

Addressing Personal Vulnerability Through Planning

A guide to identifying and incorporating intentional safeguards when planning with adults with developmental disabilities and their families

Developed by Community Living British Columbia for use by CLBC staff, service providers, self advocates, families and members of personal support networks.



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This Guide is about how to design and incorporate intentional personal safeguards when planning with adults with developmental disabilities and their families. It is based in part on the CLBC Discussion Paper *Responding to Vulnerability: A Discussion Paper about Safeguards and People with Developmental Disabilities* and draws on key concepts from a paper by Dr. Michael Kendrick called *Developing, Negotiating and Implementing Personal Safeguards.* This guide is consistent with the concepts and terms used in CLBC's Discovery Goal Based Planning.

Thank you to the many people who reviewed drafts and shared their experience in developing this guide.





Why you should read this document:

This Guide is for anyone who is involved in person-centred planning. It is a companion to other documents about how to do person-centred planning and is consistent with *Discovery Goal Based Planning* (DGBP). You can use it to help create a complete plan that acknowledges the person's unique vulnerabilities and builds intentional safeguards to reduce them.

CLBC believes adults with developmental disabilities and their families have the right to pursue good lives in welcoming communities. Part of a good life for people is feeling safe from harm where they live, go to school, work and play. This includes physical harm, emotional harm or financial harm.

One important way to make sure that people are safe from harm is through safeguards. Safeguards are actions that are done on purpose to help reduce the risk that someone will be harmed. Safeguards are about:

- Reducing the chance that bad things will happen
- Having confidence to deal with bad things if they happen
- People knowing how to get help if they need it
- Making sure there are good things in people's lives

Safeguards help people achieve their dreams. Person-centred planning should include a discussion about safeguards.

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Person-centred planning requires thinking about safeguards

Getting Started

Person-centred Planning

Person-centred planning is based on each person's unique preferences, abilities, gifts, and strengths. It involves people who care about the adult with a developmental disability and their family, and the people who play a role in assisting them to achieve their goals. Planning is about exploring an individual's dreams for the future and then setting goals and activities to reach those dreams. Person-centred planning is an important part of supporting people to live good lives and individuals having opportunities to contribute to their community.

Intentional Safeguards

Safeguards are actions that help a person to be safe in community, to take advantage of opportunities, and to prevent harmful things from happening. Safeguards may be specific to the adult and their family, or apply to everyone in community. Safeguards may be formal or informal actions. Safeguards developed through person-centred planning are intentional and individualized. That means they are designed to address the unique situation of each person.

Safeguards promote opportunities that are the same for everyone in community. Having opportunities for work, school, recreation and a social life are important parts of quality of life and contributing to community. Safeguards help reduce vulnerabilities and increase the chances that good things will happen in a person's life. Safeguards are identified, designed and implemented based on the unique circumstances of each adult with a developmental disability and their family, using the person-centred planning process as the vehicle.

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.

David is a 47 year old man. He identified in his personal plan that he wanted to travel to far-away places. David has an overwhelming fear of flying. To date, he had been limited to short day trips that did not meet his goals.

Through David's personal planning process, his support network gained a better understanding about his individual vulnerability around flying. As a result, they found a community travel club.

With help from his support network, David joined the club. David loved the meetings and soon began to participate in the trips as well. These included bus trips to Disneyland, Barkerville, Reno and Alaska.

David's support network worked with several key members of the club to identify potential risks on the trips, and organize specific safeguards to offset them. David feels comfortable on the trips because he is with people he knows from the travel club. David's family and support network have emergency contact information and trip itineraries when David is away.

These personal safeguards reduce David's vulnerability while he travels, and help him fulfill his dreams of going to far-away places. Who knows where he will go next!



Need More Information?



You need to have a good understanding of both person-centred planning and safeguards to help you incorporate safeguards into a person-centred plan.

For more information about safeguards, read the CLBC paper called *Responding to Vulnerability*. It explains the different kinds of safeguards, and the roles of CLBC and community in making them happen.

