

Together is Better: Collective Family-Governed Use of Individualized Funding in Policy and Practice

Presenters:

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What do we know about Individualized Funding/Self-Direction?

- Enables greater independence and community inclusion, provides greater flexibility and reliability of services, generates higher satisfaction, and improves quality of life, physical health and emotional well-being.
- Increases the capacity of individuals, families and communities, promotes integration of individuals in community, and allows for creative programmatic solutions, in some cases at a cost less than traditional services.

(Laragy & Ottman, 2011; Haliwell & Glendinning, 1998; Stainton & Boyce, 2002; Simon-Rusinowitz, et al., 2005; Witcher, et al., 2000; Glendinning, 2008; Carlson, et al., 2007; Blackman, 2007; Lord & Hutchison, 2003; Stainton et al., 2009).

However, take up has been slow....

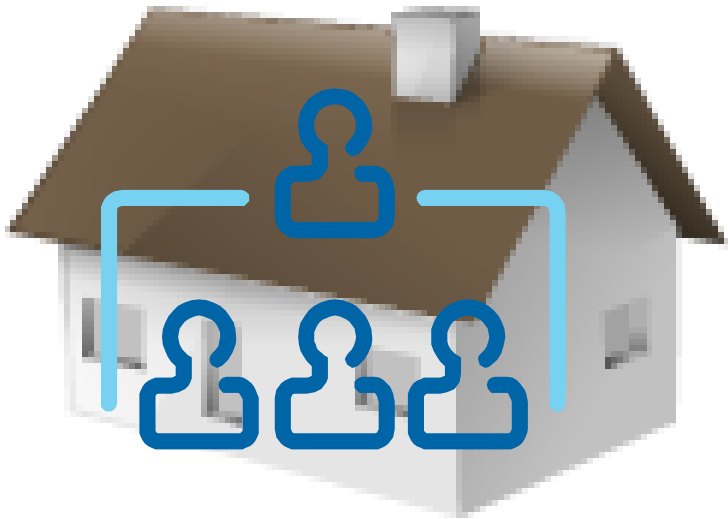
- Criticisms relate to the safety of individuals, the difficulties in managing budgets and services, and the risks of inequality, dependency, increased isolation and lack of peer support.
- Concerns over the strength and stability of support systems, accountability over public funds, its disproportionate use by middle class individuals/families, and its role in a larger movement towards the privatization and individualization of welfare, the erosion of public responsibility, and the weakening of public services and, further, the collective voice in support of a strong, public system of supports.

(Glendinning et al., 2008; Riddell et al., 2005; Blackman, 2007; Leece & Leece, 2006; Barnett & Barnett, 2006; Lawson, 2007; Gleeson & Kearns, 2001; O'Brien, 2001).

What is Collective Family Governance?

- A way for “families to work together to identify and meet their needs.”
- 3 collective models:
 - 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
 - (CLBC, 2009, p. 2; see also Kendrick, M., 2011).

Families consider Possible Models of Support



Traditional Provider
Managed Services



IF/Self-Direction



Microboard



Family Governance

Examples of Collective Family Governance

- The Benambra Intentional Community Co-operative (Canberra, Australia)
- Homes West Association (Brisbane, Australia)
- Lifestyle Options Incorporated (Stones Corner, Australia)
- Deohaeko Support Network (Pickering, ON)
- GIFTS: Gulf Islands Families Together Society (Saltspring Island, BC)
- Coco Café: Cedar Opportunities Co-operative (Cedar, BC)
- Project Inclusion [formerly Comox Valley Youth Project] (Courtney, BC)



History of InclusionWorks! Victoria

- Started in 2010: Little or no government funding for adults with disabilities.
- Two Single Moms hatched a plan, and included other families – some with and some without funding.
- IW! Victoria started with 7 families (now has 8).
- Started collectively with 30 IF hrs/wk from CLBC (now 120).
- Staff – started with 2 contract support workers (now has 4).



Following InclusionWorks! Victoria...

InclusionWorks! Saanich

- 2012
- Started with 6 families (now 7).
- Initially provided with 56.5 IF hrs/wk (now has 99.5).
- Started with 2 contract support workers (now has 3.5).

InclusionWorks! South Island

- 2014
- Started with 11 families (now 10).
- Initially provided 88 IF hrs/wk.
- Started with 3.5 contract support workers.
- Started this last September.

