



RESPONDING TO VULNERABILITY

A DISCUSSION PAPER ABOUT SAFEGUARDS & PEOPLE WITH DEVELOPMENTAL DISABILITIES

Developed by Community Living British Columbia (CLBC)
For Discussion with Self-advocates, Families, Service Providers,
Caregivers and other Concerned People

April 2007

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Introduction

Community Living British Columbia (CLBC) has prepared this paper for discussion with all kinds of people who have a connection to people with developmental disabilities. This includes individuals who have developmental disabilities and the people who care about them - families, friends, advocates, caregivers, and service providers. In this paper, we call these people concerned citizens.

The paper is an invitation to learn and talk about safeguards. It explains safeguards as a way to respond to people's vulnerabilities. We hope that by reading the paper, you will want to get more involved in safeguards for yourself or for someone you know.



There is a role for everyone in safeguards and you can make a big difference in someone's life by participating. Working with others, you can actively do things to reduce vulnerability for yourself or for other people you care about. Lots of people have been thinking about and working on safeguards for a long time. We know there are knowledgeable people and good ideas in community.

This paper is talking about safeguards for adults with developmental disabilities, as well as children and youth with special needs and their families. There are differences among people at different stages in life. However, learning about safeguards can help build better lives with people of all ages. It can also be extended to other groups of people who live with vulnerability in community.

Everyone is at risk or vulnerable at some time, and we all have safeguards in our lives, even if we don't call them safeguards.

Safeguards are deliberate actions to help reduce the risks a person or family might face because of their vulnerabilities.

Responding to Vulnerability

Everyone is vulnerable at times. Being vulnerable means you are at risk of being harmed or having bad things happen to you. Harm can come in many forms. It can be physical harm, like falling down or being beaten up on the street. It can be emotional harm like being yelled at, called names, or not having your choices taken into account. It can be financial harm, like not having enough money to live a good life, or having someone steal your money. Being vulnerable can also mean that people don't have good things in their life that others take for granted.

THINGS THAT CAN MAKE PEOPLE WITH DEVELOPMENTAL DISABILITIES MORE VULNERABLE

- Not having a job or enough money
- Not having friends or family in your life
- Not belonging to clubs or groups
- Not taking part in community activities
- Not knowing your rights or how to recognize if your rights are violated or you have been taken advantage of
- Not participating in roles you want as a citizen
- Only spending time with other people with disabilities or with people who are paid to support you
- Discrimination at work or school
- Disrespect and negative attitudes from other people
- Difficulty communicating what you need
- Having challenging behaviours
- Not being listened to
- Not being taken seriously

People with developmental disabilities are more vulnerable than other people. These vulnerabilities put people in danger. You face bigger risks of being harmed, of having bad things happen, or of not having many good things in your life. Things that can happen include being abused or neglected by families or caregivers, getting in trouble with the law, not being able to go out, and not having good friends to do things with.



People who are vulnerable have a harder time dealing with bad things that happen. You may not be connected to people and resources to help you deal with bad things, and to help prevent other bad things from happening in the future. You may not have much confidence or information about how to protect yourself, or how to create good things in your life. This might make you feel like you are ‘invisible’ even though you are living in community.

Safeguards are things or actions that help reduce someone’s vulnerability. Safeguards can help people manage their vulnerability themselves. They can help protect things that are good in people’s lives. They can also help prevent or reduce the impact of things that are bad or unsafe.

"People with disabilities share the same vulnerabilities as everyone else in society; with even less power to deal with them.

No one has the power to control all the threats to safety and well-being. But people with disabilities typically have a much smaller area of power over the environments they live in than the rest of us."

(John O'Brien et al)

Defining Safeguards

When we talk about safeguards in this paper, we are talking about **intentional safeguards**. Intentional safeguards are things that we do on purpose to help reduce people's vulnerability.

There can also be unanticipated safeguards – things that happen by chance. These safeguards can be quite powerful, but we cannot count on them being there for everyone who is vulnerable. We need concerned people to intentionally participate in safeguards for themselves and the people they care about.



Vulnerable people need intentional safeguards in their lives – things that they and others do on purpose to reduce vulnerability.

There are different aspects to intentional safeguards:

Community safeguards are for everyone in a vulnerable group or community.

Personal safeguards are specific to one individual or family.

Formal safeguards result from laws or policies.

Informal safeguards are based on caring connections between people.

