

Aging with a Developmental Disability



A planning guide for families, personal support networks and other supporters of adults with developmental disabilities who are getting older

October 2017

A joint project of:

Community Living British Columbia (CLBC)

British Columbia Ministry of Health

British Columbia Ministry of Social Development and Poverty Reduction
Services to Adults with Developmental Disabilities (STADD)

Table of Contents

1. Introduction.....	3
2. A word about words... ..	4
3. Who is this guide for?.....	5
4. Networks of support are key	6
5. Getting ready to plan for aging	9
6. Making the plan	14
7. Caring for yourself.....	41
Glossary	43

THANK YOU!

Many people helped create this guide. Our thanks to:

- Spectrum Consulting (Shelley Nessman and Aaron Johannes)
- STADD Pilot Site on Aging Adults (John Bergman)
- Members of the CLBC Aging Advisory Committee
- Participants in community forums and conversations about aging
- Members of the STADD OAS Inter-Ministerial Governance Committee
- Jule Hopkins, Tamara Kulusic and Frank deWaard

1. Introduction

People with developmental disabilities are living longer, healthier lives than ever before. This is a result of improved medical care, as well as the improved quality of life that comes with living in community rather than in institutions.



While getting older is something many of us experience, it can look and feel different for someone with a developmental disability. For example:

- Aging-related challenges may happen earlier than for other people
- People may need to plan for changes in their supports and services
- The combined experience of age and disability can result in extra discrimination or isolation
- A parent or other caregiver may not be able to provide support anymore

Aging-related changes can often require changes in how we support individuals. In many ways, we are all discovering how best to do this as we go.

Like any changes in life, making a plan can be a big help. It can help you anticipate what might happen, what help might be needed, and what opportunities might present themselves. Thinking and planning ahead can help someone maintain their quality of life as they get older. And prevent crisis situations.

As part of implementing the *Community Living British Columbia (CLBC) Strategy on Aging*, we have created this guide to help you plan for supporting an adult with a developmental disability to age in community. This means staying, as much as possible, in the community, even though support needs may change. Aging in community also means having access to the same supports, services and opportunities as other aging people in the community, who do not have a developmental disability.

Aging in community is particularly important for people with developmental disabilities, due to the legacy of institutionalization. Many people lived in institutions earlier in their lives (the last institution in BC closed in 1996) and experienced the loss of self-determination, personal choice, and community connection.

We have organized this guide using the quality of life framework that has been adopted by CLBC. It offers a way to think and talk about an individual's life and the kinds of outcomes that form part of a good life in community.

In each section of the guide, you will find definitions of key terms, a checklist of questions to ask and things to consider, and a list of resources that may be helpful. We have also included some quotes from participants in the community conversations that assisted in the development of this guide.

2. A word about words...

Getting older will likely bring new people, services and decisions into the life of the person with a developmental disability you support. New words can go along with these. You are likely to run into some terms you may not yet be familiar with.



We use the term 'aging' in this guide to refer to someone who is 55 years or older, or who is younger than 55 and beginning to experience aging-related changes.

Whenever we use a new term in the guide, we give a definition of it in a blue box. There is also a Glossary at the back that defines these terms and some additional ones you may encounter.

Throughout this guide, we use the pronoun 'he' or 'she' to refer to an aging adult with a developmental disability. This helps remind us that we are talking about an individual person when we are planning.

3. Who is this guide for?

We have designed this guide for people who support and care for people with developmental disabilities who are aging. This includes:



- Families
- Members of personal support networks
- Shared living/home sharing providers
- Agency staff who are involved in planning or coordination of services

In this guide, we use the term ‘supporters’ to refer to these people.

While we have not developed this guide specifically for aging self advocates, some may find it helpful. It does reference several related resources specifically designed for self advocates.

Planning is a lot of work. Getting help is important. This guide can help you think and talk about planning, aging, disability and inclusion and what those all mean to the person you support. Then you can work with him and others to create and carry out a plan.

This guide is only one of many resources you may need to plan. We have focussed on content that is about aging with a developmental disability. We highlight ways in which needs and opportunities related to aging may be different for adults with developmental disabilities than for other community members. And therefore where they might need to be specifically addressed in planning.

We have not included information about aging in general, or about planning in general. We do refer you to related generic resources about these topics where they may be helpful. And we encourage you to make use of and access community and generic resources as much as possible.

“As my sister and I age, I do notice differences. I have more time to socialize with friends, but we have to be much more organized to find things for her to do and people to be with her.”

4. Networks of support are key

As anyone ages, and as they develop aging-related conditions, they become more vulnerable. Loneliness and social isolation can become a part of their reality. For people with developmental disabilities, who may already live with vulnerabilities or social isolation, this can be magnified or play out differently.



DEFINITION: What is vulnerability?

Being vulnerable means you are at risk of being harmed or having bad things happen to you. This can be physical harm, emotional harm or financial harm. We can all be harmed, so being vulnerable is part of being human. People with disabilities are more likely as a group to experience greater vulnerability. They are also often more severely affected by the vulnerability they experience.

This increased likelihood and greater impact is called **enhanced vulnerability**. Enhanced vulnerability happens because people with disabilities are more likely to experience disadvantages in life and often have fewer opportunities. This comes from factors such as having less money, limited access to resources, fewer friends and close relationships. It also comes from negative treatment by others.

Everyone has vulnerabilities. However people with disabilities or people who are older have less power to deal with them.



Here are some ways that vulnerability and social isolation can manifest for a person with developmental disabilities who is getting older:

- Losing connections with people after retiring or leaving a volunteer position
- Not taking part in community inclusion activities due to reduced mobility
- Not accessing all the financial benefits she is entitled to
- Loss of a long time caregiver due to their own aging
- Loss of a sense of belonging if he has to move to a new home or neighbourhood or away from his community
- Death of family members or friends who support her
- Support networks that become fragile and vulnerable if a key person coordinating things gets ill, moves away or dies

These kinds of vulnerabilities do not have to result in smaller lives or less quality of life for people. Having meaningful relationships is the key to aging well in community. Networks of support are an important safeguard in helping people stay well, be safe, have opportunities and feel a sense of belonging.

They offer opportunities not just for the person being supported, but also for participants and the broader community to create innovative community-building strategies that can benefit many other vulnerable people.

DEFINITION: What are safeguards?

Safeguards are things we do on purpose to help reduce someone's vulnerability.

Formal safeguards result from laws or policies or funded services.

Informal safeguards result from caring connections between people.

We all need a mix of formal and informal safeguards in our lives. A network of support is one type of informal safeguard. It is made up of two or more people who care about the individual and who work together to help and support him to be safe and well. Families, friends, neighbours, co-workers and members of the local church are examples of who may be in a support network.

Having a strong network of support that works together to support an aging adult is likely the most important thing to pay attention to in planning. Attracting new people to join the network, educating them, and coordinating what they do with more formal safeguards and services are all important. It is about developing capacity with and around the person.