**InclusionWorks! North Shore started up on Mainland and
InclusionWorks! 2015 forming in Victoria.**

Philosophy and Values

- We believe that:
 - Self-advocates and families are best positioned to make choices regarding their future and with the appropriate opportunities, training, and support, can make a meaningful contribution;
 - Canadian society is enriched by inclusion;
 - The presumption of legal capacity should be upheld through supported decision-making;
 - Everyone is entitled to have friends; and
 - We adhere to the principle of the “dignity of risk.”



Family Governance means

- Self-advocates and family members form the decision-making team for all matters
- Self-advocates and family members select the support workers, who are hired or contracted through a Host Agency
- Self-advocates and family members decide how to use resources
- Self-advocates and family members determine programming
- Self-advocates and family members form partnerships.



Why *Inclusion Works!*

Right to continue
as part of community



Differing needs from
previous generations

Limited
funds available
for Community
Inclusion



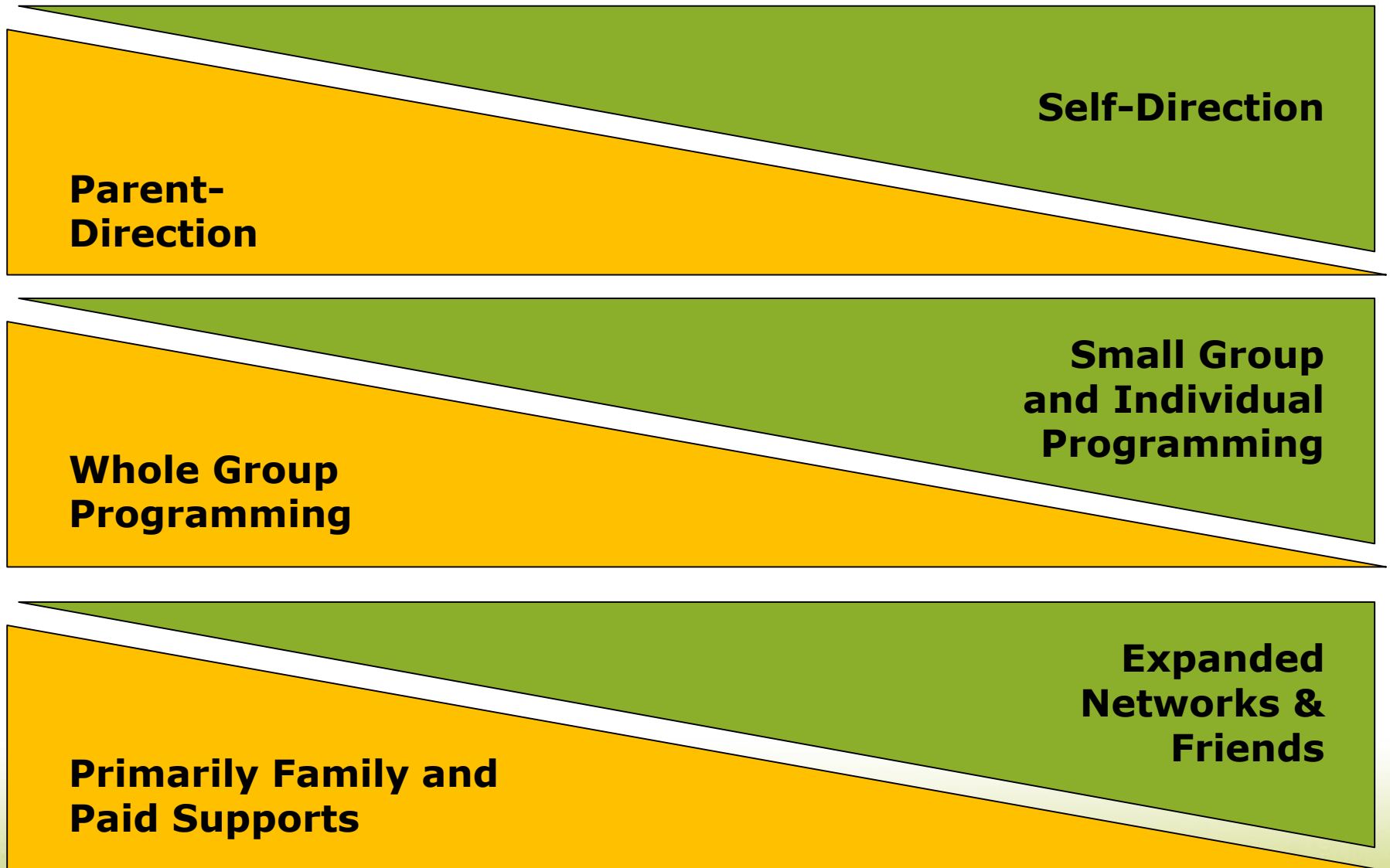
Families wish to take
more responsibility

InclusionWorks! is...