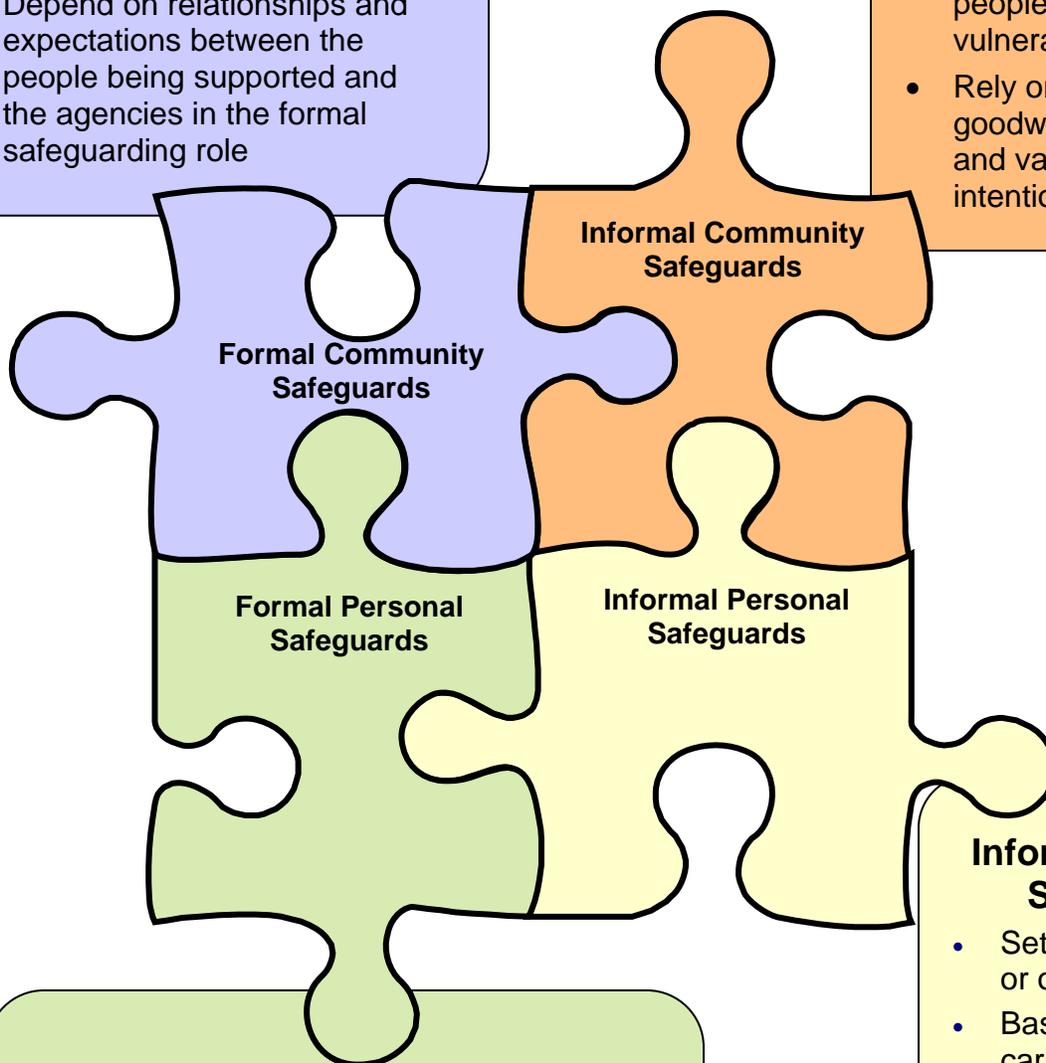
The diagram on the next page explains how these aspects come together to create four different kinds of safeguards.

Formal Community Safeguards

- Law, regulation, or policy/standards designed to reduce the vulnerability of everyone, or of a group of people
- Depend on relationships and expectations between the people being supported and the agencies in the formal safeguarding role

Informal Community Safeguards

- Set up by concerned or ordinary citizens
- Involve valuing all people, or a group of vulnerable people
- Rely on people's goodwill, creativity, and values-based intentions



Formal Community Safeguards

Informal Community Safeguards

Formal Personal Safeguards

Informal Personal Safeguards

Formal Personal Safeguards

- Based on a law, regulation, or policy/standards, but designed to reduce the vulnerability of one person or family
- Often take the form of a contract, protocol or individualized plan
- Can be tailored to address a person's unique vulnerabilities

Informal Personal Safeguards

- Set up by concerned or ordinary citizens
- Based on trust and caring personal relationships - listening, valuing and knowing an individual
- Provide opportunities for creative and unique responses to individual situations

The diagram looks like a puzzle for a reason – each kind of safeguard is like a piece of the puzzle. For a person to experience the benefit of safeguards, all the pieces have to exist and they have to fit together in a way that works.