You can also go to these websites:

www.kendrickconsulting.org or www.inclusion.com

For more information about person-centred planning, check out these CLBC documents:

Developing an Individual Support Plan for an Adult Individual and Family Support Policy

and Discovery Goal Based Planning Guidebook

You can get copies at your local CLBC office, or call toll-free 1-877-660-2522.



Take time to increase your understanding about both safeguards and person-centred planning before you move on.

Understanding Vulnerability

What is vulnerability?

Being vulnerable means being at risk of being harmed. 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.

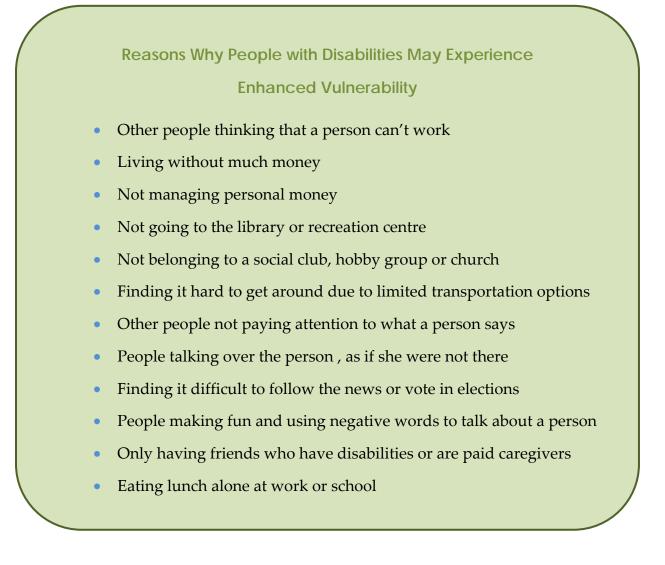
Enhanced vulnerability is largely based on the low value that many people in society place on the lives of people with disabilities. People with disabilities are often seen in a negative way. Being seen in a negative way makes it more likely that people will treat someone in a negative way, which in turn makes the person more vulnerable.

On the next page, there is a list of some of the ways that people with disabilities may experience enhanced vulnerability. You can probably think of other examples from your own life, or the life of someone you support.



Joanna has a developmental disability and epilepsy. Even with the help of medication, she still has some seizures. She finds it difficult to get out and about on her own, due to the possibility of having a seizure, falling and hurting herself.

This enhances Joanna's vulnerability for physical injury, loneliness and depression.



These are examples of what enhanced vulnerability is like for people with disabilities as a group. Not everyone has the same experiences. Remember that each person is unique, with specific vulnerabilities related to his or her circumstances. Think about the unique and specific vulnerabilities of a person and their family, rather than making assumptions or generalizations. Gail is 25 years old. She is often made fun of when she goes swimming at the local pool. She feels hurt by the things that she hears people saying about her. She often does not want to go swimming, and complains of stomach aches or other ailments. Her feelings affect her participation in swimming and other community activities.

This is an example of what enhanced vulnerability feels like for this woman.





Think about the person and family you are planning with. What are some ways that they personally experience vulnerability in their lives?

Six Steps to Safeguarding Through Planning

The rest of this Guide explains these six steps. Following these steps will help you think about, design and implement safeguards as part of person-centred planning. Think about these steps when learning about Discovery Based Goal Planning and other approaches to planning.

You may repeat the steps many times to get a deeper understanding about vulnerability and risk. This can be incorporated into reviews of person-centred plans. Additional supports may be needed to enable the person and their family to participate.

Step 1	Develop a safeguarding mentality
	Look at the world from the perspective of safeguards.
Step 2	Apply a safeguarding lens to a personal plan
	<i>Look at goals and activities from the perspective of the person's vulnerabilities.</i>
Step 3	Understand risk and the dignity of risk taking
	Figure out the risks for the goals and activities in the plan.
Step 4	Identify ways to address risks
	Determine the best ways to reduce specific risks.
Step 5	Design new or improved safeguards
	Develop specific actions to reduce risk for the goals and activities in the
	plan.
Step 6	Implement and renew safeguards
	Implement safeguards as part of the person-centred plan.



