unfortunately worsening and, due to his cardiac issues, his doctor thought he was not going to live much longer.

In his early fifties, Jim had a stroke, which increased his physical disabilities more than before and began to have an impact on his mobility. However, despite these changes, he was still comfortable and able to manage living in a house with stairs, and did not need care at night. As time passed though, he began falling more frequently, particularly at night when he got up to go to the bathroom. Jim was also having fairly significant dental problems; his teeth were getting weaker and he was losing more and more of them. As a nurse, I've learned that careful attention to dental health is important at any time of life, however with an aging individual who is already frail, Jim's dental issues were a major concern for several reasons. There was worry that he was experiencing a lot of pain and that he was at risk for infections which could impact on his cardiac condition. As well, his tooth loss was having an effect on his dietary choices and therefore his nutrition. While his dentist recommended putting implants in, Jim's doctor thought he was too weak for the procedure.

Jim's family and friends felt strongly that that Jim likely needed to move to a home which offered more support in order to safeguard his health and well being. That is when

I met Jim - when he moved into our staffed residence. It is worth noting, that from my perspective, it was not Jim's identified disability that made his move necessary, but issues that many of us without the label of "disability" experience as we get older; mobility issues, falls, and dental problems for example.

Once Jim was settled in his new home, he began to thrive. The household rhythm was such that he could do as much or as little as his energy dictated - there were no extra demands on him and the pace of the household matched his. A very social man, Jim thoroughly enjoyed the connections with his peers. The social world of his home, and new friendships, enhanced his overall sense of wellbeing. He also had the benefit of staff support at night to assist him to get down the hall to the bathroom, thereby preventing falls and keeping him comfortable. These changes made a world of difference to Jim's health. His doctor, who had been very pessimistic about his future, now thought he was improved enough to go through with dental implants, a procedure previously considered too risky for consideration. Jim managed the dental procedures with minimal discomfort, and was proud to show off his new teeth after it was done. Jim's overall health continued to improve and his family remarked on how much Jim was enjoying his new home. "I love my house" he would declare. Now that Jim was living in a home where the natural changes in his abilities could be easily and successfully accommodated, he was free to enjoy his life without worrying about such simple tasks as getting up to the bathroom at night. As Jim would joyfully state, "I'm happy today".

Unfortunately, Jim had another stroke, this one leaving him unable to speak or eat in the ways he had done before. Neither of these changes have dampened his spirits however. He now eats via a tube feed and uses both a symbol board and a computerized talking device to support his communication. And, because of the experience and training of his support staff, he has not had to manage another move. Jim's support team received training in lifts and transfers, tube feeding, augmentative communication, and other individualized care needs in

order to assure his quality of life. Jim's daily activities have continued with minor modifications to his home and the addition of some helpful equipment.

Jim's aging process has been enabled and safeguarded because he can age in place in a home where his changing and increasingly complex needs can be met. He faces the same challenges as many members of our aging population do where they suddenly find themselves unable to cope in the environment they have spent many years in. The challenge of offering supports to honour the person's unique changes as they age is not an issue just for people with disabilities, but an issue that affects all of us.

The home where Jim lives has been designed to support individuals of all ages with mobility issues. Sustaining these resources is vital to creating the array of residential options that allow aging individuals to receive the supportive care they need without having to endure frequent moves every time their care needs change. It has been my experience that better outcomes for aging individuals are ensured when the safeguard of a caring, home environment can be sustained and maintained.

Working Together to Build Capacity

Our individual health and well-being are influenced by many factors including our personal characteristics, lifestyle, resources, and our ability to access necessary supports and services. Research on the social determinants of health affirm the interrelated nature and contributing factors of income and social status; social support networks; education; employment/working conditions; social environments; physical environments; personal health practices and coping skills; the impact of supportive and healthy child development; gender; and culture. Of vital importance are social connections, a sense of belonging, and the degree to which communities embrace and enable active aging. Focused, community building strategies have become the hallmark of many community living organizations, family groups, individuals with disabilities and partnering organizations. The vision is to create and sustain inclusive and welcoming communities; communities that are able to celebrate and safeguard aging persons with developmental disabilities.

The World Health Organization defines an age friendly community as one that “enables people of all ages to actively participate in community activities. It is a place that treats everyone with respect, regardless of their age. It is a place that makes it easy to stay connected to those around you and those you love. It is a place that helps people stay healthy and active even at the oldest ages. And it is a place that helps those who can no longer look after themselves to live with dignity and enjoyment.”

