



The Role of Informal Community-Level Safeguards

A paper that discusses the role of informal, community-level safeguards, their relationship to formal safeguarding mechanisms and policy and strategic planning implications for the future role of Community Living British Columbia

Prepared for the Board of Directors
of the Interim Authority for Community Living British Columbia by
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Purpose of this Discussion Paper

This discussion paper follows a small think tank meeting that was convened by the Interim Authority on April 2nd 2004 to discuss the role of informal community safeguards.

This paper is intended to serve a variety of purposes, including:

- Discussing the role of informal, community-level safeguards.
- Clarifying the relationship between informal formal safeguarding approaches.
- Identifying next steps that the broader disability community can pursue [and which CLBC can support] to promote greater understanding of, and commitment to, the acceptance and implementation of informal safeguards.
- Suggesting some preliminary policy and strategic planning implications for the future role of Community Living British Columbia

Background

Western jurisdictions that provide community-based supports and services for people with developmental disabilities endeavor to protect or safeguard “vulnerable people” through the use of formal “systems” like accreditation and monitoring. CLBC will, in all likelihood, as part of its own accountability and safeguards framework [discussed in Appendix 1] implement similar mechanisms.

Experience has demonstrated that systems which utilize formal approaches that rely on “minimum standards”, or occasional visits by professionals, cannot really keep people safe. In fact, the most effective safeguard is the willingness of everyday citizens to become involved and do the “right thing” in the lives of those who are vulnerable. This is not to suggest that formal mechanisms do not have a place – they do – but they must co-exist with informal community-level safeguarding initiatives.

Broadly speaking, creating an array of effective informal community safeguards requires the following areas to be addressed:

1. Attitudes and perceptions.
2. Culture and values within organizations.
3. A clear commitment to social inclusion.
4. Adherence to and understanding of concepts that support inclusion and self-determination.
5. Supportive relationships [particularly those involving family members].
6. Informal monitoring by concerned everyday citizens.
7. Consciousness raising activities around the issue of vulnerability.
8. Individually negotiated safeguards with service providers.
9. Advocacy.

These areas are discussed in greater detail below, along with some suggestions regarding how they can be more effectively promoted as important options. Note: additional information on the role of “intentional safeguards, prepared by Michael Kendrick, is found in Appendix 2. There is a certain amount of cross over between this topic and informal community safeguards.

Historically, Government in BC has relied on formal mechanisms such as the Provincial Monitoring Group and more recently the decision by the Ministry of Children and Family Development to pursue accreditation through groups like CARF and COA. While examples of effective formal community-level safeguards can be identified, this approach has questionable legitimacy in BC, due in large part to the strength of a technocratic approach by many policy makers and providers on disability issues.

Given the recognition by the Interim Authority of the need to combine both formal and informal mechanisms, a meeting was convened by the Interim Authority on Friday, April 2nd, 2004 to discuss how informal safeguards might become more prominent in both discussion about safeguards within the field, and to identify specific strategies to achieve this end. Additionally, the meeting sought to identify where informal safeguards will fit within the Interim Authority's implementation of a safeguards and accountability framework

Invited participants included:

- Doug Woollard – Acting CEO, Interim Authority
- Michael Kendrick – Consultant to the Interim Authority
- Brian Salisbury – Senior Advisor, Interim Authority
- Nancy Hall - Senior Advisor, Interim Authority
- Jane Holland – Advocate for Service Quality
- Doug Barr – MCFD social worker [and Phase One Individualized Funding Implementation Plan Facilitator]
- Steve Thiessen – Executive Director, Mennonite Central Committee
- Dan Collins – Executive Director, Langley Association for Community Living
- Janice Barr – Executive Director, Richmond Society for Community Living
- Neil Belanger – Executive Director, Vernon & District Association for Community Living
- Muriel Hanson - MCFD

There was general agreement that:

- A discussion paper that sets out CLBC's overall approach to safeguarding, and which clarifies the relationship between formal and informal approaches, needs to be developed for the CLBC board's consideration. This discussion paper, to a large extent, serves that function. From this, CLBC hopes that a specific policy will emerge to support community developed safeguarding initiatives.
- CLBC is but one of many partners that need to work together with community partners to develop a coherent safeguarding strategy. Accordingly, the development of effective community partnerships is critical in order to effectively expand and implement informal safeguarding options.
- CLBC can demonstrate leadership by stimulating public dialogue and debate, and working with communities to develop a multi year, multi level strategy that supports all stakeholders [Individuals, families, government, CLBC, providers and community members] to increase their understanding of key issues.

