

# Think Tank on Collective Family Governance

A Summary Report  
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COMMUNITY LIVING  
BRITISH COLUMBIA

## Background

Historically, families have relied upon service providers to honor their wishes in the design and delivery of services for their sons or daughters. To help broaden the range of sustainable, user led service options, CLBC is interested in supporting the capacity of families to work together to identify and meet their needs. Known as collective family governance, such projects can be local, regional or provincial in scope, and can focus on meeting the needs of individual family members, or broader family support needs that are defined by families themselves.

Families are now using individualized funding (IF) to re-shape the provision of needed supports and services, as an alternative to traditional contracted services. IF can be accessed in one of two ways (below); both support consumer control and can potentially support family governed projects.

**Direct Funding** - enables an individual or his/her agent to receive money directly from CLBC to arrange, pay for and manage required supports and services

**Host Agency Funding** - enables an individual or his/her agent to use a Host Agency, typically a service provider, who works with or on behalf of the individual and agent to arrange and manage required supports and services

Thus far, IF has been used primarily by individuals or families, rather than collectively. When services are already provided, families can request CLBC to help them move their portion of service funding to a different provider. However, this requires an ability to “unbundle” or individualize funding and for this reason it is not yet a widespread practice. CLBC is exploring how it can support increased portability of funding.

It is clear that families are interested in family governance. In 2007-08 and 2008-09, CLBC funded 13 family governed projects through its Innovation Grants program. Other family governed projects have also been supported by progressive providers in the last decade, although this is not widely known. However, advancing knowledge about family governance to the point it is a widely understood option, and how it can be effectively implemented, will require strategic investments by CLBC over the next few years. This includes provision of training and

development of a supportive policy framework and practice tools.

To help begin to develop an action plan, CLBC hosted a one-day forum on Monday May 11, 2009. The forum included participants from across B.C. (see Appendix1) as well as Dr. Michael Kendrick, an international disability consultant with knowledge and expertise on family governance.

**This report summarizes and builds upon these discussions, and outlines some next steps that CLBC can take to advance a family governance agenda over the next few years. **

## The Forum Process

Dr. Kendrick began the day discussing the following six levels of consumer empowerment regarding decision making in the design and operation of services and the role that different authority models play in this process:

**Level One** - service users are passive and/or compliant

**Level Two** - service users are selectively informed

**Level Three** - service users are selectively consulted and/or advised

**Level Four** - service users make a significant minority of decisions

**Level Five** - service users make a significant majority of decisions

**Level Six** - service user makes most decisions

While levels 5-6 are the most desirable to promote consumer driven options, most service users experience levels 1-4. The basic authority model used by most human service systems (on the right) helps explain this situation. In what is a “managerial model” which evolved in the latter part of the 20th century, someone with authority (A), usually a professional, decides for an individual or family (B).



This was contrasted with another authority model (to the right) in which someone with authority (A) partners or works with a service user (B) to establish support and service arrangements that are empowering to the user, and at the same time meet the system’s needs for accountability.



The model of **A working with B** describes a variety of family governance options which involve some degree of delegation of authority. Examples of common things that can be delegated include the definition of needs, wants, priorities and values; imagining a better future; planning and leadership; service design; budgeting; and program negotiations.

Dr. Kendrick offered two important definitions of governance:

**Delegated programmatic governance** - the assignment (with support) of specific oversight authority over service design and implementation to service users and families, either individually or collectively or both, and typically includes the delegated conditional power to design and guide all service development matters relative to meeting their specific personal needs

**Self-management / administration of services** - direct “hands on” operational management role by service users and families (and allies). This role may be in regards to some or all aspects of service and may be shared and supported with any combination of others including staff

Examples of long-lived consumer directed options cited by Dr. Kendrick were:

- Unincorporated, self-directed individual support arrangements
- Incorporated, self-directed individual support arrangements (e.g. Microboards)
- Agency hosted (unincorporated) self-directed individual support arrangements
- Unincorporated / unaffiliated, collectively governed mini-projects to create individualized and other service arrangements
- Collectively member governed organizations to create individualized and other service arrangements (e.g. incorporated cooperatives and mini-agencies)
- Agency hosted, unincorporated, collectively member governed organizations to create individualized and other service arrangements