Look at the world from the perspective of safeguards.

The most important point about safeguards is not the safeguards themselves. Safeguards are the tools that people use to deal with their individual vulnerabilities. The important part is having a **safeguarding mentality**. This step can help you develop your safeguarding mentality.

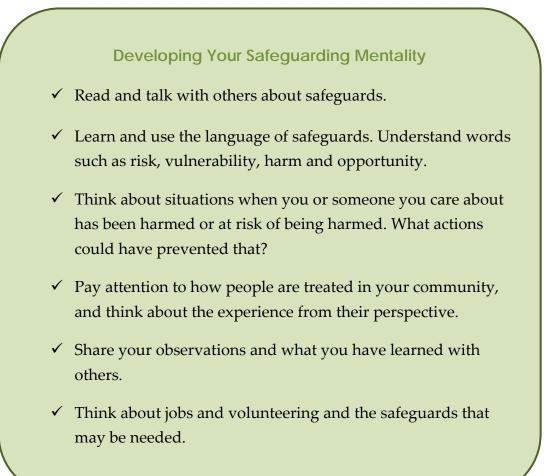


Mark takes the bus to work every day. He often sees a young man with Down Syndrome travelling on the same bus. One day, he noticed that some people were snickering and making fun of the young man. The next time he saw the young man get on the bus, he invited him to sit next to him. They became regular travelling companions. No-one made fun of the young man when he was sitting with Mark.

This is an example of developing a safeguarding mentality and acting on it.

A safeguarding mentality is a way of looking at the world that enables us to see vulnerabilities and recognize what safeguards might help reduce them. It is like having an antenna that picks up on how some people may be vulnerable. It helps you notice things that could be done to reduce the chances of someone being harmed, or create positive things in a person's life. Having a safeguarding mentality means being careful and thoughtful when planning, but not being overprotective. A safeguarding mentality means being aware of possible risks, but not getting in the way of an individual's dreams and goals.

Developing a safeguarding mentality occurs over time and with experience. It comes from the practice of appreciating each person's unique vulnerabilities and ways to reduce their impact. On the next page is a list of ways to develop your safeguarding mentality.





Take time to think about the vulnerabilities of people in your workplace or community.



Look at goals and activities from the perspective of the person's vulnerabilities.

Personal planning occurs within a context that is specific to the person, their values and beliefs, and what is happening to the person at the time. It is also affected by the experience and values of the person facilitating the planning, and by the relationships with other people involved. Planning always involves judgments. Our understanding and response to the specific vulnerability affects our judgment. For example, if we don't understand a person's vulnerability to being abused, we may judge important safeguards as not needed. This step can help you bring your safeguarding mentality to developing goals in a person-centred plan.

Remember that goals represent desired change for people. There may be vulnerabilities related to many of the goals and activities in a person-centred plan. Here are some examples:

- Getting a job may involve a person taking the bus by himself, or remembering to take medication on his own.
- Going to visit a new friend on her own may mean a person needs to walk alone in an unfamiliar area.
- Joining a club may mean depending on other club members for help in getting to and from club events and meetings.

Vulnerability affects each person differently. A person's own experience of feeling vulnerable affects their tolerance of it, both for themselves and for someone they care about. Exploring vulnerabilities in a person-centred planning process will help you better understand the individual and what he needs to be successful.

Have a conversation about potential vulnerabilities related to the person's goals. Keep it geared to the unique situation of the individual. Identify specific conditions that make the person more or less vulnerable. This is not always easy. It may be repeated many times, as the person's life changes.

On the next page there are some suggestions about how to apply a safeguarding lens to a person-centred plan.