What follows is a general summary of the 9 informal safeguarding approaches discussed at the meeting.

Discussion of Informal Community-Level Safeguards

1. Attitudes and perceptions

Positive attitudes and perceptions about the role and place of people with disabilities in society make people much safer. Seeing the “glass as half full”, as opposed to “half empty” [the essence of negative attitudes and perceptions], is more likely to see people’s inherent gifts and capacities, resulting in a greater likelihood that people will be seen as appropriately fulfilling valued social roles.

Attitudes and perceptions can be changed, but this requires a commitment to such things as consciousness raising activities in the form of greater training and education.

2. Culture and values within organizations

Culture and values are important determinants of both personal and organizational behavior. There has been some progress in BC during the past 25-30 years. Social Role Valorization training has made a real difference in how people view issues of marginalization, and how agencies and staff approach their work.

However, recent fiscal cuts, and the emphasis on “technocratic” and “managerial” approaches to disability supports during the 1990’s demonstrates how vulnerable this area is to outside influences. As David Braddock has observed, “Disability policy is a function of fiscal availability.” Many people who have worked in this field for more than a decade recognize comment that the same degree of excitement and enthusiasm, the sense of optimism from earlier days, is less pronounced today. To this end, with the growing fiscal crisis in this sector, we have witnessed far less adherence to the culture and value statements that are so prominent on the walls of many community agencies. With some agencies there has even been erosion in their commitment to core values, and associated operating principles.

So, while both culture and values are factors which can exert a negative influence, both can also be changed. To continue to make progress in their area however requires continued values based training for staff and community members alike.

3. A clear commitment to social inclusion

If people with disabilities are to enjoy the same rights and opportunities that most non labeled individuals take for granted, they must be included in all aspects of everyday life. But because so many people with disabilities rely on formal services, many continue to be supported in programs that do not maximize opportunities for inclusion. Some services, by virtue of their design and operation, actually segregate, and further marginalize.

This requires us to be vigilant, and to continuously review the types of supports and services we are providing, or intend to develop. The reality is that many residential arrangements of all kinds, not just group homes, contribute to people’s isolation because residents are not supported by staff to join social groups and clubs and to form important relationships with non paid people. Many day program options also segregate and segregate those they serve. Practice in the field is extremely uneven.

4. Adherence to and understanding of concepts that support inclusion and self-determination

Concepts help us to make sense of the world around us. They also shape our responses to critical issues such as how we view people with disabilities and how they should be supported both individually and in terms of the programs and services we develop. So, our use and understanding of concepts [such as self-determination; inclusion, social justice, empowerment, rights; informed consent, just to name a few] has a direct bearing on how we support people on a day to day basis to exercise choice and be participants in their communities.

For example, a number of people in Canada, and in BC, have do not resuscitate [DNR's] orders. It is one thing for a person to identify that they want a DNR order to be followed under certain circumstances, an example of a concept being understood and used appropriately – it is another to use a DNR order that in essence supports a view that the life of a person with a disability is “less worthy” of medical intervention. This says more about how certain people “value” people with disabilities, than those individuals’ medical needs or wishes. In short, it is a concept that is misunderstood and inappropriately employed.

Similarly, with the concept of self-determination, it is not uncommon for support staff to intervene and stop self-advocates from making important [and even not so important] decisions in their everyday lives, because they assess that the person may somehow be at risk of being harmed. In such cases, the autonomy of the individual is trumped by professional adherence to the principle of beneficence.

Efforts are needed to ensure that we understand and use concepts in this field that are consistent with the rhetoric of choice and citizenship.

5. Supportive relationships [particularly those involving family members]

Relationships are the lifeblood of our existence. For people with disabilities, social relationships play a key role in enabling the person to have “quality of life”, and in this regard relationships with family members should be viewed as particularly important. After all, family is usually there for the long term, and their commitment to the person is based on love and a sense of reciprocity, not because they are paid to be there to provide support. Staff comes and goes in their work, but most families, if supported to be involved and welcomed, remain involved. Yet, at the same time, it must also be acknowledged that not every relationship we enter into is beneficial or supportive.

The current system has, generally speaking, failed to assist people with disabilities to establish relationships with non paid people. For example, many group home residents have relationships with only staff members, a situation that is particularly problematic for those who have left institutions.