**It is the last example above that was the primary focus of the forum.** 

## Benefits of Collective Family Governance

Benefits that result when families join together to direct support arrangements or special projects include:

- The value of families is affirmed
- Family isolation is decreased
- Families can access highly relevant and necessary support
- Involvement and influence of families is increased and the funder's role is reduced
- Families can define, invent, improvise and direct versions of support that meet their needs in an individualized manner
- Culture and language is respected and influential
- Families achieve partnership status

Indirect benefits that are derived from family governed projects include:


- Sustainability of family governed initiatives over time
- Cost effectiveness and cost benefit
- Connected and informed leadership is developed and educated
- True person centered service design is permitted and supported when collective governance is deliberately linked to the individualization of support
- The system adds value and options with each satisfied family

Following Dr. Kendrick's presentation, representatives from 3 family governed projects talked about the challenges and successes they have experienced thus far in their journey. Each is an example of a collective family governed project, or what Dr. Kendrick would define as an agency hosted unincorporated collectively member governed organization.

Each project was funded by CLBC's Innovation Grants program during the past two years as part of a commitment to grow understanding and awareness about family governance.

Denise Lawson, a parent, discussed **The Friendship Project** which provides workshops and practical assistance to support young adults in the Comox Valley to reach their goal of forming and keeping friendships. Other key outcomes the group is working toward include creating a permanent network that will continue the project once funding runs out and an increased willingness by local citizens to establish relationships with marginalized people. The project uses L'Arche, a local service provider, as the host agency.

Karen Delong, a parent, gave an overview of **Supporting Everyday Lives**. This project addresses the needs of a group of adults with complex support needs by improving access to, and providing training for, skilled staff. Coordination support is provided to families, who carry core responsibilities of managing all aspects of their sons and daughters supports. The project is also looking at identifying individualized housing options and uses the Microboard of one of the project participants as the host agency.

Linda Perry, a parent and executive director of the Vela Microboard Association discussed **Families Helping Families**. This project provides one-time only funds to families of CLBC eligible individuals who make requests for individualized, short term supports that assist the family to care for their family member in ways that make sense for them. Funds are pooled from surpluses that families who have Microboards generate as a result of annual savings. As the host agency, Vela Microboard Association handles the application and payment processes. 

## The Working Group Process

To think about how to best advance collective family governance as an option for families, participants worked in 4 break-out groups to discuss three questions:

1. What are the challenges and tensions moving forward?
2. How can we increase knowledge about family governance?
3. What supports do families need to successfully use this approach?

Below is a summary of some of the key issues raised in the discussions.

### 1. What are the challenges and tensions moving forward?

- Some providers aren't receptive to a change of this magnitude which requires a paradigm shift
- There is a lack of clarity about what governance means and where it fits with other initiatives
- There is a need to connect with younger families who are tomorrow's leaders, especially now that children's services are being transferred to MCFD
- A gap exists between younger and older families about how best to meet their needs
- Policy and practice must be sensitive to, and include, families from other cultures
- Knowledge about governance issues should come from families as much as possible, not the "system"
- It will be a challenge to find family "champions" of this approach
- Financial sustainability of such initiatives will likely remain an ongoing issue


- Workload pressures resulting from employer of record responsibilities must be addressed to maintain family interest
- The system must recognize that mistakes will be made as families take on a governance role
- Better family support is needed in transition beginning as early as elementary school
- Tensions which can exist between the needs of families and individuals must be addressed
- Financial accountability needs to be balanced with risk-taking
- We need to consider how individuals who do not have families can be involved in such projects
- There is a danger governance may become an exclusive option for savvy parents better able to navigate systems
- Many professionals don't trust that families will do the right thing
- Families may become overwhelmed and lost in the system if too many demands are created
- Agencies may not have the capacity to respond if the demand grows for host agencies
- Families who work together won't always agree
- Jurisdictional issues can impact aboriginal individuals and need to be addressed
- The multiple systems involved in people's lives don't always co-ordinate their work
- Some families do not trust the "system"
- Challenges remain in attracting needed staff
- It will be a challenge to scale up family governance across the sector

