



THE UNIVERSITY OF BRITISH COLUMBIA

Canadian Institute for Inclusion and Citizenship

Individualized Funding

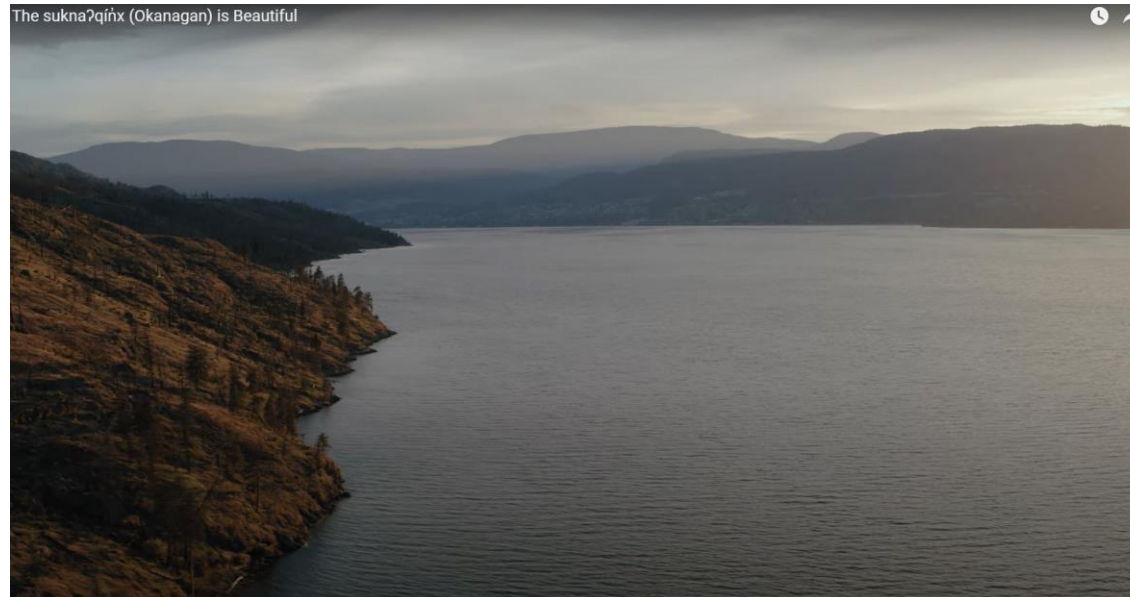
Professors Rachelle Hole and Tim Stainton

Co-Directors of the UBC Canadian Institute for Inclusion and Citizenship

And

Laura Mudde (PhD Candidate), Maddy Cote-Dear (MSW Student),
Trevor Grey (PhD Student), and Arielle Lomness (UBC Librarian)

We would like to acknowledge that today we are joining in today from the unceded, traditional and ancestral territories of the sylix people (Rachelle) and the Tsawwassen Nation (Tim)



Individualized Funding

❖ AGENDA

- ❖ Definition of Individualized Funding
- ❖ Brief overview of what we did (Methods)
- ❖ Findings
 - ❖ Barriers and Facilitators of Individualized Funding in the International Literature
 - ❖ Policy Findings
 - ❖ Implications – So what?
- ❖ Questions



THE UNIVERSITY OF BRITISH COLUMBIA

Canadian Institute for Inclusion and Citizenship

Individualized Funding Definition

Funding allocated directly to an individual or in the case of a child their parents or legal guardian, to provide the support necessary to meet disability related needs...

Individualized Funding has two fundamental characteristics: The amount of funding is determined by direct reference to the individual and/or family's specific needs, and aspirations; the individual and/or their family determine how funds are used to meet those needs eligible for funding. (Stainton, 2009).