A key issue here is the need to understand the significance and value of intentional development of relationships, especially where there are none. Support circles and Citizen Advocacy are conscious examples of this strategy. Ongoing education about the role and importance of a personal support network in every person’s life is also a key, as are strategies to assist staff to help marginalized people to develop friendships.

6. Informal monitoring by concerned everyday citizens

There are many everyday citizens who are somehow involved in the lives of people with disabilities – the neighbor down the street, the shopkeeper, the friend of a friend, etc. The current system does not value this informal monitoring capacity and has does nothing overt to harness or expand its role.

With greater public awareness, and training and orientation for interested community members, this resource could play a more vital role. Simply making more people more aware of the issues, where they can turn if they are concerned about something that they see, would be a conscious strategy that could lead to this resource being more dependable and helpful.

Efforts must be undertaken to make informal monitoring a legitimate part of safeguarding thinking. Part of this involves educating community members about when, where and why they can go to do something, if they feel they should act, and to instill confidence that if they *do* act, that something will be done in response [for example, by those who have an obligation to intervene].

7. Consciousness raising activities around the issue of vulnerability

If citizens are more mindful of the fact that people with disabilities, who are supported by systems, are at risk because of the inherent nature of systems, people's safety will be increased. A concerned and aware citizenry is much more likely to become involved if their interest or concern is "tweaked".

Through education and training, and by having services and supports willing to engage with community, "mindfulness of vulnerability" can be cultivated.

8. Individually negotiated safeguards with service providers

Individually negotiated safeguards entail the person or those closest to them, working with a provider to identify a conscious, deliberate approach or strategy to address a specific concern or vulnerability in the person's life. While it is an informal strategy because it is instigated at the community level, it crosses into the formal realm. It is incumbent upon the system [e.g. CLBC and service providers] to acknowledge their validity and to give them status and where necessary, act upon them.

The effective use of individually negotiated safeguards requires a commitment to education and training. This could be experimented with a number of small communities as CLBC Facilitators come on board, and what is learned could be shared with other communities.

9. Advocacy

At its heart, the primary role of the advocate is to "plead the case" of another. In short, this is someone who willingly sticks up for another person. Many people in community are willing to fulfill such a role.

Through training, and the recognition by the system that advocates can and must play a role, more community members will willingly step forward, and can be supported to effectively engage in this role.

The preceding discussion is not meant to suggest that community is not without its dark side. Not everything about any given community is necessarily good. This reality in itself requires consciousness-raising because there has been to some extent a “romanticizing” of the virtues of community.

However, a key aspect of these various strategies is that they can all be addressed at the local community level. While some clearly will require funding support, they don’t require official sanction or oversight. Many of these strategies require commitment and dialogue, not a programmed approach.

Based on the group’s discussion, there was agreement that supporting the development of informal safeguards is a major developmental issue in BC. Many people – government representatives, individuals, family members, providers, professionals and community members alike - simply don’t understand them well, if at all. A deliberate strategy is required and while CLBC can support such a strategy, it must not control it. The development of informal safeguards will only come if more effective partnerships are developed between CLBC and local communities. However, given the historic under use of informal safeguards, a broad developmental process must be implemented before they can become a robust part of a safeguarding strategy that effectively combines informal with more formal mechanisms.

Informal community safeguards need to try and take advantage of, and strengthen, the authenticity of people’s basic values. Many people will become involved, and will do the “right thing” if they understand the issues, and feel that they have a legitimate role to play. To this end, the next generation of leadership is critical. Making investments now in values based leadership, to counter the power of technocratic thinking, will reap major rewards over time. If we reflect on the investments made in the 1970’s and 1980’s we can see that there was a significant return [introduction of more service options, the advent of individualized funding, and the closure of many institutions is a prime example].

Working Group Suggestions

Some of the suggestions made by the small working group to advance the thinking on informal safeguards included these community-led examples:

- Identify what is happening in the area of informal safeguarding right now in BC and disseminate this information throughout the province [as example of a partnership approach here would be involving College students taking community support worker programs to do research and write up stories].
- Develop a multi-year, multi-level action plan focused on training and leadership [as an example, a training program for emergent leadership modeled after the US Partners in Policy Making Project].
- Engage with current community leaders to build momentum around the issue of informal safeguards.
- Create forums for members of generation x and y; groups that are critical to the sector’s future.
- Clarify the role of different organizations such as the BCACL, Family Support Institute, and other advocacy groups with respect to this issue.