Feedback from participants at the community forums highlighted several strategies which can support community building, collaborative alliances, and aging.

Partnerships are vital

Successful practice focuses on a broad network of collaborative partnerships with other service providers, funders, health professionals, and generic community resources. These resources provide specialized knowledge, and links to other community services. Participants at the community forums emphasized the importance of learning about dementia, dysphagia, nutrition, and other health topics which impact on the quality of life of people as they age. Gaining access to and the effective utilization of these complementary resources is essential to successful aging. This includes thoughtful planning for end of life, accessing palliative and hospice resources, and building strong partnerships with legal and financial planners to support effective life planning for individuals and families as they age. These community partners help spread the web of care and concern beyond the paid service sector and enhance awareness of the needs of aging persons, regardless of disability.

Aging with Grace: Navigating the Hospital System



Aging in community may involve using the services of community hospitals on both an emergency basis and for regular treatment procedures. Being able to access these community resources provide a vital safeguard as people age, however many health care professionals have only limited experience supporting people with developmental disabilities.

Elizabeth Antifeau offers this illustrative story of an Emergency Department visit by a man named Ben, and how the supportive role of the caregiver encouraged a team approach with hospital staff that helped ensure positive outcomes for this individual.

Ben is a 52-year old man who has lived with Janice and Lyle, his home share providers, for the past 5 years. Ben has some on-going health challenges including living with diabetes and hypothyroidism. In addition, he has many chronic conditions which have resulted in frequent illnesses and encounters with the health care system. Ben has a few words he uses as part of his communication, he also has some sign language and many gestures that convey his intent. Ben's mother does not live in his community however she is an important part of his life and is his legal decision maker with respect to any health care decisions. On a recent evening, Ben became quite ill with a fever, vomiting, and abdominal pain. Janice brought him to the Emergency department, where the doctor decided to admit Ben for tests and observation. A comprehensive nursing assessment was performed to assist with developing a treatment plan. This assessment included six areas which are considered important to building a clearer understanding of who the patient is and creating an individual care plan, particularly in the case of seniors. Janice was interviewed and provided a helpful picture of Ben's typical health to support the assessment process and assist with staff response in the emergency ward. Her information and accuracy helped ensure Ben's health needs were thoroughly considered. The areas of assessment included:

- **Medication:** a current and accurate list of medications including dosages and dose interval was provided by Janice. Potential medication interactions can be averted; treatment plans often rely on this assessment.
- **Cognitive functioning:** Janice helped provide information about Ben with respect to his memory, thinking, judgement, and other skills. Special attention was paid to the possibility of delirium, depression, dementia, and the unique ways in which Ben may be demonstrating changes in this area.
- **Functional mobility:** Janice offered a clear picture of Ben's ability to stand, walk, and transfer from bed to chair. This part of the assessment is because extended bed rest can inhibit the person's capacity to perform



these functions as it contributes to muscle atrophy and reduced endurance. Strength and balance were also considered in Ben's mobility assessment.

- **Nutrition and hydration:** information about the amount and types of food and liquid Ben consumes, any swallowing difficulties and/or food allergies were provided.
- **Bowel and bladder management:** Janice described Ben's usual bowel and bladder function and how his current presentation varied from this. As a result, interventions, where necessary, were initiated to assist and comfort Ben.
- **Pain management:** Medications and other interventions (such as massage, exercise, or physiotherapy) to prevent, reduce, or stop acute or chronic pain were also reviewed to ensure his comfort.

Ben found the experience in the emergency area very distressing. He was upset, protesting he wanted to go home, crying and shouting, and rattling and banging on the bedrails. Hospital nursing staff, unfamiliar with Ben, were uncertain about his behaviours, what he was trying to communicate, or how to comfort him. His home share provider was able to offer essential information to help support the hospital staff be empathetic and care for Ben.

She described how Ben usually communicates his needs

and whether or not he was expressing fear, pain, and/or anxiety through his behaviours. Janice was also able to offer suggestions for ways that Ben could be comforted. These included reducing the stimulation in the room by closing the curtains, and Janice staying by his side in the emergency ward. With her support, he was able to become much calmer and was transferred to a semi-private room in the surgical ward, away from the busy Emergency department. The local CLBC office was contacted to advise them of Ben's hospitalization. Throughout Ben's time in the hospital, beginning at the initial admission to the emergency department, Janice ensured that his mother was aware of the assessment process and outcomes and with having her provide her informed consent for the treatment recommended.