Applying a Safeguarding Lens to a Plan

 ✓ If this is a person's first plan, talk about vulnerabilities in different areas of a person's life:

- Health and well-being
- Living arrangements
- Work or school
- Financial and legal situation
- Self-determination
- Social inclusion
- Personal identity and communication style
- ✓ If the person already has a plan, think about vulnerabilities related to the goals or activities identified in it.
- Look at other supporting plans such as a positive behaviour support plan, health care plan or employment plan.
- Talk about your concerns. Remember these are different for everyone.
- Don't prejudge a goal just because a person's unique vulnerabilities may create a risk associated with the goal. Be open to the possibility of safeguards that can address the vulnerability.
- Be patient. This can be a very personal and emotional conversation that brings up deep fears. The answers can be complex and contradictory. Be prepared to talk about this more than once.

Person-centred planning requires thinking about safeguards

There are some common goals or activities that many people have in their plans. For instance, getting a job or making new friends. However, the vulnerabilities are different for each person and family. Think about the unique and specific vulnerabilities for the person involved.

For example:

- A person who has difficulty walking may be more vulnerable taking the bus by themselves than someone who does not.
- A person who has difficulty speaking may not have friends. This may make her more vulnerable to being isolated or lonely than a person who speaks easily.
- A person who does not take care of his own finances may be more vulnerable to having his money stolen or misused.
- People who cannot communicate well are often more vulnerable to being physically or sexually abused and less likely to report it.

Pam is 19 years old. She has a developmental disability and cerebral palsy. Pam and her parents have identified making friends as a goal for Pam. Specifically, they want Pam to go to movies and parties – two of her favorite activities. Pam's unsteadiness on her feet makes her vulnerable to being knocked over in the hustle and bustle of a movie line-up or crowded social situation. Pam's family want her to participate, but are not sure they are willing to risk her getting hurt or embarrassed.

This is an example of a vulnerability related to a goal, and a family's concern about related risks.





Do you have a good idea of the person's specific vulnerabilities in relation to their dreams and goals?



Figure out the risks for the goals and activities in the plan.

Before finalizing goals and activities in a plan, identify any **risks** related to the person's vulnerabilities. A vulnerability is a quality of the person or a condition of their situation. A risk is something that might happen as a result of that vulnerability. It does not mean that something bad <u>will</u> happen, it just means that there is an increased chance it will happen because of the person's unique vulnerability. The process of understanding specific vulnerabilities and then identifying the risks associated with them can help to further describe goals relevant to the person. This step can help you move from understanding a specific vulnerability to identifying how it can result in risk for a particular individual.

Sometimes people may not reach their goals because of vulnerabilities that have not been recognized or addressed. For example:

- A person wants to make friends at her job but doesn't get to know anyone because she is afraid of talking to her co-workers.
- An individual wants to join a social club but doesn't because of lack of safe transportation home.
- A person wants to attend an overnight event but doesn't due to severe food allergies.
- A person may lose his job because he has a sleep disorder that means he is often late for work.

Be clear about the risk associated with each vulnerability. For example, the risks associated with the above examples of vulnerabilities might be:

- Loneliness or rejection
- Physical attack or mugging
- Anaphylactic shock
- Being poor

Here are examples of other possible risks you might identify in relation to vulnerabilities:

- Being abused or neglected
- Having money or belongings stolen
- Not seeing a doctor as quickly or regularly as other people
- Not feeling in control of their own life
- Being bullied
- Falling down

Taking risks is not a bad thing. There is **dignity for each person in risk-taking**. It may be said that a life without risks is not much of a life at all. Walking down the street carries risk for everyone – we might fall or get hit by a car. But we would not want to give up the freedom to walk down the street.

The dignity of risk-taking is an individual thing. It depends on the person's tolerance for risk and how important the goal is to them. Risk-taking can be an empowering thing that is important to a person's development and independence. The greatest learning often comes from making mistakes. A person's risk tolerance may not be the same as their family's or support network's. You may need to negotiate to reach a common understanding of risk tolerance, so you can move forward.

Be patient with yourself and others in this conversation. Many people have never thought about the risks in their lives or have never been asked before. Sometimes people are afraid of the things that could go wrong, especially for someone they love. It can be an emotional and difficult thing to do.

Risks Worth Taking

Life and living in community is about making your own choices and decisions. Sometimes these choices involve risk-taking. It is an important aspect of everyone's life to have the opportunity to decide on taking a risk if it is worth it.