Networks can also help an individual develop self advocacy skills and confidence. Building and maintaining a network requires intentional effort.

Family members are often the leaders of a network but not always. Different cultures have different concepts of family. There can also be ‘chosen’ family – people who feel like extended family even though they are not actually related.

Families may have many overlapping roles. They often organize and coordinate actions or activities. They may also facilitate conversations – not always easy ones. They are usually the ones who know the individual’s ‘baseline’ best, and can see changes.

Sometimes brothers and sisters or in-laws who may not have been very involved until now are looking for a ‘way-in’ to the person’s life as they all get older. It is important to remember that parents and siblings are also aging and may need supports themselves in order to maintain the relationship with the individual.

Other families can be a great help. There are support groups and networks at the local and provincial level that can provide information, mentoring, training and a listening ear.



5. Getting ready to plan for aging

Planning is a lot of work. Getting help is important. This guide is designed to help you think and talk about planning and work with the person you support to create and carry out a plan.



Planning is a process of identifying potential aging-related needs and opportunities, and deciding what you need to do, now and in the future, to respond to them. It is also about identifying who you can ask to help and how you intend to respond to changes - including unexpected changes.

Planning creates a team for figuring that out – or strengthens and empowers an existing team. Good planning results in you feeling more confident and knowledgeable about where to go for what, and when. It can help you and the individual with a developmental disability navigate the changes and opportunities that aging brings. And it can mean that the individual experiences less vulnerability and better quality of life as they get older, than if there was no planning in place. Good planning makes a difference. It enables people to provide direction for their future - to make sure others know what they want.

Think of it as transition planning – just like for other big life transitions, such as leaving school or moving away from home. You can incorporate it into annual planning reviews if you are already doing planning.

“f you don't design your own life plan, chances are you'll fall into someone else's plan. And guess what they have planned for you? Not much.”

Jim Rohn

Earlier is always better – being proactive means you will feel more prepared down the road, and less likely to have to respond in crisis-mode. Start by age 50 if possible– and definitely by age 55. Expect change – be prepared to revise the plan at least every year or two – or when there is a significant change in the person’s circumstances or the circumstances of their closest network members.

Remember to plan with the person, not for the person. The process is as important as the result. Think about who should be involved – it is likely that new people or agencies need to be included. Planning around aging must be collaborative, as the individual will likely have different needs and access different or more services as she gets older.

Here are some things to keep in mind as you get started:

- Start with what the individual already has – gather any existing plans and information about the person and review to see what is useful.
- People’s stories matter – and they need to be held by people who care about them. Their preferences, values, cultural traditions and life history need to be central to conversations around planning.
- Sometimes the most important positive result of planning is that the whole picture starts to emerge – instead of unconnected pieces and people not knowing what others are seeing or doing. This makes navigating the systems and complexities easier.
- Clarify the roles of the people around the planning table. Things can get quite complex. Someone needs to be the coordinator. Set up ways to communicate and share information.
- Look for positive opportunities as well as needs (many retail senior discounts begin at age 55 and community senior recreation programs may be a good opportunity).
- Document plans – write things down or use pictures or video.
- Set milestones or checkpoints to help you keep track of where you are at in planning and in implementing the plan.
- Be aware of new types of planning people need to consider as they age – such as wills, estate planning, and end-of-life planning.
- Plans only work if the right people know about them – be sure to identify who needs to know and then share with them and keep them updated.
- Planning should be balanced- focussing on both what is needed to support healthy aging and on what is needed to support happy aging - these things are really inseparable.
- Other people have done this before - ask for help and access resources.



CHECKLIST

- ✓ Where are we starting from? Is there already a plan of any kind? Is there background information, personal history, baseline health information, list of network members?
- ✓ Do you need or want to get help with making a plan?
- ✓ Do you have a clear process for how to approach planning? Is everyone on-board with it? Who is coordinating? Who is in charge of communicating? Do people understand each others' roles?
- ✓ Who is already involved in planning? Who should be involved in planning as the person gets older? Here are some possibilities:
 - Family, friends, support network members, neighbours
 - Staff from agencies providing service
 - Shared living caregiver
- ✓ Are there people who need to be involved in planning but cannot come to meetings? How to connect them?
- ✓ Do you have the information you need to get started – such as a list of generic supports for seniors in the community? Or will you generate that at the first planning meeting?
- ✓ Are supporters who might be involved also aging? Do they need support?
- ✓ Who needs to know about the plan? Service providers? Family doctor? Health Services for Community Living nurse? Other health care providers? CLBC facilitator? Neighbours?





RESOURCES

Here are some resources about planning with people with developmental disabilities that might help. They are not all specific to aging, but are helpful in setting out a process:

- Planned Lifetime Advocacy Network (PLAN) provides help with building support networks and facilitating planning:
www.plan.ca

- Information about safeguards and how to plan for them:
www.communitylivingbc.ca/individuals-families/support-for-adults/safeguards/ and
www.communitylivingbc.ca/learn-more/safeguards-publications/

- Safe and Secure: Seven Steps on the Path to a Good Life for People with Disabilities* by Al Etmanski, Jack Collins and Vickie Cammack:
www.safeandsecureplanning.com/get-the-book/
Print copies may be available through PLAN and at London Drugs

- Information for self advocates who want to take charge of their own planning:
www.communitylivingbc.ca/wp-content/uploads/Plain-Language-Planning-Workbook.pdf

- An inventory of resources on aging:
www.communitylivingbc.ca/projects/growing-older-in-community-aging/inventory-of-resources-on-aging/

- LOOKING FORWARD TO THE FUTURE: Supporting Individuals with Developmental Disabilities as They Age
www.communitylivingbc.ca/wp-content/uploads/Looking-Forward-To-The-Future.pdf

Here are some generic resources about aging. They are not all specific to people with developmental disabilities. However, they can be useful in helping figure out what to expect as we age and what aspects of life we need to plan for.

- ❑ Comprehensive list of services for seniors in BC:

BC Seniors Guide

www2.gov.bc.ca/gov/content/family-social-supports/seniors/about-seniorcbc/seniors-related-initiatives/bc-seniors-guide



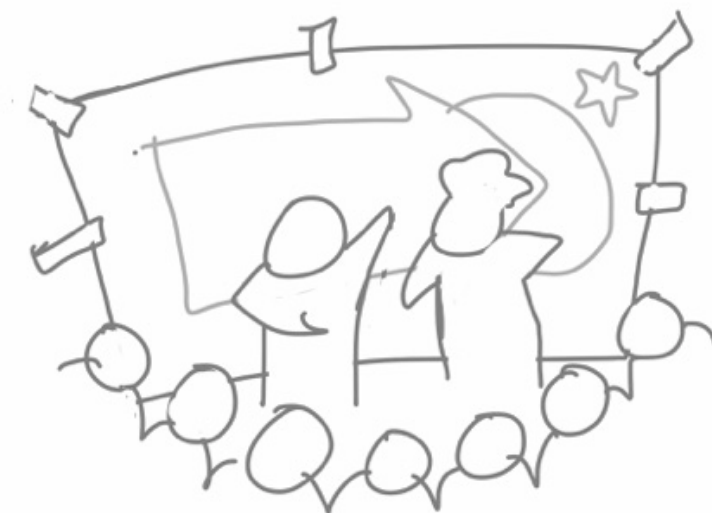
- ❑ An adapted version of the *BC Seniors Guide* done by the First Nations Health Authority for Aboriginal individuals and communities:

BC Elder's Guide

www.fnha.ca/wellnessContent/Wellness/BC_EldersGuide.pdf

- ❑ *Ontario Partnership on Aging and Developmental Disability Transition Guide:*

www.opadd.on.ca/Caregiver/documents/transitionguide-final-sept0105.pdf



6. Making the plan

This section uses the quality of life framework as a ‘way-in’ to creating or updating a plan. This framework has eight sections – called domains. Each domain has desired outcomes attached to it – aspects of an individual’s quality of life that are related to the domain. Use them as touchstones to help you figure out questions to ask and areas to focus on.