It was determined that Ben had a twisted bowel. He underwent minor abdominal surgery. During his time in the hospital, Janice and Lyle took turns staying with him. In order to assist nursing staff to connect and support him, they provided information about his usual ways of indicating his needs, foods he enjoys, as well as daily routines and objects which provide comfort and would assist with adjusting to the hospital environment.

Ben was ready to go home after a three-day stay in the hospital. In anticipation of his discharge, planning involved a discussion with Janice and Lyle about wound care, follow up doctors visits, worrisome symptoms to be alert to, and accessing equipment he would need to assist him with walking and toileting during his recovery. Initial wound care was provided by Health Services for Community Living (HSCL) nursing support, however both Janice and Lyle were taught the care protocol so they could take over responsibility in a few days.

New short term medications were prescribed and information about managing these prescriptions and potential side effects was provided. The HSCL nurse was available to provide in home support and telephone consultation as needed. Ben's recovery proceeded well and he has resumed his regular routines. The support of Ben's caregivers was vital to helping ensure that all the necessary information regarding his health conditions and his personal care was exchanged with the hospital team. As a result, their support to Ben was better informed and his outcomes from his time in hospital were more positive.

Raise awareness

Promoting “age friendly” communities helps everyone age successfully in their neighbourhoods, towns, and cities. This means engaging with local governments, community organizations, and community resources to ensure access, and raise awareness about the needs and potential contributions of people with developmental disabilities. Many community based services may not have had the opportunity or experience of including individuals with developmental disabilities – they may need support, education, and mentoring to build bridges of welcome.

Age friendly communities support housing options which sustain participation and presence. For many people with developmental disabilities, their families and friends, there are serious concerns regarding any consideration of a return to an institutional setting. This is particularly traumatic for those who survived the experience of institutionalization. Collaboration, vigilance, and advocacy within community are important in making sure that everyone has options to age in the right place, where their personhood is protected, and where separation and segregation don't reoccur.

Look out life!



Richard McDonald is an articulate advocate for the rights of people with developmental disabilities. Along with others, Richard has been active in helping change people's attitudes and improve supports and opportunities in our communities through education and awareness projects.

As a senior himself, Richard offers his perspectives on aging well in his community and some of the ambitions he still has to fulfill. Richard was interviewed by Jandy who met him through her work in his community of Burnaby.



Richard McDonald was born in 1943 in Vancouver, BC. He was the sixth child in a family of seven children. Richard lived in both Woodlands and Tranquille. His experiences in these two large institutions in our province have been the source of his passionate advocacy on behalf of other survivors of institutions in British Columbia. Richard was a key member of the coalition who worked to ensure that the Centre Block at Woodlands was razed to the ground. For this conversation, Richard was interviewed by his friend Jandy. They talked about his getting older, what he knows now at 72, and what he feels he has yet to do.

When asked for his insights about getting older, Richard offered "the thing is, everybody is getting older...I just want to continue what I am doing...talk about things while I've got a good mind and can help people realize what aging is about."

Richard uses a ladder as his metaphor for the aging process - one side representing younger years, and the other the changes and rungs of aging.

"My way of thinking about getting older is you start at the bottom step and keep climbing, accomplishing things along the way. You climb up one side - to the mid point of your life, go over the top, and down the other. When you get to the bottom rung on the other side, you'll know you accomplished what you'd want to do."

Richard has a keen sense of responsibility to be a force of change; to challenge injustice and discrimination. To him, climbing the ladder of life is part of a commitment to accomplishing the changes he feels are necessary to help others with developmental disabilities live full, happy, and safe lives as members of their communities.

Richard recommends planning ahead to be responsive to the aging process, including ensuring a Representation Agreement is in place which includes all the important details. "People need to talk about getting older...others need to know what you want, and think about things so that they can help you." He also reflected on the importance of friends and family for support. "I never did



Richard and Jandy

get married or have children...one thing I wish I had done, (because) then I would have a family for support. I would have if I hadn't ended up in Woodlands - that was taken away from me."