Some examples of risks that might be worth taking for one person, and not for another person:

- ✓ Risking rejection to make a new friend.
- ✓ Applying for a job that involves travelling to a different part of town.
- ✓ Making your own lunch in spite of possible risks involved in using the kitchen.

"A life spent making mistakes is not only more honorable but more useful than a life spent in doing nothing."

George Bernard Shaw

How to Better Understand Risks and the Dignity of Risk Taking

- ✓ Talk about why the person is having or might have difficulty with each goal in their plan.
- Explore the reasons and figure out which ones have to do with their unique vulnerabilities. Make the link between a specific vulnerability and risks associated with it.
- Pay closer attention when the same vulnerability comes up related to more than one goal or need. For example, communication style might be a vulnerability at work and in social situations.
- Describe the risk. How is the risk unique to the person and situation. Talk about how family relationships, cultural preferences, and individual history affect the risks.
- Describe the impacts of the risk for the individual and others. Would taking the risk help a person develop their independence – which might actually reduce their vulnerability?
- Avoid vague generalizations like poverty, unemployment or risk of abuse. These are too general to be helpful in designing personal safeguards.
- Prioritize the list of risks. Top priority should be the ones likely to cause greatest or immediate harm; and the ones associated with the goals that are most important to the person.



Think about the risks related to each goal or activity in the plan, and how to prioritize them.



Determine the best ways to reduce specific risks.

Risk is present for everyone in community. The level of risk depends on the individual's specific vulnerability to that risk. People cannot avoid vulnerability. But they can reduce it and the risks associated with it. This step can help you use a personal plan to reduce these risks.

Reducing vulnerability to risk does not happen by accident. It happens when people deliberately make a constructive effort. This is called **intentional safeguarding**. Sometimes a person might develop his own safeguards. Sometimes he works with others. A person's life and well-being can be improved by one intentional safeguard, or by multiple safeguards.

Ways to Reduce Risks

Reduce the impact of the vulnerability

- Reduce the risk of having money stolen by a person learning to do their own banking and getting to know the people at the local bank or credit union.
- Reduce the risk of medication errors by arranging for the pharmacy to pre-package medications for each medication time.
- Reduce the risk of a person not being able to communicate their needs and feelings by accessing communication equipment.
- Identify ways to build competence in new skill areas.
- Promote more community involvement with people with disabilities.

Strengthen positive factors that offset vulnerability

- Reveal the gifts and talents that a person brings to a relationship.
- Create a circle of friends or expand a personal support network.
- Join a group where others may have common challenges and interests.



Jay wants to control his money and do his banking. While he knows how to count money, he does not always understand the value of money. This vulnerability puts him at risk of being taken advantage of or manipulated by others into giving them his money.

Jay takes great pride in taking his pay cheque to the bank. More than once, an unscrupulous person has convinced him to cash his cheque and give them all his money.

His brother and a friend worked with Jay and the bank staff to find ways to reduce the risk of Jay being taken advantage of. They arranged for two tellers to be Jay's tellers. These tellers support Jay and they know it is okay to ask him if he is not depositing most of his cheque, or to ask who he was talking with. This has acted as a deterrent to people taking advantage of Jay. This arrangement has helped Jay with his banking and also given the bank staff an opportunity to get to know Jay better.

This is an example of reducing the risk associated with a unique vulnerability, without restricting a person from reaching their goal. Look at the list of risks you identified in Step 3. Create and discuss options for addressing them. Write down the options that fit best with each risk. Be aware that different people will prefer different approaches. People have different levels of tolerance for risk. One person might decide not to take a risk. Another person might be fine with sharing the risk by having someone do the activity with them the first few times.

Remember the dignity of risk taking and the potential for learning from making mistakes. People may be more willing to accept risk related to the goals that are most fundamental to them and their values. Always make sure that addressing a risk does not restrict the person from reaching their goal.