THE UNIVERSITY OF BRITISH COLUMBIA

Canadian Institute for Inclusion and Citizenship

Methods

- ❖ **Scoping review of the international literature**

- ❖ **Barriers and facilitators to successful IF models**
- ❖ **IF implications and operational considerations**

- ❖ Search yielded **4,523 articles** after duplications

- ❖ **58** of these met the inclusion criteria for this scoping review



THE UNIVERSITY OF BRITISH COLUMBIA

Canadian Institute for Inclusion and Citizenship

Methods

❖ Australia	36
❖ UK (England, Scotland, Northern Ireland)	14
❖ Europe	2
❖ New Zealand	1
❖ United States	4
❖ International focus	1



THE UNIVERSITY OF BRITISH COLUMBIA

Canadian Institute for Inclusion and Citizenship

Benefits of IF

- ❖ **Person-centred – self-determination**
- ❖ **Sense of control, choice, reliability, and flexibility**
 - ❖ Greater access to and choice of therapy providers



THE UNIVERSITY OF BRITISH COLUMBIA

Canadian Institute for Inclusion and Citizenship

Facilitators

- ❖ **Clear lines of communication** (timely, accessible, clear information)
 - ❖ Value of expertise and information sharing (particularly important early childhood)
- ❖ **Family status, social capital, capacity, and geographic location**
 - ❖ Highly correlated with socio-economic advantage (Fisher et al., 2023; McDonald et al., 2016; Russo et al., 2021)
 - ❖ Supportive family and community relations facilitated positive experiences (Bisp et al., 2023; Boaden et al., Cowen et al., 2011; Dew et al., 2023; Fisher et al., 2023; Howard et al., 2015; Leatz et al., 2015; Mitchell 2014; 2015).



Facilitators

- ❖ The role of trusted service providers or supports workers (Navigator)
 - ❖ Trusted service providers were especially important for early childhood intervention supports, information, and community networks (Boaden et al., 2021; Brien et al., 2017; Brien, 2018; Clark & Dissanayake, 2022; Comito et al., 2023; Gavidia-Payne 2020; Nucifora et al., 2022; Tracey et al., 2018)
- ❖ Interagency collaboration



Barriers

❖ Lack of access to information

- ❖ Relating to IF application process and provision (Alexander et al., 2019; Boaden et al., 2021; McDonald et al., 2016; Prowse et al., 2022; Small et al., 2020; Smethurst et al., 2021)
- ❖ Contradictory advice from professionals (Alexander et al., 2019)

❖ Administrative Burden

- ❖ Burden and unequal capacity to take on self-management (Alexander et al., 2019; Boaden et al., 2021; Fisher et al., 2023; Nucifora et al., 2022; Ranasinghe et al., 2017)
- ❖ Restricted choice and control



Barriers Continued:

- ❖ **Aged-based transitions** (Alexander et al., 2019; Gavidia-Payne 2020; Loadsman & Donnelly 2021; McDonald et al., 2016)
 - ❖ Transition from youth to adults services (Cowen et al., 2011; Duffy & Murray, 2013; Mitchell 2012; Nucifora et al., 2022; Whitburn et al., 2017; Yates et al., 2021)
 - ❖ Transition from education system to IF → **lack of structure** (NDIS Australia; UK Cowen et al., 2011; Duffy & Murray 2013; Mitchell 2012)
- ❖ **Siloed structures** – separation between education system, health care system, and social care system (McGuigan et al., 2016; Whitburn et al., 2017; Yates et al., 2021)



Barriers Continued:

❖ Socio-economic barriers

- ❖ Lack of family resources and capacity presents various challenges (Boaden et al., 2021; Ellem et al., 2019; Laragy & Ottman, 2011)
- ❖ If families need to pay upfront – causes financial hardship
- ❖ IF operates within existing socio-cultural disparities and thus can lead to further alienation of equity deserving (marginalized groups) and those with more complex support needs (Laragy & Ottman, 2011; Martks et al., 2022; McDonald et al., 2016; Simpson & Douglas, 2016; Small et al., 2020)
 - ❖ Four studies explicitly recognized the compounded marginalization of people with Indigeous and culturally and linguistically diverse families in accessing IF (Boaden et al., 2021; Dew et al., 2023; Laragy & Ottman 2011; White et al., 2021)