Richard now acknowledges he is more concerned about safety in his neighbourhood, including advocating for better lighting at bus stops and the need for sidewalks to keep pedestrians safer. Stairs are more of a problem he must consider as he ages and he has made some recent changes in his housing as a result. "I could run up them when I was younger, but in my 70's, there is arthritis in one knee now...just another reason to be careful. I've noticed

my balance is changing and I have to hold on to a railing.”

When asked about what he knows now that he is in his 70's, Richard said, “I hope I've left a legacy for others to benefit from I want others to know what I did so that they can continue the work.” He is deeply proud of his involvement in bringing down the Centre Block at Woodlands and the creation of the Memorial Gardens there. He also knows how important it remains to keep speaking up for and with others about the harm that institutions have done in order

to prevent their use again to house people with disabilities.

Despite his many accomplishments, Richard has more to do. Although already a published author, he would still like to write a book of jokes to market and has aspirations of having his “name in lights as a stand up comic.” As he puts it, “I have accomplished a lot in my life, but there's more I want to do - look out life!

Strategic planning yields better outcomes

Anticipating the future requires thoughtful planning, especially if we are going to honour our commitments to sustain the lives of people with developmental disabilities in community as they age. Service providers that have incorporated aging into their strategic planning processes report more successful outcomes in supporting older individuals. The conversation on aging impacts budgets, infrastructure, training, recruitment and retention, as well as linkages to community resources, and health and wellness considerations for employees.

As well, family members reinforced the need to plan, well in advance, in order to safeguard the future and create the kinds of supports their loved one would need.

Honouring our Commitment



Janice Barr has been active in building welcoming communities for her entire career.

She provides this reflection on her organization's thoughtful strategies for honouring their commitment to community living for the individuals they serve.



In the 1980's and 90's, our organization the Richmond Society for Community Living (RSCL), was privileged to be able to assist a number of people, that had previously been institutionalized in one of the major institutions in the province (Woodlands, Glendale, and Tranquille), to come home and regain their rightful place in community. For RSCL, as with many other organizations, welcoming people home was not just about housing and care; it was the embodiment of a lifelong commitment. We promised that we would honour the person's wishes to live in their home and community through the course of their life. We remain faithful to this promise and we could not have imagined, at the time, the implications of this lifelong commitment.

As people age, our commitment to their personhood and the sanctity of home, has taken on a different and, in many ways, deeper meaning for the people we serve and RSCL. Most people leaving the institutions in the 80's and 90's were in their middle years. Approximately 30 years later, these people are now in the later stages of their lives and, our support and care has had to shift significantly to support their aging process and sustain and fulfill our commitment. For most people this has meant developing responses that are able to honour the person's or their family's desire to "age in place".

For our organization, supporting people to "age in place" began with considerations of whether or not where they were living was still meeting their needs and if not, what might require changing. These were essential conversations that led to renovating and re-purposing housing for people who were aging. As we pursued these adaptations, and thought creatively and through the lens of aging, our decisions and actions have led to a much more significant shift in the way the agency responds to all the people we serve. Below are a few examples of changes that have been adopted to help better support those individuals who are aging.

Renovations & Equipment: In order to accommodate people in their later years, we have had to renovate many of our properties including, creating accessible bathrooms, installing lifts, moving bedrooms to the main floor, etc.



"There's a difference between interest and commitment. When you're interested in doing something, you do it only when circumstances permit. When you're committed to something, you accept no excuses, only results."

– Ken Blanchard

These changes have prompted us to reconsider the criteria we use for our future purchases and leased properties. As opposed to renovating when the need is identified, we have decided to only lease and/or purchase properties that are accessible or can be easily modified thereby intentionally planning for the changing needs which aging may precipitate for the individuals we serve.

Assessment/Early Detection of Changes Associated with the Aging Process: We have often known the people we serve for many years and as such are able to discern both subtle and overt changes in their abilities. In order to support our person centred planning process, we now use an early detection screening tool for dementia for all of the people we serve.¹⁴ This helps us identify changes, hopefully well in advance of a crisis, and enables more proactive future planning with the people we serve and their families.

Planning in Anticipation of End of Life: Although planning has always been a hallmark of our services and supports, our response to the aging individuals who are part of the RSCL community, has renewed our focus on the importance of broaching the difficult questions (e.g. end of life care) before the situation presents itself.

Hospitalization and Post-Operative Care: Aging is often accompanied by visits to the hospital. Staff support in the hospital and advanced planning for post-operative care has been a significant issue which we identified required our attention and response.