In this section, we set out the eight domains, along with these outcomes, and make some suggestions about things to consider in planning, and resources you can access.

There is more information under Domain #7 - Physical Well-Being – and Domain #8 – Material Well-Being - than the other domains. This is because so many of the changes related to aging are physical in nature and often generate health care-related needs. And because the financial safety net for individuals changes at age 65.

However don’t ignore the other domains. The other aspects of people’s lives are just as important. Be careful that physical changes and health care needs do not becoming the only driving force in planning, as that can lead to reduced quality of life and missed opportunities in the other domains.

There is of course some overlap among the domains, as life is a complex and inter-woven thing. Use the domains as they work for you.

At each stage, and especially when you feel stuck, ask yourself how can we support this individual to maintain her quality of life as she gets older?

“I am old enough to retire from my job, but now I get to do what I always wanted to do and be a volunteer with Habitat for Humanity. I like talking to people who are building things. I just love it!”

Domain #1: Personal Development

Quality of Life Outcomes

- Individual pursues his interests
- Individual has opportunities for personal growth and skill development
- Individual has access to necessary information and support

Many individuals and their supporters may be unaware of some of the personal challenges and opportunities for growth and learning that aging can present. Choices about retirement, volunteering, loss of loved ones and possible new roles, such as mentor, are things to think about.

Challenge yourself to think about ways to protect and enhance the individual's personhood and to look for positive ways that they can make a contribution and add value to their own lives and their community as they age. Plan for activities that make the person happy - that are important and meaningful to them, connect them to others and broaden their circle.



CHECKLIST

- ✓ What are the individual's gifts and where can he make a contribution?
- ✓ What are his interests, talents, hobbies?
- ✓ Are there new things he wants to learn about or get involved in?
- ✓ Goals? Things he wants to accomplish in this part of life?
- ✓ What opportunities are there in his community? Seniors' centre? Volunteering?
- ✓ Who on the team is best placed to help him pursue one or more of these interests or opportunities? How?
- ✓ What additional information do you need and who will get it?

Domain #2: Self-Determination

Quality of Life Outcomes

- Individual makes decisions in her life about things that matter to her

Individuals with developmental disabilities often face barriers to self-determination their whole lives. As they age, they will face decisions about some new things – such as retirement or end-of-life care planning. Maintaining self-determination to the full extent of their capacity is an important consideration in aging. Planning for that can reduce crisis situations – in which the individual often loses all self-determination.



CHECKLIST

- ✓ What are the things related to her aging that are most important to her?
- ✓ What decisions and choices does the individual make for herself now? Does she have help doing that?
- ✓ How can the person be ‘at the steering wheel’ of what comes next? What accommodations does she need to do that?
- ✓ Are you seeing or anticipating changes that may require some form of supported decision-making in the future?
- ✓ Does the person have a representation agreement in place now?
- ✓ Does the person have a will? Does she need or want a will? Are there estate planning considerations to be addressed?
- ✓ Does she want to make her wishes known about what happens to her belongings after she dies? Whether she will be buried or cremated? What kind of funeral or memorial she would like?
- ✓ Does the person want to create some instructions for end-of-life care? Has she been offered a way to do that? Health services providers, her doctor, and/or a church or other spiritual leader may be able to assist with advance care planning.

DEFINITION: What is supported decision-making?

Supported decision-making is a process to help an individual make decisions. About things like health care, personal care and finances.

You might do this informally, by speaking with the person about their options and rights, and answering their questions so they can make a decision. This might include helping them communicate the decision. However, no-one else is allowed to make a decision FOR the person.

It is important to learn about and develop formal agreements, such as representation agreements, to support people with decision making. A **representation agreement** allows the person to name someone to make decisions on her behalf. This cannot be a paid staff person and is usually a family member or friend.

DEFINITION: What is advance care planning?

Advance care planning is the process of learning, talking and deciding about what kind of health care a person wants in the future if she is unable to make or communicate those decisions herself.

This process involves conversations with family, support networks and health care providers. It is important that everyone understands what the person wants. When these wishes and instructions are written down formally, it is called an **advance care plan**.



RESOURCES

- NIDUS is a planning resource centre and registry that offers help with representation agreements and related issues:
www.nidus.ca/

- Information for self advocates who want to take charge of their own planning:
www.communitylivingbc.ca/wp-content/uploads/Plain-Language-Planning-Workbook.pdf

- Information from the Law Students Legal Advice Program about free legal advice and representation for individuals unable to afford legal assistance:
www.lslap.bc.ca/
604 822 5791

- A Notary Public offers a range of legal advice including advance care planning:
www.notaries.bc.ca/findnotary/searchform.rails

- A BC Ministry of Health guide for doing advance care planning:
www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf

- Information from the BC Ministry of Health on advance care planning:
www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning

- ❑ Each Health Authority has tools and resources for advance care planning:
 - Fraser Health:
www.fraserhealth.ca/health-info/health-topics/advance-care-planning/
 - Interior Health:
www.interiorhealth.ca/YourCare/PalliativeCare/ToughDecisions/Pages/Advance-Care-Planning.aspx
 - Northern Health:
www.northernhealth.ca/YourHealth/AdvanceCarePlanning.aspx
 - Vancouver Coastal Health:
www.vch.ca/your-health/health-topics/advance-care-planning/
 - Vancouver Island Health:
www.viha.ca/advance_care_planning/
 - First Nations Health Authority:
www.fnha.ca/wellness/sharing-our-stories/my-journey-into-advance-care-planning

- ❑ No Cardiopulmonary Resuscitation Form-HLTH 302.1; and No CPR MedicAlert® bracelet contact information:
www2.gov.bc.ca/assets/gov/health/forms/302fil.pdf

- ❑ Information from the BC Ministry of Health on how to have an expected/planned natural home death:
www2.gov.bc.ca/assets/gov/health-safety/home-community-care/care-options-and-cost/expectedplanned-home-deaths/expected_home_death.pdf

Domain #3: Interpersonal Relations

Quality of Life Outcomes

- Individual has meaningful relationships with family and friends

People may experience loss of a sense of belonging, connection, safeguards and dignity as a result of aging-related changes. They may lose continuity of contact and relationships with family and caregivers, especially if they have to move. Their supporters may face their own aging-related issues. Social isolation can become a real barrier to meaningful relationships. This is where personal support networks are critical. See Section 4 for more information.