Remember that intentional safeguarding is not <u>only</u> about preventing bad things from happening, or correcting them when they do happen. It is also about increasing the chances of good things happening in people's lives. This helps bring about positive things, rather than just reducing negative things.



Does your list of risks now have possible safeguard options listed for each risk?

Step 5: Design New or Improved Safeguards

Develop specific actions to reduce risk for the goals and activities in the plan.

This step can help you use the planning process to decide on what safeguarding actions to take, who is going to take them, and what resources might be needed to make that happen. It also provides suggestions about working with safeguarding partners and supporting the person's dignity and self-determination in the process. Make decisions about safeguards within the context of the personal plan, so that they are rooted in the individual's unique dreams, vulnerabilities and circumstances. Start with safeguards that are already in place and look for opportunities to learn from the experience of the individual and family.

Assessing Existing Safeguards

- Make a list of existing safeguards. Focus on the ones that address the risks on your list. Consider:
 - Personal supports and professional supports
 - Formal and informal safeguards
 - Community and personal safeguards
- ✓ Assess how these existing safeguards are working:
 - Are they effective for the person?
 - Are they clearly linked to specific risks?
 - Are they restricting the person from reaching their dreams or having the same life experiences as other citizens?
 - What does the experience tell you about approaches that work well with this individual?
- ✓ Decide together how to make them more effective and write it down.

Designing New Safeguards

If this is the first person-centred plan, or if the current plan has no safeguards identified, move on to designing needed safeguards:

- ✓ Start with the areas of the person's life with the most desirable opportunities and the greatest risk of immediate harm.
- ✓ Discuss what intentional actions could reduce the risk. Include ways to prevent or reduce the impact of negative things and ways to increase the chances of positive things happening. Safeguards should enable a person to have a good life – not restrict her.
- Decide together on the proposed safeguard actions and write them down.
- Move on to areas of lower risk or less importance to the person. You may not cover all areas in one meeting.
- For each identified safeguard action, discuss who will help the person follow through and make it happen. Determine if other resources are needed.
- ✓ Consider when each safeguard action should be reviewed.
- ✓ Make sure the safeguard actions are included in the person-centred plan.

Negotiating with community partners

Many personal safeguards require the active participation of other people and agencies. It is important to have a common understanding about what is needed, why, and who will do it. This is called **negotiating safeguards**.

Negotiations about informal safeguards are likely to involve friends, family members, neighbours, co-workers or acquaintances. Agreements about informal safeguards may be unwritten. But they still require intentional action. Informal safeguards rely mostly on goodwill, shared values and a deep sense of caring for another human being. People are not usually paid to be involved. Here are some examples:

- A parishioner agrees to accompany someone to church and to coffee afterwards.
- A bicycle club includes a person on a day trip by arranging for a two-seater bike and for the personal network to provide training about how to support the person during the trip.
- A library volunteer agrees to help a person use the computer at the library and call for a ride home.

Negotiations of formal safeguards are more likely to involve written agreements with agencies or professionals, and may require funding. Here are some examples:

- A caregiver develops a missing person protocol with the help of the local police.
- A family develops a representation agreement with their adult daughter to help with important decisions.
- A service provider negotiates a protocol with the local hospital about how to best support people with developmental disabilities in the Emergency Department.

Angela is a senior with friends and supporters in her life. However, they are not informed and mobilized around her most fundamental goals. So they are often not as effective as they could be in supporting and safeguarding Angela as she gets older.

This is an example of an existing safeguard that could be consciously improved.

The person is the key player

Everyone has talents and capacities that can help them take charge of their own lives, including recognizing vulnerabilities. This is true of all people, of all ages.

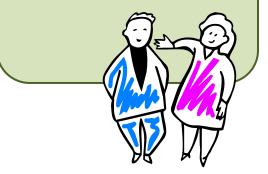
Adults with developmental disabilities who have valued roles in their lives and a positive presence in their community have more self determination.

Support from others can enable people to do as much as they can, even if they cannot fully take care of their vulnerabilities. In situations where someone may need assistance to implement their safeguards, it is possible they can direct what that assistance looks like to a significant extent. There is value in enabling people to be the authors of their lives.