To that end, we have created a respite option for people that may not be able to return to their home to receive post-operative care. In addition, we have made a commitment and arrangements to provide staff support to individuals during hospital stays. This support is particularly vital to safeguard the people we serve that do not have an active support network and to provide advocacy on their behalf.

On-going Professional Development: We realized that being able to successfully support people in their later years meant that we needed to learn new skills and develop expertise within our staff and our organization. As a result, we have initiated training for our staff teams on issues, skills, and techniques not previously part of our regular professional development. These areas include: dementia, end of life care, dysphasia, grief and bereavement to name a few.

It can be truly said that the commitment to community living is a success. We are privileged to be part of the lives of individuals as they age and although the changes required to respond to the advancing years of the people we support has not always been smooth, we have learned so much. The people we support continue to educate us on how to provide better support and we are grateful for the teachings.

And, most importantly, after more than 30 years, RSCL continues to honour its original commitment - to provide supports to individuals and their families throughout the course of their lives.

¹⁴ The NTG - Early Detection Screen for Dementia can be used for the early screening of those adults with a developmental disability who are showing early signs of a mild cognitive change or dementia. The tool can be found at www.aadmd.org/ntg/screening

The future depends on what we do in the present

- Mahatma Gandhi



Wendy Padwick explains the proactive and person centred measures North Shore ConneXions Society has taken so that people they serve can age in the right place.





North Shore ConneXions Society was established in 1956. As such, we now provide support to a number of individuals who are in their senior years and have long histories with people we serve.

One of the group homes owned by the Society was on a fairly large piece of property. The house on the lot however, was old and needed a lot of ongoing maintenance.

After spending years updating some of our existing homes to make them more accessible, we wanted to do some proactive planning. A committee was struck to explore the possibility of subdividing the large property and building a new home on one lot with the proceeds from the sale of the other lot.

Although the individuals who lived in the group home did not yet require any accessibility accommodations, we felt it was important to plan in preparation for the future and build a house that would allow the individuals to age in place.

In the fall of 2015 the people who live there moved back to their new house which has been designed to be fully wheelchair accessible. Equipped with wide halls and doorways, ramps, accessible bathrooms and an elevator, members of this home are now supported to gracefully age in place.

As we age, maintaining our independence as long as possible is something we all hope for. This is no different for individuals with developmental disabilities. We believe that the fine balance between maintaining independence and managing health and safety risks should always be approached from a person-centred perspective.

North Shore ConneXions Society supports a man who had previously lived independently and accessed the community on his own every day. As he aged, we noticed a change in his cognitive abilities. A transition plan was established to help him move to a more supported environment. Although he was open to the move, he still wanted to be able to access the community independently. However, concerns were raised over fears he might get



lost. In order to honour his desire for independence and mitigate safety concerns, he was asked about using a watch that allows staff to track his whereabouts from a computer. For him it is his “James Bond” watch - a successful option for his aging.



Other proactive measures or person-centred practices at ConneXions include:

- Completion of baseline assessments on all individuals in residential services. This provides historical information regarding skills and abilities which can be used as a reference point in the future.

- Individual, employee and family education on service and supports for seniors to expand awareness and skills.
- Fall prevention and memory retention class.

Biographies of Contributors

Cathy Alpaugh, Western Human Resources, Kelowna, BC

Cathy Alpaugh has been in the community living field in British Columbia since she moved here in 1988. She has held a variety of roles, including working in group homes and day services providing direct support, as well as participating as a member of the Provincial Review Team and Monitoring Group for four years.

She has been a program manager with Western Human Resource Corp since 2003 and is now responsible for much of the policy development, implementation and monitoring, as well as program direction. For a very important year of her life, she also worked as a Seniors' Coordinator at a community centre in Richmond. Western now has several homes well-suited to individuals with age and mobility related needs and she has been instrumental in their success.

Elisabeth Antifeau, RN, MScN, GNC(C), Nelson, BC

Elisabeth graduated from VGH School of Nursing in 1979, and her professional credentials include a Bachelors of Science in Nursing (UVic, 1986), Masters of Science in Nursing (UBC, 1997) and Gerontological Nursing Certification (Canada) since 2002. She has 36 years of front-line clinical, education and management experience working with older adult populations in acute, community, residential and mental health settings. Elisabeth works as the Home Health Practice Lead for Special/Complex Populations and Palliative & End-of-Life Care in Community Integration Health Services in Interior Health.