Maintaining and even improving quality of life in this domain while aging is about careful attention to who is in the person's life and who could enter the person's life. It is about deliberately nurturing existing and new relationships.



CHECKLIST

- ✓ Who is already in the person's life?
- ✓ Who needs to be in his life as he and his family get older?
- ✓ Is there already a network in place? Is it written down? Is it mapped?
- ✓ Is there contact information?
- ✓ Do the individual and their supporters have a way to stay in contact?
- ✓ Who might the individual want to have in his network?
- ✓ Does the network reflect the individual's cultural background, community and preferences?
- ✓ Who in the network is also aging?
- ✓ Are the family's needs for support being met? How will these be met in the future?
- ✓ Is there a back-up if the main network coordinator gets ill or dies?
- ✓ Would this all work if the person went into hospital?



RESOURCES

Here are some CLBC resources you can get from your local CLBC office or at www.communitylivingbc.ca. While they are not specific to aging, they do offer ideas and guidance about vulnerability, safeguards and networks of support:

- ❑ A personal story about building personal support networks:
Building Personal Support Networks: Barbara and Zackery`s Story (video)
www.youtube.com/watch?v=qjrp8arezyM

- ❑ The Importance of safeguards in responding to people`s vulnerabilities:
Responding to Vulnerability: A Discussion Paper About Safeguards and People with Developmental Disabilities
www.communitylivingbc.ca/wp-content/uploads/Responding-to-Vulnerability.pdf


- ❑ A plain language guide about the process of building support networks:
Support Networks: A Guide for Self-Advocates
www.communitylivingbc.ca/wp-content/uploads/Support-Networks-A-Guide-for-Self-Advocates.pdf

- ❑ Stories about the unique connections families have built with their family members who have a developmental disability:
The Power of Knowing Each Other: Stories About Informal Safeguards Told by BC Families (joint with Family Support Institute)
[www.communitylivingbc.ca/wp-content/uploads/ThePowerofKnowingEachOther\(web\).pdf](http://www.communitylivingbc.ca/wp-content/uploads/ThePowerofKnowingEachOther(web).pdf)

- ❑ Stories celebrating how the relationships between brothers and sisters create more inclusive and safer communities:
Brothers and Sisters: The Power of Growing up Together (joint with the Family Support Institute)
www.communitylivingbc.ca/wp-content/uploads/Brothers-and-Sisters-FSI-FINAL.pdf

Here is an organization that has other resources about safeguards, families and networks:

- BC Family Support Institute
www.familysupportbc.com/



“As our parents aged we wanted to be sure we knew all the information necessary to support our brother – the part we hadn’t thought of was who his friends were, are and will be. Getting this information actually gave us a whole new sense of who he was and what people appreciated about him.”

Domain #4: Social Inclusion

Quality of Life Outcomes

- Individual participates in community life in roles she and society value

It can already be hard for people with developmental disabilities to make new friends and social connections in their community. And to keep the ones they have. This can get harder as they get older and perhaps live with new mobility or communications challenges. It requires planning and intentional actions.

At the same time, getting older is also a time for reflecting on life, for gaining wisdom and for finding ways to give back. Volunteering and mentoring are two ways to do that. There are positive opportunities out there – you have to look for them. Use the individual’s support network as much as possible, as they know her best. Local seniors’ centres can be wonderful resources. You may need to do some facilitating and educating to enable the person to access their services successfully. Look for cultural connections.

This domain is closely related to Domain #1 (personal development) and Domain #3 (interpersonal relationships). You can use the checklists and resources from those domains to help you here.



“I grew up in Japan. I feel at home at the Japanese Seniors Centre.”



CHECKLIST

- ✓ Do you know what roles the individual already plays or might want to play? Volunteer? Mentor? Role model? Is there a role that is specific to her culture?
- ✓ Are you clear on what social activities she is already doing? Where? With whom? What supports might be needed for her to continue?
- ✓ What else might be of interest to her or more appropriate as she ages?
- ✓ Does she already have people in her life who share her interests or activities? Could they buddy up to participate?
- ✓ Do you have information about local seniors' centres and seniors' activities in the community? Can someone on the planning team or in the network call or visit and find out more?
- ✓ Try creating a match map – things the person is interested in, things available in the community, and others who might go with her.
- ✓ What supports might be needed in order for the person to successfully participate? Transportation?
- ✓ Is the support for social inclusion now in place going to be transferable as the person ages?



RESOURCES

- Supporting friendships and social connections for people with developmental disabilities:
Belonging to One Another: Building Personal Support Networks
www.communitylivingbc.ca/wp-content/uploads/Belonging-To-One-Another-final.pdf

Domain #5: Rights

Quality of Life Outcomes

- Individual has autonomy
- Individual's decisions are respected

People with developmental disabilities who are getting older often face discrimination, accessibility or attitudinal barriers, and ageism, when accessing services, expressing their preferences, or protecting their personal privacy. They often do not have the knowledge or support they need to recognize and address violations of their rights. Vigilance and advocacy become more important.

Changes related to communication can add to this challenge. They can affect an individual's ability to communicate their wishes and to manage in difficult situations such as a hospital, with new caregivers, or in discussing difficult emotional or spiritual topics such as end-of-life care. As much as possible, help the person communicate in the environment they are most comfortable, with the supports they prefer. Use different ways to prepare someone for an unknown situation – such as drawings or videos. As someone ages, individualized and adaptable approaches to communication may be needed.

Individuals, and their families, may also not be aware of legal and personal rights issues they may face as they get older.

This domain is related to Domain #2 (self-determination). Check back to Domain #2 to help you here.

DEFINITION: What is an advocate or a self advocate?