Each type of safeguard has different strengths and weaknesses. Formal safeguards often have funding and the power of a law or policy backing them up. However, formal safeguards can be slow to respond to changes. Informal safeguards are easier to tailor to a person’s unique vulnerabilities, and lend themselves to creative solutions. Informal safeguards can often respond faster than formal safeguards. In a disaster for example, individuals,

families, and neighbourhoods usually respond to people’s immediate needs faster than formal systems. However, informal safeguards do not have the power of a law or a policy behind them, and can fall apart if there is no one to sustain them.

Vulnerable people need a mix of all four types of safeguards in their lives. The safeguards should overlap each other. The people involved should understand, respect, and support the different types of safeguards. They should all work together to reduce the person’s vulnerability. Here are some examples of the four kinds of safeguards:

	Formal	Informal
Community	<ul style="list-style-type: none"> • Accessible recreation centres • Audible cross walk signals • Anti-bullying programs at schools • Fire drills in agencies • Licensing for group homes or child care centres • Reporting a crime like abuse 	<ul style="list-style-type: none"> • Neighbourhood that invites local group home residents to the block party • Self-advocacy groups • A church that makes accommodations in their Sunday School for children with special needs • Awareness campaign about people with disabilities
Personal	<ul style="list-style-type: none"> • Behavioural support plan for an individual • Representative for someone who needs help with decisions • Foster family • Person-centred plan with a risk assessment • Health Services for Community Living protocol for someone with medical needs 	<ul style="list-style-type: none"> • The trust a family has in a caregiver • Staff at a coffee shop who know an individual and watch out for him • Friends and neighbours who check in with each other • A circle of friends at school

Some safeguards are a mix of **formal** and **informal**:

- A personal support network is an example of a **mixed personal safeguard**. The informal part is the volunteer involvement of family and friends and the kinds of things they do with the individual. The formal part is the involvement of paid caregivers and the support from an agency or CLBC.
- A Block Watch Program is an example of a **mixed community safeguard**. The informal part is the volunteer involvement of families in the neighbourhood. The formal part is the support and training from the police.



As you can see, safeguards do different things. Some help prevent something bad or unsafe from happening to a person. Some help a person learn to safeguard him or herself. Some help create and keep positive things in people's lives.

People have been doing things that we call safeguards for a long time. They may not have called them safeguards, or thought about the difference between the different kinds of safeguards.

We are starting to use the word safeguard when talking about ways to reduce the vulnerability of people with developmental disabilities. Other vulnerable groups, like seniors, are also starting to use the word. It is a way to discuss the concept of vulnerability that everyone can understand. It can also bring more public awareness to the issues affecting people living in community.

Safeguards help reduce the risks a person or family might face because of their vulnerabilities.

Safeguards can be things that a person does for themselves, or things that other people or agencies do with or for them.

Safeguards can prevent something bad from happening, make something better, create something positive, or help a person be better prepared.

What CLBC is Doing About Safeguards

CLBC is committed to working with others to create “Good Lives in Welcoming Communities” for people with developmental disabilities. Feeling safe and confident in your home and community is a big part of this vision of full citizenship. Safeguards help people do that. So improving safeguards is an important part of working together to reach the CLBC vision.

CLBC Vision: Good Lives in Welcoming Communities

The CLBC vision is one of full citizenship, in which people with developmental disabilities lead good lives, have rich relationships with friends and family, choices in how they live, meaningful employment opportunities, and are accepted and valued as citizens. As a steward of this vision, CLBC is committed to supporting the growth of inclusive, supportive communities.

There are four roles for CLBC in contributing to better safeguards:

1. Formal Safeguard Initiatives

These safeguards take the form of policies, standards, or direct services that affect individuals and families. Some examples are:

- Helping people develop person or family-centred plans that include safeguards designed to address the vulnerabilities that a person may have.
- Monitoring services, including identified risks and personal safeguards that are part of a person’s plan.
- Quality service reviews if there are complaints about a service, or a serious incident such as an unexpected death.
- Developing program standards that promote quality of life and safety.
- Strengthening policies in areas that have to do with safeguards – like behavioural intervention support, monitoring, and critical incident reporting.
- Investigating critical incidents and allegations of abuse.
- Working in cooperation with the Advocate for Service Quality, who helps people with concerns that cannot be resolved directly with CLBC or a service provider.