Over the past 10 years, Elisabeth has actively participated and contributed to many local and provincial level practice and research initiatives, focusing on caregiving and dementia, culturally sensitive dementia care, and the use of a palliative approach in nursing. She has developed a wide variety of best practice supports and is a regular speaker at interdisciplinary, educational events aimed at improving care for various vulnerable populations. Elisabeth is the author of the four part, free e-learning series, "Prevention, Screening, Diagnosis and Support for Persons with Developmental Disabilities who Develop Dementia": <https://goo.gl/gDTxyH>

Pam Balog, posAbilities, Burnaby, BC

Pam has been involved in supporting individuals with developmental disabilities for 25 years. She found her passion for community living when she landed her first job in the sector, assisting individuals who lived in Woodlands to move from the institution into a community home. Pam is currently a Team Manager with posAbilities, and is responsible for overseeing nine homes serving individuals with complex medical needs. The ages of persons served range from young adult through to octogenarian!

Janice Barr, Richmond Society for Community Living, Richmond, BC

Janice Barr has worked in the community living field for over 25 years. Her experience within this field is both broad and varied. Janice is currently the Executive Director for the Richmond Society for Community Living. Janice is a Social Worker by training and received her degree from the University of Victoria.

Lorna Dittmar, Prince George, BCc

Lorna has been a part of the community living movement for many years. She was the Executive Director for AimHi providing leadership for change and working hard to welcome people home from the various institutions into residences in her community during the pivotal deinstitutionalization years. Lorna then moved on to become the ED of Employment Action - an employment agency for injured and disabled workers. She has provided residential care for seniors and through this avenue was able to help care for her aging parents to the end of their lives. She has now retired from paid work, but volunteers for the Prince George Council of Seniors, and is chair of their Advocacy Committee.

Charles Fox, Victoria, BC

Charles is a retired registered nurse who worked in the community living field for many years. In his last role, he was part of the team at an organization in Victoria for 18 years, during which he had the privilege of supporting many adults with both physical and developmental disabilities. He has been an advocate for supporting individuals to age in their homes and for the vital conversations about end of life issues. He was responsible for creating responsive strategies to support people as they aged and supported his team members to build their skills and capacity to serve older individuals.

Brenda Gillette, Chilliwack, BC

Brenda Gillette has been a leader in supporting individuals with developmental disabilities for over 35 years. She retired as the Executive Director of the Chilliwack Society for Community Living in December 2015. Over the years, Brenda has been instrumental in planning and implementing changes to services to ensure they reflect the unique needs of both the consumers and their families. This includes developing and maintaining collaborative relationships with families including those who are aging. She has provided training and support to families both individually and in groups. In this capacity, Brenda has also been actively involved with families at the local, regional and provincial levels.

Pam Balog, posAbilities, Burnaby, BC

Pam has been involved in supporting individuals with developmental disabilities for 25 years. She found her passion for community living when she landed her first job in the sector, assisting individuals who lived in Woodlands to move from the institution into a community home. Pam is currently a Team Manager with posAbilities, and is responsible for overseeing nine homes serving individuals with complex medical needs. The ages of persons served range from young adult through to octogenarian!

Elizabeth Hamilton, Kamloops, BC

Elizabeth passed away on March 15, 2017 at the age of 94. She was retired and enjoyed movies, attending community concerts and other events, shopping, and relished socializing with friends both at the senior's program she attended, and around her kitchen table. Elizabeth lived in Kamloops, BC.

Roni Keely, Penticton, BC

Roni is one of her communities' leading volunteers – she actively supports several events on an annual basis and particularly relishes the social aspects of her involvement. Born and raised in Penticton, Roni is an exemplary representative of the ideals of active aging and giving back to her community.

Marie Yvette Lepage, Whitehorse, Yukon

Prior to working as a medical social worker in hospice and in palliative care, Marie Yvette Lepage spent many years assisting people with developmental disabilities and their families – as a community support worker and later as a social worker and therapist. Ms. Lepage is currently in private practice, in Whitehorse, Yukon where she also teaches part-time with the Bachelor of Social Work program at Yukon College. She explored the experience of grief and loss for people with developmental disabilities in her graduate work. Yvette has graciously made her work available online: <http://www.mylepage.ca/>

Kim Lyster, Penticton, BC

Kim Lyster has had an extensive and successful career holding key leadership roles in the community social services sector for over 30 years including as the Executive Director of a large, multi-service non-profit organization in the South Okanagan region of BC. Prior to that, Kim provided leadership in community development, training, and advocacy initiatives in the community living movement, where she remains active as both a writer and consultant. Kim is the author of several publications, is respected for her innovative facilitation skills, and has extensive experience in program design, organizational reviews and evaluation, and community based planning and project delivery. Kim has a Bachelor of Education from Simon Fraser University, and a Masters from the University of Victoria in the Studies in Policy and Practice program. Her research focused on an examination of a sense of belonging.