- Consider developing an independent leadership and training institute that would work with all stakeholders.
- Provide individuals, families and staff with more values based training.
- Explore with schools and post secondary institutions how curriculum can be influenced.
- Clarify the potential roles that local Governance Boards could play [this is part of *Bylaw #3 - A Bylaw to Empower Community Level Governance and Innovation*] in promoting and reviewing the effectiveness of informal safeguards.
- Learn from other sectors who are concerned with similar issues [e.g. local Coalitions created to protect frail elders].
- Develop strategies to address issues and needs associated with advancing an informal safeguards agenda with each segment of the disability sector [e.g. individuals, families, providers, government, CLBC]
- Hold conferences, think tanks and other forums on the wide variety of informal safeguard approaches and issues associated with their advancement and implementation.

In terms of CLBC's role, this new organization could:

- Stimulate dialogue in communities about this issue and why it is important. To this end, thought could be given to the "enabling role" that Community Living Centers and their staff [Facilitators] might play. It would need to be remembered at all times, however, that while formal safeguards are within CLBC's purview, informal safeguards must exist within the realm of community or they will lose their effectiveness and vitality.
- Develop a CLBC policy that clarifies the role and relationship of formal and informal safeguarding mechanisms, and which clearly gives informal mechanisms 'standing' [for example, it is conceivable that someone who negotiated an effective individually negotiated safeguard agreement could opt out of certain formal mechanisms]. This policy must permeate other aspects of CLBC like its job descriptions, staff training, contracts, etc.
- Notwithstanding that the issue of the role of local governance bodies is something that communities themselves must engage in, CLBC needs to clarify the scope of such roles that it will deem acceptable because as the corporate provincial body, it is CLBC that would ultimately "sign off" such agreements.
- CLBC will need to consider the resourcing implications of its commitment to support community level safeguards, and budget accordingly.

Appendix 1

Community Living British Columbia's Accountability and Safeguards Framework

The Interim Authority is currently developing an Accountability and Safeguards framework. The following material is a high level overview of this framework and was obtained from a Power Point presentation made to the Board of Directors of the Interim Authority for Community Living British Columbia on November 6, 2003 entitled *Safeguarding Vulnerable People in the Community*.

Guidelines Underlying the Development of Safeguards for Vulnerable People

- In protecting vulnerable people from risk of abuse there are no existing safeguards as effective as the involvement of community members in the lives of people with disabilities.
- An array of safeguards - "*multiple and redundant*", "*formal and informal*" - is more effective than reliance on the *single* "silver bullet" approach
- Facilitators will have a primary responsibility to assist those without family or friends in their lives, and their service providers, to develop personal networks of non-paid relationships
- To ensure individuals are not put at risk by improper conduct by caregivers. Facilitators will have a "duty of care" to report any issues of quality of service or suspected abuse, neglect, or violations of the criminal code to the proper authorities.
- CLBC Operations staff will monitor service provision and hold service providers accountable.
- Delegated governance status will include responsibility for community-level safeguards [e.g. "buddy" programs, "friends visiting friends"]
- Service providers will be responsible for being part of "multiple and redundant" safeguards through expanded accountability requirements in contracts
 - Increased training requirements
 - Development of personal support networks
 - Internal and external safeguards
 - Individual quality of life outcomes
- Safeguards Office will have investigative and "order powers" to intervene in any care situation and / or stop any process that puts a person at risk.

Safeguard Strategies for Consideration

- Health and Safety Standards with Self-Reporting
- Monitoring by Operations Staff
- "Duty of Care" for Facilitators
- Service Outcomes with Self-Reporting
- CLBC Sponsored Evaluation and/or Accreditation
- Safeguards Office

Appendix 2

Safeguards Enablement

This material has [with minor edits] been taken from a February 2004 discussion paper prepared by Michael Kendrick and John Lord for the Board of Directors of the Interim Authority for Community Living British Columbia.

There is a need in all publicly accountable service systems to develop intentional safeguards to help both reduce the vulnerability of persons with disabilities, and to offset the many vulnerabilities existing in the system in regards to its performance and quality. Both people and services can be better safeguarded by implementing thoughtful measures that help accentuate what is needed, and constrain factors that create unfavorable conditions. Conceivably, much of this could be left to chance, but such a strategy would likely invite criticism as being negligent.