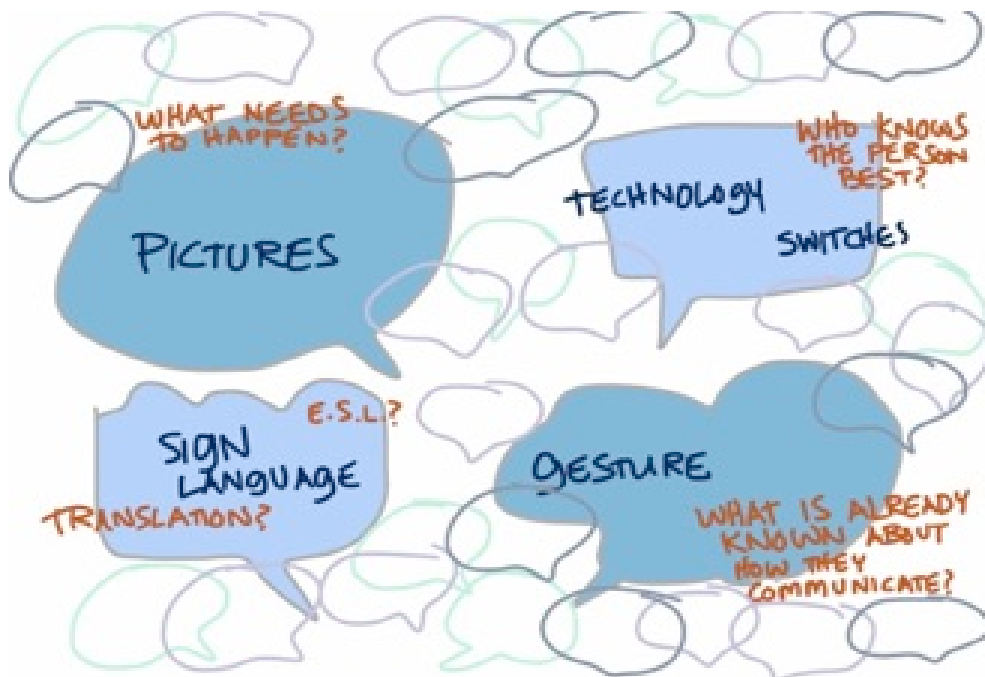
An advocate speaks or writes in support or defense of another person. He or she does not speak on behalf of the person or make decisions FOR him. No-one else is allowed to make a decision FOR the person.

A **self advocate** is a person with a disability who speaks up for himself.



CHECKLIST

- ✓ Does the person advocate for himself? Does he need more help to do that as he gets older?
- ✓ Does he have information about what his rights are?
- ✓ Does he want or need an advocate?
- ✓ Is there already someone in his life who can help him be understood?
- ✓ Is his communication changing? Why?
- ✓ Does the person have learning disabilities that affect how he communicates?
- ✓ Is there an up-to-date communication assessment? Does it include a plan for how to best help him communicate? Does it include hearing, speaking, seeing and understanding?
- ✓ Are there concerns about his privacy or how others are treating him? About protection from elder abuse and neglect?





RESOURCES

- Office of the Seniors' Advocate:
www.seniorsadvocatebc.ca/

- The Office of the Advocate for Service Quality (OASQ) provides support for adults with a developmental disability:
www2.gov.bc.ca/gov/content/family-social-supports/services-for-people-with-disabilities/supports-services/advocate-for-service-quality

- Information about seniors' rights and elder abuse and neglect:
www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/protection-from-elder-abuse-and-neglect

- B.C. Centre for Elder Advocacy and Support:
www.bcceas.ca/

- Canadian Network for the Prevention of Elder Abuse:
www.cnpea.ca/en/

- Information for self advocates on their rights and being safe in community:
www.communitylivingbc.ca/wp-content/uploads/Rights-and-Safeguards1.pdf

“I had just met her and was trying to understand what she was saying; I thought she was gesturing and I didn't understand some of what she seemed to be saying. Later on I found that she had been spelling, making letters to spell out what she was saying.”

Domain #6: Emotional Well-Being

Quality of Life Outcomes

- Individual feels safe in her home and community
- Individual has a positive sense of self and trusts the people in her life

Having conversations about an individual's emotional state can be difficult. People are not always able or willing to express how they feel, and whether that is changing. They may wonder about what it will be like to get old, whether their family will be there to support them, what will happen when they retire. They may feel upset or confused about new routines or health care procedures they are not used to.

Individuals may not have dealt with long standing challenges or issues in their lives. Individuals receiving services and support may or may not have ever participated in planning for their future. Some individuals or care teams may hesitate in planning for the future due to concern that it might disrupt current services. Loss of family members and friends through death or illness will happen as the person gets older. For healthy processing, loss needs to be acknowledged – often many times. People who know the person very well are key here. Personal support networks that can create and sustain safeguards are vital. See Section 4 to help you here.



CHECKLIST

- ✓ Does the person have a confidante – someone she talks to about her feelings and how they might be changing?
- ✓ Is the person grieving? Does she have someone to talk to about it?
- ✓ Does the person want to attend the funeral of a loved one? Or create other ritual acts of remembrance? Who will help her with that?



RESOURCES

- ❑ *Supporting People with Disabilities Coping with Grief and Loss* (booklet)
www.easyhealth.org.uk/sites/default/files/SUPPORTING%20PEOPLE%20WITH%20DISABILITIES%20COPING%20WITH%20GRIEF%20AND%20LOSS.pdf

- ❑ LOOKING FORWARD TO THE FUTURE: Supporting Individuals with Developmental Disabilities as They Age (See Grief and Loss Page 44)
www.communitylivingbc.ca/wp-content/uploads/Looking-Forward-To-The-Future.pdf

- ❑ Local counselling services, universities with counselling students, or hospice facilities may have grief counselling services, including private and group grief counselling or social groups.

Domain #7: Physical Well-Being

Quality of Life Outcomes

- Individual is physically healthy and active
- Individual has access to the health care he needs

The physical changes that come with aging can be significant and limiting. They can be gradual or sudden. Here are some of the common areas where you may see changes:

- Sleeping patterns
- Swallowing
- Mobility
- Nutritional needs
- Dental needs
- Hearing or vision
- Sexual health

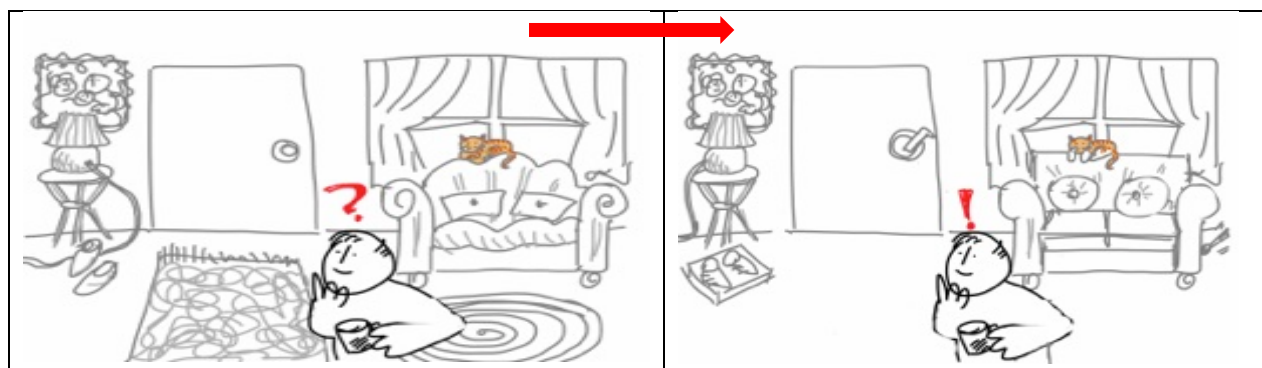
It is important to have good baseline information about the person's physical health and abilities. And to have people involved who are spending time with him and can notice small changes and track them. Using standard checklists, such as the frailty tool listed under Resources below, to establish a baseline and track changes can be very helpful.