Do not underestimate the capacity of a person and their family to design and implement their safeguards. The starting point should be that people are the agents of their own lives. To do otherwise makes people feel powerless in their own lives. Underestimating a person's capability can invite well-meaning domination by others, and may violate ethical relationships.

Some families and paid caregivers may find it hard to allow the adults they care about to make their decisions, and take risks. This is a process that takes time and understanding. Steve has dinner at a restaurant with a friend and then walks home on his own. When he gets home, Steve calls that friend to let him know he got home safely.

This is an example of an informal safeguard that a person can do for himself.



Person-centred planning requires thinking about safeguards

Respect people's privacy, dignity and autonomy

It can be tempting to rush in and try to fix things when someone experiences vulnerability. This can sometimes be done at the expense of the person's dignity and choices. Sometimes it can restrict the person's capacity to have the same kinds of life experiences as other citizens. Sometimes it can be used to restrict the person from reaching for their dreams.

A respectful process of designing safeguards <u>with</u> rather than <u>for</u> the person and family is important. It may result in the same decisions, but the relationships will be more empowering, sensitive and ethical. These are deeply personal issues and the nature of the relationships matter.

There is rarely any excuse for dominating a vulnerable person's life or ignoring his or her rights in the name of well-meaning safeguards.

The exception is truly extreme circumstances where there is no time to obtain consent and the consequences are immediate and grave. For example, if a person is at risk of serious physical harm or of having all of their money stolen. A combination of formal and informal safeguards - intentional and personalized - works best.

Safeguards can form a circle of commitments and partnerships around an individual and their family that help offset or reduce their unique vulnerabilities.





Does the person-centred plan include agreed-upon safeguard actions and/or improvements?

Step 6: Implement and Renew Safeguards

Implement safeguards as part of the person-centred plan.

Now that you have agreed-upon safeguards, they need to be implemented and monitored along with the other actions agreed to in a person-centred plan. This can present opportunities to educate others about safeguards and to carry over an understanding of a person's unique vulnerabilities and safeguards into all aspects of their life and support system. This step provides some things to think about as you implement safeguards.

Beware of unintended impacts

Watch out for things that you did not mean to happen. Sometimes there are unexpected or negative results of safeguards. This is usually because the safeguard is too restrictive. Unintended impacts can affect the person and other people. Here are some examples:

- An individual is prevented from participating in her favorite walk to the park because the risks of getting lost or being taken advantage of by others are considered to be too great.
- The decision to lock the fridge door to prevent an individual's overeating means that other people living in the home cannot access food when they choose. It also does not help the person learn alternative ways to deal with her vulnerability.
- Having the same person accompany someone to church every week means that he may not talk with anyone else or meet new people.

Safeguard the safeguarders

Everyone has vulnerabilities. So the people involved in safeguarding will have vulnerabilities as well. Everyone has human weaknesses and limitations that can affect their capacity to provide safeguards. These can put them at risk of getting sick, burning out, or getting into conflicts with other people involved in safeguarding. It is important to be aware of this, and build in supports to offset it. This is called **safeguarding the safeguarders**. Person-centred planning is a natural place to discuss this, as these actions can apply to all aspects of a person's life and support system. See the next page for ideas about safeguarding the safeguarders.

John and Gail are the parents of Grace, a 38 year old woman with a developmental disability. Grace lives in a suite they have built in their family home. They provide her home living and social support. Grace attends a day program, but does not contact the other day program participants outside the program hours.

John and Gail have no respite funding and little support from family members. They have never spent a weekend away or taken a holiday without Grace. They feel vulnerable and recognize that they are at risk of burning out. They worry that they may get sick and there will be no place for Grace to go.

John and Gail discussed their vulnerabilities as Gail's main safeguarders with the CLBC Facilitator and the day program staff. Together, they made a list of people who knew Grace growing up - neighbours, family friends, and classmates. They added people that Grace liked at the day program. They approached people on the list to see if they wanted to connect with Grace, and help support John and Gail. Most of them said yes.