2. Internal Safeguards

CLBC also does some things internally to help safeguard itself. Reducing the vulnerability of the organization helps safeguard the services that people rely on. Some examples of these internal safeguards are:

- Health and safety procedures to reduce risks to CLBC staff, offices and services
- Providing support and resources for developing and sustaining regional Community Councils
- The Advisory Committee to the Board, which gives feedback from self-advocates, families and others on how well the system is working
- Satisfaction surveys asking for feedback from individuals, families and other stakeholders

3. Working in Partnership with Others

There are some things that CLBC cannot do by itself, but only in partnership with other organizations. These are usually formal safeguards or things that are a mix of formal and informal safeguards. Examples are:

- Facilitating development of community-based crisis response capacity
- Working with Health Services for Community Living to support people with health care needs
- Working with Mental Health Teams to support people with challenging behaviours or mental illness
- Working with service providers to meet contract expectations, including accreditation and program standards
- Establishing Community Councils to provide feedback, strengthen local partnerships, and help develop personal support networks
- Hiring a Self-Advocate Advisor to work with self-advocates and agencies to ensure that issues faced by self-advocates are central to CLBC's work

4. Supporting Informal Safeguards in the Community

There are some safeguards that CLBC cannot do, and which must be done by other people. These are informal safeguards that rely on the interest, caring and goodwill of concerned citizens and organizations. CLBC is committed to providing support and leadership to help these kinds of informal safeguards. We need to hear about the best ways to help improve informal safeguards in community.



In all of these roles, CLBC promotes an organizational and community culture that is focussed on safeguards - this is called having a **safeguarding mentality**. It means that people think about safeguards in all aspects of what they do. It also means that lots of different people and organizations are engaged in thinking about and planning ways to improve safeguards.

Informal Safeguards in Community

Lots of different people and organizations can participate in improving informal safeguards.

Concerned people can get more actively involved, including:

- People with developmental disabilities themselves
- People who care about them – families and friends
- People who are paid to provide support like caregivers, respite workers and other service providers

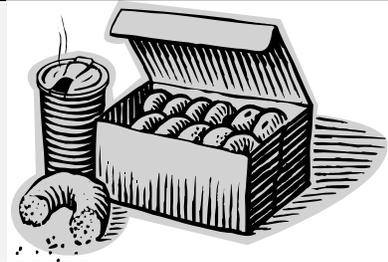
Ordinary people who may come into contact with people with developmental disabilities can take an active interest, including:

- Clerks at the grocery store or coffee shop someone uses
- Next door neighbours
- Co-workers or classmates
- People who take the same bus regularly
- People who go to the same church or fitness class

Here are some stories about how concerned people and ordinary people are reducing the vulnerability of people with developmental disabilities in community.

Make That a Double Double...

Dave has been a regular customer of the local Tim Horton's in our community for the last five years. It is within scooter distance of his home. Dave enjoys going to Tim's on a daily basis. Staff and regular customers have become an important part of Dave's daily support network. Sometimes Dave is a bit



unsteady on his feet. If Dave has a fall or his scooter breaks down, the staff at Tim Horton's contact the people who support him at home. Dave has been provided with his own parking spot at the Tim Horton's, right in front of the door. This is a unique privilege not extended to others.

Dave's a regular who knows all the other regulars at Tim's. He considers the staff to be friends and they help him out when he needs it. Dave has been known to provide the staff with his impromptu Elvis impersonations – a sure sign he knows he is among friends!

(This is an example of an informal personal safeguard done by ordinary people who have become Dave's friends as a result of their involvement.)

You've Got a Friend...

Our daughter Erin is a young woman who has a developmental disability. Throughout her life, our family has strived to provide her with a loving, inclusive environment. While she was in elementary school, we advocated strongly for her to be included in the regular school community and we were successful. We also learned about and started a "circle of friends" for her in her class. Initially it was not easy because some of the adults at the school were not supportive, but we did have success with some of Erin's peers who spent time with her at recess and lunch and came over to our home to play. Her circle continued through her school years with varying success. During senior high school Erin developed a wonderful relationship with two young women who became a part of her circle in Grade 8. These relationships continue to this day.

As a family we were concerned about what would happen with Erin's relationships when school finished. I can truthfully say that Erin's life has never been better. We researched and decided that a Microboard would best support Erin to live an inclusive life. We invited close friends to sit on the board and they have been an invaluable help to us over the years. Erin has held two volunteer jobs for over nine years and has participated in others throughout the years as well. She participates in community events and many recreational activities. She has even done two "swim-a-thons" to raise money for good causes.