It is also important to focus on positive actions to prevent or slow down these changes. This can lead to conversations about things like exercise, good nutrition, cultural supports/connections, social interaction and preventative care such as massage. These are things we know help determine how healthy a person is. Think of these things in a holistic way.

The impact of physical changes can result in someone having to move to a new home and maybe a new community. The intent of aging in community is to support an individual to stay in their own home as long as possible, and to make the transition to a new home as easy as possible, if it has to happen. Planning ahead can make all of this much easier.



Staying in his own home can sometimes be a matter of simple changes, such as replacing doorknobs with handles, getting furniture that is easy to get in and out of, or clearing away scatter rugs or other tripping hazards. If things need replacing soon anyway, think about replacements that will support accessibility. Occupational therapists can often help with this.



Changes in mobility can affect not only how someone gets around in their own home, but also in the community and on the bus. Services such as HandyDart can be accessed.

Communities often have seniors' health services for all aging adults - such as fall prevention clinics. There is also Home and Community Care and Health Services for Community Living (HSCL), through your regional health authority, that may be able to assist with planning around physical changes, or direct you to someone else in your community who can. Home and Community Care or HSCL may provide a range of supports including: nursing, occupational therapy, nutrition, dental hygiene, and mobile labs for individuals needing help managing diseases or wounds, or help such as fitting for equipment or meal planning coordination. They may also be able to suggest fitness or other programs, and advocate with specialist health care providers.

More regular doctor's visits may be a good idea. Finding a family doctor is important if the person does not have one. It is also important for people to have a dentist and have regular dental check-ups because dental changes may occur for people as they age. Screening tests for conditions such as high blood pressure, cancer and diabetes are also helpful. Perhaps consider a referral to a geriatrician - a doctor who specialises in treating seniors with multiple conditions. AwareShareCare.ca is a website that was developed to increase awareness and understanding about the needs of aging adults with developmental disabilities in the health care community and for families and caregivers- visit this website to learn more.

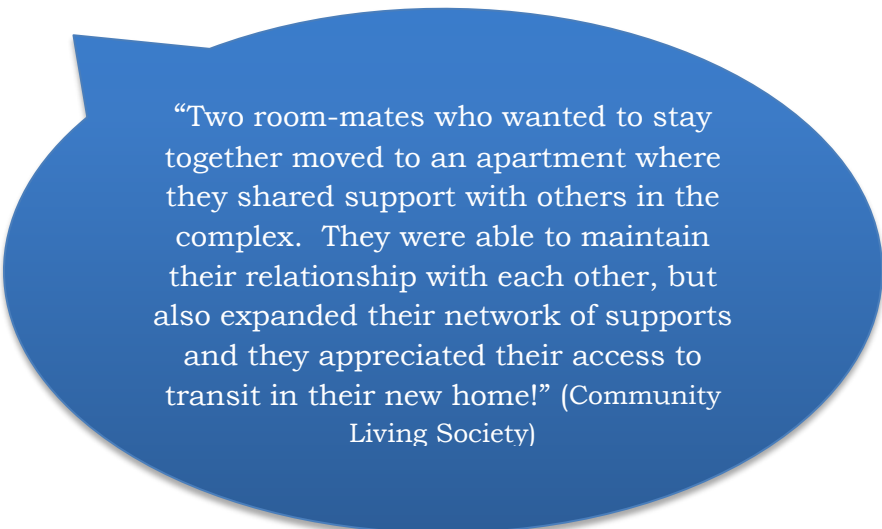
While doctors and dental professionals won't likely be members of an individual's planning team, their role is essential to an individual's overall health. They are usually the ones designated to follow up after a hospital stay or a specialist assessment, and who make referrals for additional tests or assessments. Consider ways to ensure their roles are addressed in the plan.

Preparing for physical exams is important. Make sure the person has a list of their concerns, and someone to help them if they need assistance expressing themselves to the doctor. Regular reviews of medications are particularly important to avoid drug interactions that can themselves contribute to physical symptoms such as dizziness or falling. Pharmacists can help with this.

One of the most challenging health changes that can come with getting older is changes in mental health or dementia. It is important for individuals with developmental disabilities, their families and caregivers, to check changes in their thinking ability that may impact behaviour and skills in daily living. A tool has been developed specifically for use with aging adults with developmental disabilities. See the link to the *National Task Group Early Detection Screen for Dementia* on the Resources list below.

This tool helps track changes that may be early signs of memory loss. Use it to review and share information to start the conversation with health care professionals. It is not an instrument for the diagnosis of dementia. The intent is that supporters will use the information to begin a dialogue with health care practitioners and that it will serve as an aid to shared decision-making.

People with developmental disabilities may be more likely to require mental health supports than others, and yet have difficulty accessing such supports. Community Living BC can assist people to learn about referrals for to a local Developmental Disabilities Mental Health Team (DDMHS) for information and support.



“Two room-mates who wanted to stay together moved to an apartment where they shared support with others in the complex. They were able to maintain their relationship with each other, but also expanded their network of supports and they appreciated their access to transit in their new home!” (Community Living Society)

Regardless of what aspects of physical or mental health you are planning around, expect to need to advocate for services the person needs. And you will also need to follow-up often to make sure everybody involved is aware of changing needs.



CHECKLIST

- ✓ Does the person see a doctor regularly? Is he accessing all the health care services he needs and that are available to him?
- ✓ Do all caregivers and supporters have up-to-date health information so they are doing the best job possible supporting the person? Are prescriptions being well-managed?
- ✓ Are there new health care providers in his life who need education about how to interact with and support him?
- ✓ Is he having trouble getting around? Doing things he used to do on his own? Getting to neighbourhood services or using the bus?
- ✓ Has there been a home assessment done to identify any barriers to the person staying there for, say, the next five years? Do you have the information you need to make such an assessment?
- ✓ Do you need professional help with a home assessment? Referral to an occupational therapist?
- ✓ Can family help with the cost of home adaptations or equipment needs? What about applying for grants? Finding an equipment lending service such as the Red Cross?
- ✓ Is there a plan for supporting his fitness and nutritional status? Do you need help with this? Is Meals on Wheels an option?
- ✓ Do supporters need more training about aging-related health needs?
- ✓ Does he need a referral for mental health assessment or support?
- ✓ Has someone been identified to accompany him to Emergency if that happens?