As a consequence, most systems need to both be proactive about establishing sensible safeguards, and conveying a sense of responsibility about their importance. In almost all instances, "intentional safeguarding" needs to involve the creation of an interlinked array of intentionally designed safeguards, given that the target of such safeguarding differs as to the precise vulnerabilities that need to be countered. In most instances, public authorities need to assure that vulnerable people are responsibly safeguarded. On another level, such authorities are customarily expected to take active measures to ensure that the operation of their system does not result in significant deficiencies in terms of either performance or quality. Obviously, these major tasks of safeguarding are interrelated to some degree, but it is also apparent that they are distinct challenges requiring their own special strategies.

In order to properly safeguard individuals, it is important to recognize that public systems can best do this by working with other partners to combine their efforts to maximum effect. The key partners include interested elements of communities, families and friends, service providing organizations, government agencies, grass roots organizations, and independent advocates. Each has a contribution to make in ensuring that vulnerable people are properly supported, and the combining of their contributions within a common strategy offers the most hope for a comprehensive approach to safeguards development.

Broadly speaking, intentional safeguards could be organized around the following key functions as it relates to individuals. These are;

- **Creating consciousness, concern and an ethic of "responsibility taking" about vulnerabilities.**

This will require the establishment of specific training and education initiatives targeted to both staff of the system and community partners. Safeguarding is highly dependent on developing a "safeguarding" mentality" that assures the proper vigilance and conscientiousness that vulnerable people will require.

- **Strengthening the attentive monitoring of what is happening (or not) in people's lives.**

This will require the establishment of a broad base of citizens and staff who see it as their role to be very alert to what is happening with people who are vulnerable, and being trained and willing to act if they are alarmed. By relying on the combined effort of both government and community partners it increases the mass of people involved in monitoring and enlists their sense of concern proactively.

- **Creating the capacity to devise, negotiate and implement targeted individual safeguards as per each person's specific vulnerabilities.**

It is important to recognize that “across the board,” standardized and bureaucratized safeguards are highly ineffectual when it comes to dealing precisely with the very unique vulnerabilities of a given person. This is why it is advantageous to allow people close to such individuals to be able to propose, negotiate and amend as needed, highly targeted individual safeguards.

- **Ensuring that the system must respond promptly and conscientiously to concerns when they are surfaced.**

It would be extremely useful for the system to put in place mechanisms that would ensure prompt attention to conditions in people's lives that are thought of as being worrying to either formal or informal monitor “partners”. Monitoring without prompt and proper follow up would be extremely neglectful and should be avoided.

- **Setting system wide priority on the most vulnerable and accompany this with specialized initiatives with these persons.**

With the most vulnerable of people it is important that there be proactive outreach and priority given to those judged to be most endangered.

This determination can be made on regular occasions by convening government leaders in this area with their community partners such that priorities for preventive outreach are set, and plans to ameliorate the conditions that are producing vulnerability are undertaken in time to make a difference.

- **Providing all partners with a measure of independent technical assistance and consultation so that they are more competent to create highly specialized safeguards.**

In regards to safeguarding services and systems, as opposed to individuals, the challenges are addressed by attending to the broad functions that follow;

- **Developing an independent training, consultation and technical assistance capacity that helps prepare people to do better on quality and performance.**

It is important to recognize that the basis of quality and performance is ultimately a function of human capacities, and these can be strengthened with the right support and assistance. It is also important to make this available to all “partners”, since these partners are integral to the way services and systems operate.

- **Developing the independent capacity to help evaluate, design and reconfigure services so that they have the highest degree of relevance to people's actual needs.**

It is unlikely that many services will be able to take up this challenge without the provision of additional independent assistance to perform better. This assistance is developmental in nature, as it is an investment in “capacity building” such that more can eventually be expected from people and organizations.

- **Developing the independent capacity to undertake both targeted and random independent evaluations in order to monitor quality, stimulate improvement and to produce recommendations for change.**

While there may be some merit in producing evaluations and accreditation exercises that focus on compliance with minimum standards, these are usually not rigorous enough to enhance quality nor do they particularly assist with foreseeing serious performance and quality problems. For these purposes, a type of more optimal standards evaluation is more useful as it permits a deeper probing of issues.

- **The creation of an independently governed Institute on leadership, safeguards and quality that acts to bring together people and organizations into initiatives that can enhance quality, performance and innovation.**

Such an Institute would house the various independent functions mentioned and serve as a catalyst for both quality and safeguards, as well as provide a support mechanism to encourage leadership and innovation.

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