## 2. How can we increase knowledge about family governance?

- Develop clear definitions and share stories about what is working well so people don't make the "same" mistakes
- Connect families to each other to help them understand the organic nature of family governance and that it is intended to give families more influence without increasing administrative burdens. Related to this is the need to convey the idea that family governance is not the service, rather the structure behind it
- Use existing networking forums to reach out to families, including younger families
- Begin a dialogue with MCFD about transitioning youth
- CLBC can play an information broker role as could its Community Councils and different family led groups such as the Family Support Institute, PLAN and VELA
- Practical information sharing vehicles include an electronic newsletter, DVD, website on family governance, a booklet on successful projects, You Tube videos to highlight success stories, making community presentations, etc
- Learn more from what is happening elsewhere, for example, Australia
- Ensure project funding, driven by the principle that one size does not fit all, supports creativity and does not become overly bureaucratic
- Empower families through education and training, including better connecting with schools to get information to families
- Invite agencies into the dialogue and support them to share information with families
- Highlight family governance as an option when promoting person centred thinking and practice
- Ensure CLBC staff is knowledgeable so they can share information or steer people where they can find it

### 3. What supports do families need to successfully use this approach?

- Be honest about what family governance is and what is involved and do so using plain language
- Make any process associated with governance as clear, simple and straightforward as possible
- Support families to know how to navigate different systems
- Provide technical support and along with this, examine the balance between the system's need for accountability that can result in administrative burdens and the need to encourage family creativity (in short, minimize rules and bureaucracy). Related to this is the need to use different levels of accountability depending upon the scale / value of a particular project
- Help families understand the difference between family managed and family directed governance options
- Implement policy and practice consistently to ensure fairness and equity, and therefore greater family buy-in and confidence
- Dedicate resources to act as catalyst to promote and seed governance including support to write proposals and help families to dream differently about how needs could be met
- Strengthen capacity of service providers to become host agencies and do things differently
- Bring all stakeholders together to develop a new practice framework
- Identify resource people in each community, along with different ways to share information and support, for example, go to people in their spaces - churches, community centres, etc
- Increase people's awareness of available generic services and informal community resources
- Connect with families using technologies like Face book, videoconferencing and web casts

- Ask families for their input, and use agencies to reach out and connect with parents who are leaders in community
- Continue to improve Letters of Understanding with host agencies as this is a key document that can help clarify roles, responsibilities and expectations of both parties
- Debrief projects to identify what has worked and not worked and share this information more broadly, including the types of community resources that have been used
- Reach out to new families who may need some basic informational, for example through a brochure and/or DVD 

## Next Steps


Participants agreed clarity is needed about what collective family governance is, and how to implement it and maintain momentum. Developing a clear, easily understood definition is critical. Family governance must be part of an integrated, sector wide approach that seeks to achieve greater individualization of supports and services; this option should not be used to create traditional programs. The goal must be to ensure that individuals and families have real choices in the way inclusive supports and services are delivered, and that they effectively address disability-related needs and lead to meaningful opportunities to participate in community life. Successful family governed projects should consistently demonstrate a rigorous commitment to values, principles and processes that uphold individualization.

Pursuing this direction will require CLBC to have realistic time frames and goals, along with dedicated resources to make progress. The challenges associated with growing this new paradigm about the role of families cannot be underestimated.

In the short term, communication with families is critical, as are efforts to engage with cultural minorities. CLBC could use the newly created position of Family Partnership Advisor to connect with family leaders and family groups across B.C. to increase awareness about family governance. This could include familiarizing people with both the qualitative advantages and difficulties associated with family governance, and the role different types of supports can play to help ensure more optimal results. There is also a need to inventory successful family

governed projects and share these stories with stakeholders. This could help identify key leaders and mentors, and support the development of a learning network.