“What worked really well for him was staying in the home he knew, but moving downstairs.”
(Home Share Coordinator)



RESOURCES

- For information or support in finding a family physician:
[A GP for Me](#) website

- Call your local Home Health Unit or go to your health authority website to find out how to contact Health Services for Community Living (HSCL) or Developmental Disabilities Mental Health Service (DDMHS):
www.healthlinkbc.ca/services-and-resources/find-services
www.healthlinkbc.ca/services-and-resources/guided-search

- Guide on Maintaining Seniors' Independence Through Home Adaptations:
www03.cmhc-schl.gc.ca/catalog/productDetail.cfm?cat=17&itm=51&lang=en&sid=tYQyG3yRPUo9uDUSzdy0bIMKiMQZgSdwe8nN2t018dZQTehySujcbAWLCgquoGDf&fr=1489099803817

- Home Adaptations for Independence (HAFI) – a BC Housing program to support people to stay in their own homes:
www.bchousing.org/housing-assistance/rental-assistance-financial-aid-for-home-modifications/home-adaptations-for-independence

- Healthlink BC has a seniors health section on their website:
www.healthlinkbc.ca/health-topics/center1031

- Information for health care providers and supporters about health care needs of aging adults with developmental disabilities living in community: www.awaresharecare.ca

- Dial 811 to speak with a public health nurse anytime free of charge:
www.healthlinkbc.ca/services-and-resources/about-8-1-1

- Keep Talking About Dementia* (booklet from Downs Syndrome Scotland)
lx.iriss.org.uk/sites/default/files/resources/Keep%20Talking%20About%20Dementia.pdf

- National Task Group Early Detection Screen for Dementia (NTG-EDSD)
aadmd.org/ntg/screening

- BC Ministry of Health's Frailty in Older Adults tool:
www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/bc-guidelines/frailty

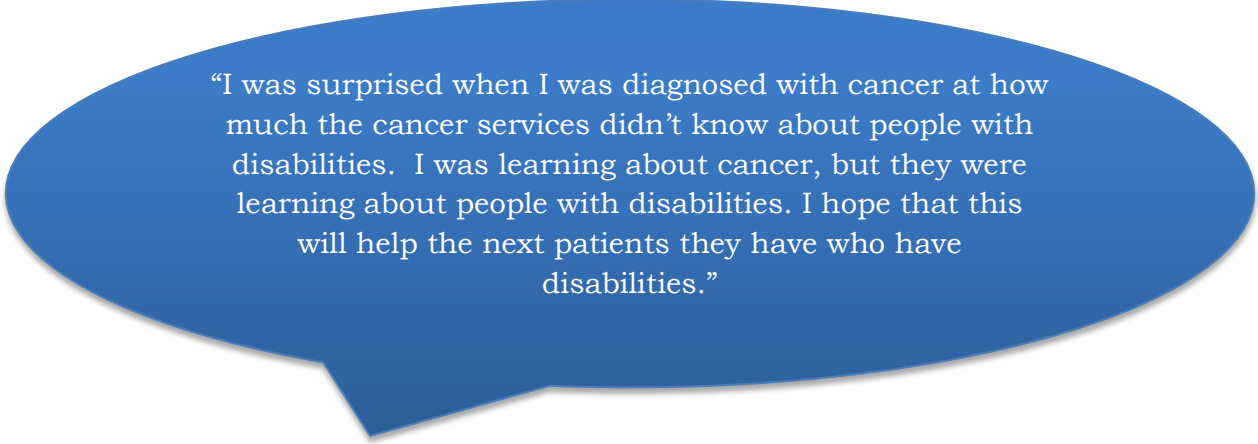
- Alzheimer Society of B.C., Dementia Journey Program:
www.alzheimer.ca/en/bc/We-can-help/Dementia-education/Shaping-the-journey

- British Columbia Association of Lifeline Programs:
www.bclifeline.com

- Physical Activity and Aging in Canada* (video series from Western Canadian Institute for Aging and Activity)
www.uwo.ca/ccaa/research/stories/aging_demographics.html

Aboriginal Resources

- First Nations Health Authority:
BC Elder's Guide
www.fnha.ca/wellnessContent/Wellness/BC_EldersGuide.pdf



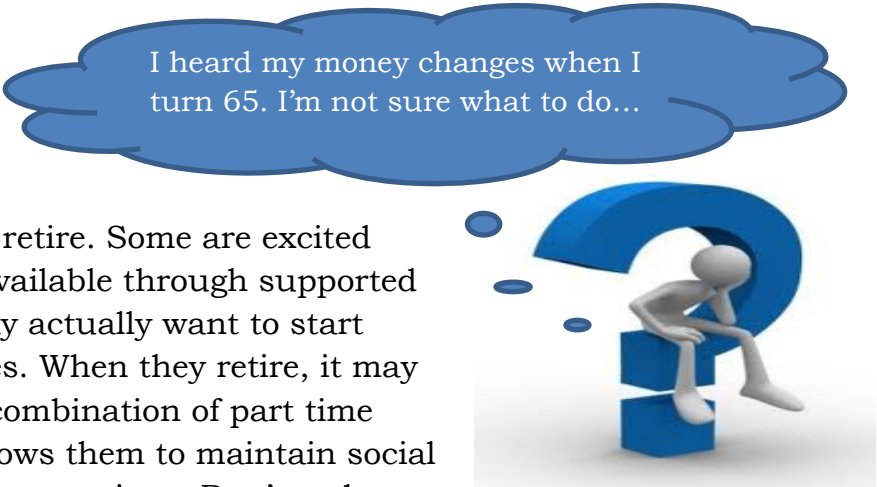
“I was surprised when I was diagnosed with cancer at how much the cancer services didn’t know about people with disabilities. I was learning about cancer, but they were learning about people with disabilities. I hope that this will help the next patients they have who have disabilities.”

Domain #8: Material Well-Being

Quality of Life Outcomes

- Individual has the financial resources to do the things that are important to her

More and more individuals with developmental disabilities are working. As they get older, they may wish to continue working, or perhaps reduce their hours or retire. Some are excited about the new opportunities available through supported employment programs and may actually want to start working in their fifties or sixties. When they retire, it may look a bit different – maybe a combination of part time work and volunteering that allows them to maintain social relationships and community connections. Don't make assumptions.



I heard my money changes when I turn 65. I'm not sure what to do...

Whether or not they have worked, or want to continue working, planning is important to ensure they have the resources they need to live a good life. There are some key things that change at age 65:

- Persons with Disabilities Assistance (PWD) from the provincial government ends.
- People become eligible for Old Age Security (OAS), and depending on their income level, also for Guaranteed Income Supplement (GIS). These come from the federal government through Service Canada.
- Service Canada does not make direct arrangements with landlords or service providers to pay individuals' rent, as PWD does in some situations.
- People can keep the medical and dental benefits and bus pass they received with PWD after they turn 65, but must apply for these.
- If somebody worked, he or she will also be eligible for Canada Pension Plan (CPP). For married individuals, there is also a spousal supplement that may be available.

- ❑ If they already get disability benefits from CPP, the amount changes.
- ❑ If there is a lag in getting the OAS, GIS and CPP benefits in place, people can apply for a PWD monthly ‘top-up’ until the paperwork goes through.

For most people applying for OAS and GIS can be a bit challenging and may mean a lot of paperwork. Most people will need help with it.

It can be confusing, stressful and time consuming. It can take a long time to hear back after you apply.