Barriers Continued:

- ❖ **Rural and remote constraints** (Boaden et al., 2021; Dew et al., 2013; Dew et al., 2014; Gallego et al., 2018; Howard et al., 2015; Johnson et al., 2020; Laragy & Ottman, 2011; McDonald et al., 2016; Simpson & Douglas, 2016; Prowse et al., 2022; Small et al., 2020)
 - ❖ Lack of information and advice
 - ❖ Limited local service options and capacity
 - ❖ Higher costs and fewer services
 - ❖ Complexity of self-managing packages

- ❖ **Availability of professional and skilled staff** (Johnson et al., 2020; McDonald et al., 2016; Prowse et al., 2022; Ranasinghe et al., 2017)



POLICY & PRACTICE

- ❖ Wide variation across jurisdictions
- ❖ Need to exercise caution in comparing/adopting directly from other jurisdictions
 - ❖ Differences: cultural, structural, jurisdictional responsibilities....



THE UNIVERSITY OF BRITISH COLUMBIA

Canadian Institute for Inclusion and Citizenship

GENERAL POLICY FINDINGS

- ❖ Various studies identified the need for system integration and collaboration between health care, social care, and education systems.
- ❖ Importance of ensuring family-centred approach
- ❖ Importance of maintaining and securing strong community relationships
- ❖ The need to account for the political and economic context in which IF models operate, such as thin markets, budget cuts, and lack of available services or skilled workers in rural and remote areas



THE UNIVERSITY OF BRITISH COLUMBIA

Canadian Institute for Inclusion and Citizenship

- ❖ Importance of person-centred planning
- ❖ Access to facilitators/case managers
- ❖ Tracey et al. (2018) To support informed choices, policy-makers and providers must communicate information in helpful and accessible ways; 8 principles
 - ❖ 1. accessible and diverse in format, mode, source and location;
 - ❖ 2. personal and targeted, appropriate for purpose and audience;
 - ❖ 3. accurate, consistent and timely;
 - ❖ 4. from a trusted source;
 - ❖ 5. from an independent source;
 - ❖ 6. culturally appropriate;
 - ❖ 7. proactive for hard to reach groups;
 - ❖ 8. gender appropriate.



-
- ❖ Importance of transition from child/youth supports to adult support system
 - ❖ Flexibility in making changes/use
 - ❖ Clear and transparent eligibility and funding level determination process
 - ❖ Clear and simple reporting requirements



-
- ❖ Importance of having administrative supports available as required
 - ❖ Consider travel cost in determining budgets for rural and remote users
 - ❖ IF has potential to undermine shared/collective services



So what's this all mean ?

- ❖ IF can be used in a broad range of ways to support children and Families
 - ❖ ECD
 - ❖ Health care, therapy
 - ❖ Respite
 - ❖ Payment to Carers (both direct to family member of independent)
- ❖ IF requires an infrastructure to work well (dependent on scope)
 - ❖ Planning support
 - ❖ Recruitment/Finding of workers or professionals
 - ❖ Employee and funding administration
- ❖ IF will not (and probably should not) replace all agency/collective services



THE UNIVERSITY OF BRITISH COLUMBIA

Canadian Institute for Inclusion and Citizenship

- ❖ IF presents unique challenges and opportunities for rural and remote communities
- ❖ IF also presents unique challenges and opportunities for indigenous and other cultural communities
- ❖ When done well IF is both cost effective and has positive outcomes for child and family



Acknowledgments

❖ We would like to thank our amazing research team who worked on this review:

Laura Mudde (PhD Candidate)
Maddy Cote-Dear (MSW Student)
Trevor Grey (PhD Student)
Arielle Lomness (UBC Librarian)



THE UNIVERSITY OF BRITISH COLUMBIA

Canadian Institute for Inclusion and Citizenship