Our family joined a group and with their help developed a network for Erin. Over the years her network has included many young women who get together regularly for a variety of activities. Many of them have become very good friends with each other as well. Since her graduation, Erin has had many wonderful experiences with her friends, including two cruises – one to Alaska and one to Mexico.

As Erin is now 29, we have begun the process of looking at alternate living arrangements. While we can't imagine her leaving home, we also understand that eventually we will need to make sure that she has a safe and secure home for when we are no longer here. We recently were pleasantly surprised when one of Erin's long time friends approached us about Erin moving into an apartment with her. Just imagine! We are now exploring this possibility.

While we certainly do need and use paid staff to support Erin, she also has a wide circle of friends who love her and want to spend time with her. She has a wonderful life, better than we ever allowed ourselves to dream.

(This is an example of a personal safeguard that has informal and formal parts, and was started by concerned people.)



We are sure that there are lots of stories like these in your community. Some informal safeguards have been in place for years and no one thinks of them as safeguards. Some have worked for a while and then broken down as people and situations changed. And some were good ideas that never got off the ground.

It is important to talk about these efforts and share the successes with other people and communities. That way, more people will get involved. And CLBC will understand more about what people need to make informal safeguards work well. Each person, family, and community is unique. No one person or agency has all the answers to reducing vulnerability for people with developmental disabilities.

We hope that stories like these will inspire you to think about what we can all do to create informal safeguards in community. Achieving the vision of CLBC will require the active creativity and participation of people and communities all around the province.

The things that can keep people safe are really the same things that are needed to have a good life – caring relationships, opportunities for participation, and power over the conditions of your daily life.



More Thoughts About Safeguards

So far in this paper, we have talked about reducing vulnerability through safeguards. We have described different kinds of safeguards, and explained what CLBC's job is in the development and implementation of safeguards. And we have told a few stories about what concerned people have done to create informal safeguards. Now we would like to introduce some more ideas about safeguards. These are things to think about as you discuss safeguards in your community. They also might be things you want to learn more about in the future.

Be Wary of Good Intentions

Some things in the past have been done with the best of intentions – like creating institutions for people with disabilities, which was done in part to keep people safe. We now know that, despite honourable intent, institutions were not the right thing to do and often didn't stop bad things from happening. Good intentions are welcome and needed. People are often motivated to become involved in informal safeguarding because they care about someone. But make sure you examine the value of your actions and motivations in practice – and any unintended negative results you have not thought about. Make sure people are motivated by caring, and that the safeguards are actually doing what they are supposed to.

Values Are Important

The values of the person or family should be at the centre of safeguarding. This includes personal values around issues such as risk-taking, as well as cultural values around things like the role of the family. It is important not to let other people's values drive decision-making. Sometimes an individual's personal values conflict with their cultural values. Family members may not always share the same values. People may not be sure what their values are, because they have been denied such personal expression in the past. Recognizing different cultural and personal values is important in designing and implementing safeguards.

Getting Relationships Right

Relationships between people using supports and those providing supports are very important. Informal safeguards can offer ways to make the relationships between people served and service providers more equal. For example, a strong personal support network that supports an individual or family can help balance the perspectives of the formal system. Personal support networks can also usually respond more quickly than formal services when things go wrong or change. Ask yourself about the relationships you are creating and supporting in informal safeguards.



New Possibilities for Partnerships

The new vision of community living requires that we broaden our thinking about who we partner with, and how we do it. Changing the attitudes and economic conditions that affect the lives of people with disabilities is a very big job. Success requires that we find new partners and allies who share some of the same values. Who are the people and organizations in your community who might be interested in working together – even if they are not connected to people with developmental disabilities? How might you change some of the traditional relationships you are involved in?

Roles for Community Councils

Community councils are just getting going around BC. Part of their role is to help build welcoming communities. Some ways that community councils could do this are to share stories about successful supports, recommend ways to expand personal support networks, and help strengthen local partnerships. These activities offer opportunities to expand informal safeguards. Think about volunteering or getting to know the members of the community council in your community.



Personal Support Networks

Having people in your life who care about you is the most important informal safeguard. Just knowing there are people around for support can help people reduce the bad things that happen and create positive things in life. Many families and advocates are actively involved in creating networks of support around the people they care about. There are many people who do not have families or friends in their lives. There are lots of opportunities for people to become involved in personal support networks.