The individual can sign a *Consent to Communicate* form allowing a supporter to talk to Service Canada on her behalf. Other agencies, such as Canada Revenue Agency, Medical Services Plan, Pharmacare and some First Nations governments, have similar forms to enable someone to get a supporter to deal with the agency for them. This can be very useful, as it is not uncommon that there will be confusion amongst agencies and someone will need to sort it out and coordinate.

Some individuals manage their own money successfully and may want to continue to do so. Others may be having trouble, be in debt, need or want more help. Others may already have someone else do it for or with them. Changes in physical and cognitive health can result in changes in any of these arrangements. Watch for signs that people may need more assistance.

Estate planning by parents may become important. Parents with the financial means may want to make arrangements for the ongoing financial support of their family member after they die. Trusts and Registered Disability Savings Plans (RDSPs) are two ways to do this. RDSPs in particular require advance planning as they must be set up before the person turns 59 – and before they turn 49 in order to get matching contributions from the government.



CHECKLIST

- ✓ Are the person's taxes up to date? It is important to make sure taxes are done before applying for OAS and GIS benefits. Taxes need to be filed for at least two years before turning 65.
- ✓ Is the person applying for the disability tax credit if she is eligible?
- ✓ Has the person applied for OAS and GIS? This should be done as soon as she turns 64. They require separate forms.
- ✓ If she has worked, has she applied for CPP? This can be done as early as age 60.
- ✓ If she is already getting CPP disability benefits, has she checked with Service Canada to see what may change when she turns 65?
- ✓ Is she married and her spouse already on CPP? If so, applying at age 60 for spousal supplement is possible.
- ✓ Has she applied to keep her medical and dental benefits and bus pass after turning 65?
- ✓ Does he want to name a supporter to speak with Service Canada on his behalf? Has this been done?
- ✓ Does she want to name a supporter to deal with other agencies on her behalf? Has this been done?
- ✓ Does he want or need someone else to manage his finances, pay his bills etc. for him?
- ✓ Is she likely to receive an inheritance at some point? Is planning in place for managing that?

"I want help continuing to manage my own money as I get older. I don't want people assuming I can't continue to decide how I want to spend it."



RESOURCES

- Information and forms about OAS, GIS and CPP through Service Canada:
www.canada.ca/en/services/benefits/publicpensions/cpp/old-age-security.html
1 800 277 9914

- More information and forms about CPP through Service Canada:
<https://www.canada.ca/en/services/benefits/publicpensions/cpp.html>
1 800 277 9914

- Information and forms about PWD benefits, medical services only coverage and bus passes after age 65: www.sd.gov.bc.ca

- Information from People's Law School about financial benefits for seniors:
www.publiclegaled.bc.ca/when-im-64-benefits/

- VanCity credit union workshops on banking and money management for everyone:
www.vancity.com/AboutVancity/Events/EachOneTeachOne/

- A guide on how to open and manage a bank account:
Banking Made Clear (Barclays)
www.bild.org.uk/EasySiteWeb/GatewayLink.aspx?allId=3748

- Information about registered disability savings plans (RDSPs):
www.rdsp.com

- Financial literacy/RDSP hotline for persons with disabilities operated by PLAN:
1 844 311 7526

- ❑ BC Ministry of Social Development and Poverty Reduction *Disability Assistance and Trusts Booklet*:

www2.gov.bc.ca/assets/gov/family-and-social-supports/services-for-people-with-disabilities/supports-services/disability_assistance_trusts.pdf

- ❑ Agency in Vancouver that can assist people with managing their finances (The Bloom Group):

www.thebloomgroup.org/our-work/adult-guardianship/

- ❑ Credit Counselling Services of BC provides help with managing finances and getting out of debt:

www.nomoredebts.org/

- ❑ Public Guardian and Trustee of British Columbia, Financial and Personal Care Management Services, can manage care and finances for individuals who cannot do it themselves and have no-one else to do it:

www.trustee.bc.ca/services/services-to-adults/Pages/personal-planning.aspx

7. Caring for yourself

As a family member or other supporter of an aging individual with developmental disabilities, you may at times find yourself feeling stressed-out or overburdened. You may also be experiencing changes in your own life.



Families may have been playing this role for decades already and now find the impacts of aging are adding new challenges. Families may also be feeling the impacts of their own aging and may not have as much mobility or energy as they used to.

Taking care of yourself is vital if you are going to be able to continue in your role supporting someone with a developmental disability as they get older. So is asking for help, educating yourself, and planning.



CHECKLIST

- ✓ Are you aware of services and supports that can assist you and your family member or the individual you support as you both age?
- ✓ Do you have the supports in your life to maintain your own health and well-being?
- ✓ Do you have access to formal or informal respite services?
- ✓ Are you able to participate in activities - with or without the individual you support – activities that bring meaning and enjoyment to your life?
- ✓ Are there younger family members you could ask to get more involved?
- ✓ Do you feel like you've planned appropriately for yourself and for the family member or individual you support?



RESOURCES

- BC Family Caregiver Support Line:
1 877 520 3267

- Family Caregivers Network Society
fcns-caregiving.org

- Family Support Institute of BC
www.familysupportbc.com/

- A great resource for caregiver awareness and self care:
alzheimer.ca/en/bc/Living-with-dementia/Caring-for-someone

Glossary

Advance care planning	The process of learning, talking and deciding about what kind of health care you want in the future if you are unable to make or communicate those decisions yourself.
Advocate	Someone who speaks or writes in support or defense of another person. He or she does not speak on behalf of the person or make decisions <u>FOR</u> him.
Ageism	Prejudice or discrimination based on a person's age.
Aging in Community	Being in the right place and accessing the right supports and services to continue to live a good life in community while growing older.
Consent	Giving permission for something to happen – often related to a health care procedure.
Representation Agreement	A written legal agreement that allows a person to name someone to make decisions on their behalf. This cannot be a paid staff person and is usually a family member or friend. Also called a rep agreement.
RDSP	Registered disability savings plan- is a plan that gives parents and others a way to save for the long term financial security of a family member with a disability who is eligible for the Disability Tax Credit.
Safeguards	Things we do on purpose to help reduce someone's vulnerability. Formal safeguards result from laws or policies or funded services. Informal safeguards result from caring connections between people.
Self advocate	A person with a disability who speaks up for herself.
Social isolation	Ongoing lack of contact with other people.
Supported decision-making	A process to help an individual make decisions about things like health care, personal care and finances.
Supporter	Someone who cares for and about an individual with a disability. Includes family, support networks, caregivers and service providers.
Transition	The process or period of changing from one situation or state to another.
Vulnerability	Being at risk of being harmed or having bad things happen to you. This can be physical harm, emotional harm or financial harm. Everyone has vulnerabilities. However, people with disabilities or people who are older have less power to deal with them.
Well-being	A good or satisfactory state of existence, usually characterized by health, happiness and comfort.



**COMMUNITY LIVING
BRITISH COLUMBIA**

1-877-660-2522

www.communitylivingbc.ca

To find the online version, please visit:

www.communitylivingbc.ca/aging