John and Gail now have some respite time, knowing that Grace is with people they trust. Grace spends evenings and weekends with friends and a wider network of people she knows. John and Gail are less stressed and more confident that there are people to support Grace.

This is an example of safeguarding the safeguarders.

Suggestions for Safeguarding the Safeguarders

- Make sure people are clear about their roles as safeguarders. Set personal boundaries.
- ✓ Find ways to identify and talk about potential conflicts of interests that people may have in their safeguarding roles.
- ✓ Ask what supports each person feels they might need to do a good job.
- ✓ Share relevant information, with the person's consent.
- Provide training, skill-development, and mentoring opportunities for people in the support network.
- ✓ Arrange to meet and network with others involved in safeguarding to talk about how things are going and to support each other.
- Create opportunities for reflection on roles as safeguarders and provide feedback on how people are doing.
- ✓ Encourage opportunities for personal renewal and inspiration.
- Use the guides on building personal support networks.
 (www.communitylivingbc.ca)

Person-centred planning requires thinking about safeguards

Be realistic

Intentional safeguards do not come with a guarantee. There is no way to ensure that someone is completely free of vulnerability. Life cannot be safeguarded so well as to eliminate all tragedy. Bad things cannot always be foreseen. People can be caught unaware and unprepared. This is true for everyone, including people with disabilities and their families.

Keep it Real

- The quality, strength and relevance of safeguards can vary widely.
- Be prepared for safeguards not to work as well as you expect.
- Safeguards involving agencies and systems do not always work perfectly. Safeguards like internal complaint systems and program plans are not foolproof. Recognize that you may need to help fully implement such safeguards.
- Always design and assess safeguards based on the unique vulnerabilities of each person, and the specific risks they present.
- Not all people or organizations have similar values, capacity and intention to implement safeguards well.
- Often the best safeguards are informal actions that prevent negative things from happening.
- Staff and members of support networks change and move on. Be prepared to do ongoing education and mentoring of people involved in safeguards.
- Be prepared to try different ways to see what works best. You may need to take some risks and work outside your usual comfort zone.
- Celebrate the small steps towards a person having a fuller and safer life. It may take many small steps to get to the most preferred place.

Review and renew safeguards as needed

People's lives change. Vulnerability is not a constant. It is affected by many factors. Vulnerabilities change and new risks arise quickly. This may mean that an individual needs new or different safeguards, or that the existing safeguards are no longer needed. Intentional safeguards are only valid if they continue to help an individual and their family reduce their specific vulnerabilities, and therefore the risks associated with them.

Renewing Safeguards

- Be aware of changes in a person's life or vulnerabilities.
- Be prepared to review and renew safeguards when something changes, or if something is not working well.
- Make sure that you change or redesign safeguards based on a unique vulnerability and a specific risk related to it.
- Look for opportunities to shift the emphasis from formal to informal safeguards. Opportunities are everywhere sometimes it is a matter of seeing the possibilities.
- Practice your safeguarding mentality every day!

In Closing

Implementing safeguards as part of the person-centred planning process means effectively and intentionally addressing the risks associated with the interaction between the goals and activities in a plan, and each individual's unique vulnerabilities. It is about honouring the person's dreams and decisions about risk; and supporting the person and their family to build confidence and capacity to recognize and address risks. This Guide provides some steps to follow and things to consider when using personcentred planning in designing safeguards with individuals with developmental disabilities and their families.

Community living is about more than simply living or being <u>in</u> the community. It is about being part <u>of</u> community. This does not happen automatically or by chance. Community living is about **building relationships and a sense of belonging**. People who are fully included and valued as citizens, neighbours, and friends are less vulnerable. Their well-being is tied to their connections and participation in community, not just the availability of funding and paid support. Thoughtful, coordinated efforts are needed to build relationships and expand people's networks. These efforts should include planning and implementing intentional personal safeguards.

The best way for an individual to be safe is to have family, friends and other people in their lives that know and care about them.

This is one way of ensuring that people do have good lives in welcoming communities



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