- A model of family governance in which transitioning youth and their families collaborate during a five year transition period.
- Individualized, age appropriate, challenging programming for each participant.
- Activities up to 7 hours daily, 5 days a week with focus on employment, life skills, friendships, and inclusion in community.
- Uses community spaces and programs as much as possible.



Process Goals



InclusionWorks! Community Partners

- **Community Living BC**
- **Community Living Victoria (Host Agency)**
- **South Island Distance Education School (SIDES)**
- **University of Victoria Faculty of Education (Centre for Outreach Education - CORE)**
- **GT Hiring Solutions (WorkBC)**
- Flow Communications
- Camosun College Community and Education Assistant Program/Family and Child Studies Program
- Lifetime Networks
- EntreActive
- The Vital Program
- University of Victoria Child and Youth Care Program/Physical Education Program/Applied Theatre Program/CanAssist
- Gordon Head, Cedar Hill, West Shore, Pearkes and Commonwealth Recreation Centers
- Vic West Community Centre
- Woiwod Dance
- Pacific Institute for Sports Excellence
- Finding the Balance Yoga
- Power to Be Society
- Conservatory of Music
- Local Businesses
- Independent Consultants

Financial Structure

- All government (IF) and other funding/resources received by the participants is pooled.
- Families pay a small monthly amount.



Why Family Governance...



“An issue for this generation is that many services provision models provided for adults with disabilities in Canada today, such as day programs, group homes, vocational services, and post-secondary options remain largely unchanged over the last 20 years and have not evolved to meet the assumed unique needs of this (current) transitioning group of young adults with disabilities.”

○ From: Leif Rasmussen, Kathleen Haggith and Jillian Roberts

Transition to Adulthood, Moving Needs Into Practice: A Canadian Community Partnership Response to New Adult Service Needs for Individuals with Disabilities, Relational Child & Youth Care Practice, Volume 25, No 3 2011

Concern About IF/Self-Direction	How Family Governance Addresses
Ability to manage supports and budgets	Diverse skills; Stronger likelihood of organizational and budget skills in group
Too bureaucratic	Combination host agency/FG lessens bureaucracy
Cost effectiveness	Leveraging of resources increased
Safety of individual	Small village; More eyes on person
Risk of Fraud in \$/Services	Host Agency; More eyes on \$ and services
Isolation of individual	Peer group; Community Inclusion
Lack of Family Support	Built-in Support Network
Privatization	Community development model
Reduced collective advocacy	Small collective; principles of social justice; linked groups; person and family driven
Risk-Averse	Support for risk-taking; risk-takers bring group along; flexibility
Individualistic	Interdependent; Programming without walls
Quality	More ideas; healthy tension of individual vs group; dependent on each other to make it work

History: The CLBC Think Tank on Family Governance and Beyond

- Grass roots project
- Benefits of Collective Family Governance
- Pilot projects
- Characteristics of sustainable groups
- Board Coffee and Conversation
- Dovetailing with the IF agenda

Enabling Conditions

- IF Policy
- IF Host Agency Policy
- Host Agencies
 - administer funding allocated by CLBC
 - have a funding agreement with CLBC
 - work with individuals and their families (or appointed representative/agent) to arrange and manage the supports
 - are guided by an agreement between an individual, his/her agent

Policy on Family Governance

- Legitimizes model
- Directs staff
- Links to mission, IF policies, strategies, systems
- Clarifies roles and responsibilities
- Provides operational framework for families and self-advocates, and funder
- Offers protections to families and self-advocates
- Risks being prescriptive and/or rigid
- Risks stifling innovation
- Potential drift from intent
- Risks becoming top-down instead of grassroots

Development of Policy

- Enabling approach
- In partnership with self-advocates and families
- In consultation with Host Agencies
- Building on IF policy
- Guidance
- Innovation

Collective Family-governed groups

- Health and safety needs
- Collective vision
- Programming priorities
- Allocation of resources
- Process to address conflicts
- When someone wants to leave
- Disbanding of group
- Other

Questions?



InclusionWorks!

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