“Positive attitudes and perceptions about the role and place of people with disabilities in society make people much safer.”

(Role of Informal Community-Level Safeguards by Brian Salisbury & Dan Collins)

Balancing Self-determination and Risk-taking

Exercising self-determination is a key part of citizenship and living a good life in a welcoming community. For people who are vulnerable, making choices that involve risk taking may be a great concern to those around them. Finding the right balance between protection and choice is an important thing to think about when creating safeguards around yourself or someone you care about. Make sure you are not stifling someone's right to live their own life by trying to protect them too much.

Age Matters

Safeguards look different for people at different stages in life. People have different kinds of vulnerabilities and different levels of family involvement. Parents carry a large responsibility when their children are under age 19. They may be less able to keep their children safe as their child grows more independent and they themselves get older. It is important to respect the different ages and stages in life, for individuals and for their families.

How Formal and Informal Safeguards Work Together

Everyone needs both formal and informal safeguards in their lives. Remember how the puzzle pieces work together to make a whole picture? Here are some things to think about to help that happen:

- Formal safeguard systems should not interfere with the flexibility and creativity of informal safeguards
- Formal safeguards should be able to respond to concerns raised by people in informal safeguarding roles.
- The people involved in formal and informal safeguards should understand and respect each other's roles
- Everyone involved in safeguarding should be open to evaluating how safeguards are working, and changing things that are not going well

"Some risk, some suffering, is integral to our common humanity. It's impossible to defend against it without destroying the fabric of human life. But without vigilant and vigorous protection, people with disabilities are far too often neglected and abused. This is the dilemma we face: How do we collectively protect people without patronizing them or destroying their opportunities?"

(John O'Brien et al)

What Do You Think About Safeguards?

Thank you for taking the time to read this paper. There are different ways you can join this discussion about safeguards, and get more involved in designing informal safeguards in your community. We encourage you to ask questions, volunteer your time, and actively participate in talking and planning about ways to reduce vulnerability for people with developmental disabilities. Here are some ways to get started:

- ⇒ Comments about this discussion paper are welcome. You may want to send a written response to CLBC at the address below.
- ⇒ Connect with your local community council and find out what they are doing about informal safeguards. Offer to help.
- ⇒ Talk to service providers or other agencies in your community about how to become involved in informal safeguards for people you care about.
- ⇒ Ask about safeguards in your next person-centred planning session.



- ⇒ Participate in a local inquiry session about safeguards. These will be offered around the province over the next few months. They will provide information about safeguards and a chance to ask questions. They will be good places to present your ideas and discuss possibilities for making informal safeguards better in your community.

We hope this discussion paper, “Responding to Vulnerability”; will form the basis for continuing discussions and community actions about better safeguards for people with developmental disabilities. Thanks for participating.

Here's How to Contact Us

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Appendix A: The Words We Use

This glossary has definitions of some of the words you might have seen in this paper or hear in community discussions about safeguards.



Accreditation

A process that an organization uses to assess how it operates and treats people, in comparison with a set of accepted standards.

Advocate for Service Quality

A person employed by the Ministry of Children & Family Development who helps individuals and families with concerns about provincially-funded services, after all other avenues, including the CLBC complaint process, have been exhausted.

Citizenship

Full membership in society, including the rights and responsibilities that go with it.

Inclusion

All people are welcome.

Monitoring

Watching to see if things are going according to the way you want, or according to a plan, contract, or set of standards. Includes observing the quality of supports provided with the goal of developing and improving services.

Office of the Public Guardian and Trustee

An agency that protects the legal and financial rights of children and youth under age 19, and adults who require help with decision-making.

Partnership

Working together on common goals.

Personal Support Network

Two or more people who care about and help support and safeguard an individual or family.

Person-Centred or Family-Centred Plan

A document that sets out dreams, goals, strengths, needs, safeguards, and services for an individual or a family, and has been developed with the individual and family.

Self-Advocate

A person who speaks out for him or herself.

Self-Determination

Living your own life, and taking responsibility for your own decisions and choices.

Vulnerable

At risk to be harmed, physically, emotionally or financially. Being exposed to suffering, needs or threats, while lacking the abilities and/or resources to cope with them.

You may want to add your own terms to this glossary for future reference:

Appendix B: Sources & Acknowledgements

This paper was written with the help of Michael Kendrick and the CLBC Accountability and Safeguards Advisory Committee, and also drew on the following source documents:

- *The Role of Informal Community-Level Safeguards*; Interim Authority for Community Living (Brian Salisbury and Dan Collins); 2004
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