Janice Michell, Victoria, BC

Janice is 65 and lives with her friend Diana, and her home share provider, Liana. Janice grew up on a farm and enjoys reading, watching TV, spending time with her boyfriend, and visiting friends at the Saanich Fairgrounds.

Richard McDonald, Burnaby, BC

Richard is originally from the Lower Mainland. He is an activist, a volunteer, a survivor, and an athlete. He enjoys bowling with friends, speaking engagements, tripping around local malls, and lunch out in the community. Richard is one of the leaders in our province who has been responsible for ensuring the voices of survivors of institutions are heard and has worked as a member of the We Survived Woodlands group to ensure justice.

Glen McClughan, Sunshine Coast Association for Community Living, Sechelt, BC

Glen McClughan cites meeting Jean Vanier in 1974 as his inspiration for developing his vision and values with respect to creating respectful, person-centred supports for people with developmental disabilities. He has lived and worked in L'Arche communities in Victoria, BC and in Calcutta and Bangalore, India. Glen has been the Executive Director of the Sunshine Coast Association for Community Living since 1998. He was also part of the team at the Community Living Society in Vancouver during the period of deinstitutionalization in BC. He lives in Sechelt with his wife Sue where he is an active part of community building projects for that area.

Donalda Madsen, Langley, BC

Donalda has been active in her advocacy for people with disabilities for over forty years, in part because of their son Shane, who they regard as a pioneer in the disability community. She has provided leadership on the Board of her local association for community living. Donalda feels the topic of aging is very important for families to discuss and plan for. She and her husband are reflecting on their own journey of aging while planning for their son.

Monique Nelson, posAbilities, Burnaby, BC

Monique is the Director of Community Engagement for posAbilities and enjoys her role providing leadership in the areas of communication and stakeholder engagement. Four years ago, she established a senior families support network, where parents convene to learn, share resources and support each other. Monique actively promotes family leadership in her work for the association and continues to appreciate the contributions of this group whose founding members are pioneers of community living. Monique also volunteers with the Family Support Institute of BC and serves as a director on the board of InCommon.TV, a storytelling society.

Wendy Padwick, ConneXions, North Vancouver, BC

Wendy worked in the community living field for over 30 years until her retirement in 2017. She was in her most recent position at ConneXions as the Director of Children and Family Services since 2006. Wendy was an active member of ConneXions Committee on Aging and provided leadership in supporting her organization to respond to the changing needs of the people they serve.

Lynn Roberts, Powell River, BC

Lynn is the Director of Adult Services for inclusion Powell River. She has worked on behalf of people with developmental disabilities for twenty-five years and is passionately committed to all individuals living the best life possible. Powell River is regarded as a model community for its supports to people with disabilities.

Terry Robertson, Prince George, BC

Terry is the mom of two children, Drew and Bree-Anna. Bree-Anna lives with multiple disabilities which has provided Terry with a life long learning curve to understand the supports, services and systems her daughter would encounter throughout her life. Terry now works in the community living sector supporting other families to learn, understand, and navigate these systems as well. Terry is a member of the Family Support Institute.

Diana Simmons, Victoria, BC

Diana is 64 years old and lives with Jan and their home share provider, Liana. During the day, Diana attends Good Neighbours in Langford. In her free time, Diana enjoys getting her nails done, organizing her room, watching TV, and talking about her day with Jan.

Mary and Gene Valeriote, Victoria, BC

Mary is now retired from professional life having been both a high school and university teacher. She has been active in advocacy for people with developmental disabilities having served on the Oakville (Ontario) Community Living Board of Directors before moving to BC. Mary continued her advocacy work as part of the Phoenix Human Services Association Board of Directors, CLBC South Island Community Council, and CLBC's Advisory Committee on Aging. Mary and her husband Gene, and another family, they were instrumental in building a home for their daughters.



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