Over the longer term, strategies for initiating and expanding collective family governance include:

- Develop a policy and practice framework to clarify the different roles and responsibilities of CLBC staff, families, self-advocates and providers
- Develop a group IF host agency policy to simplify how families could pool their resources to pursue family governed options
- Set family governance as an objective in CLBC's annual Operational Plan, initiating projects with robust evaluative criteria to serve as demonstrations of what is possible. Getting a few projects off the ground could inspire others and help address the "scaling up" problem by moving from a few projects to a growing number each year reflected in annual operational plan targets
- Invest in developing a deeper understanding about what constitutes real quality in these options, for example, use fact finding visits to successful family governed projects both inside and outside B.C., or consult extensively with leaders from such examples, particularly those with a decade or more of proven results
- Hold think tanks on key operational issues and in so doing, help address problems associated with renewal and sustainability
- As projects go on line, evaluate them against determinants of success and regularly monitor the adequacy of supports and devise corrective methods where necessary
- Regularly convene key leaders who support family governance for the purpose of uniting their thinking and efforts regarding the leadership challenges that must be faced
- Address key operational issues associated with renewal and sustainability
- Clarify and showcase the qualities of successful projects, for example, by hosting a conference every two years or doing a video documentary 

# Appendix 1 - Participants

**Carol Goozh** - VP, Policy and Program Development, CLBC

**Tamara Kulusic** - Manager, Child and Family Supports, CLBC

**Brian Salisbury** - Director, Strategic Planning, CLBC

**Michael Kendrick** - Consultant, Kendrick Consulting Ltd

**Nancy McNeill** - Project Manager, CLBC

**David McPherson** - Regional Executive Director, CLBC

**Cyndi Fournier** - Home Sharing Specialist, CLBC

**Peter Speers** - Coordinator, Innovation Committee, CLBC

**Jai Birdi** - QS Manager, CLBC

**Jamie Robertson** - Facilitator, CLBC

**Stephen Russell** - Community Planning and Development Manager, CLBC

**Andrew Wharton** - Senior Advisor, Disability Issues, Disability Services Division, Ministry of Housing and Social Development

**Odette Dantzer** - Director, Disability Strategy, Employment Division, Ministry of Housing and Social Development

**Shelley McNellis** - Manager, Disability Strategy, Disability Services Division, Ministry of Housing and Social Development

**Denise Lawson** - Parent and member, Governance Group, The Friendship Project

**Jane Holland** - Advocate for Quality Service, Ministry of Housing and Social Development

**Peter Swayne** - Parent and Chair, Community Council, Vancouver

**Linda Perry** - Executive Director, Vela Microboard Association

**Wendi MacKintosh** - Family Support Worker, Semiahmoo House Society

**Cathy Anthony** - Family Support Worker, Simon Fraser Society for Community Living

**Donna Good Water** - Aboriginal Advisor, CLBC

**Pat Hanbury** - Interim Executive Director, Family Support Institute

**Ian Brethour** - Director, Performance Management and Accountability, Disability Services Division, Ministry of Housing and Social Development

**Karen Delong** - Coordinator, Inclusive Education & Family Support, BCACL and Parent and member, Governance Group, Supporting Everyday Lives

**Norah Flaherty** - Parent

**Sherry McDonald** - Parent

**Patrice Pratt** - Parent

**Evan Thomas** - Parent

**Karen Van Rheenan** - Manager, Policy, Standards and Practice, Kardel Consulting

**Ross Chilton** - Executive Director, Director, Community Living Society

**Anna Fox** - Parent, and Board member, Community Living Society

**Jessica Humphrey** - Parent, and staff member, STEPS Forward Post Secondary Inclusive Education Society

**Shelley Nessman** - Self Advocate Advisor, CLBC

If you have questions or would like further information, please contact Brian Salisbury, Director of Strategic Planning for CLBC, by e-mail at [Brian.Salisbury@gov.bc.ca](mailto:Brian.Salisbury@gov.bc.ca) or by phone at **604 664-0105**.



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