THE UNIVERSITY OF BRITISH COLUMBIA

Canadian Institute for Inclusion and Citizenship

Individualized Funding: Key Informant Interviews

Prepared for Community Living British Columbia

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About this Report

This report synthesizes findings from key informant interviews with professional stakeholders and their observations about individualized funding in BC. This report is part of Phase Two: 'Current Status of IF under CLBC' (Ethics Approval: H24-00004).[1] Phase Two is part of a larger research endeavour providing an international, national, and regional understanding of individualized funding approaches. Our larger research endeavour includes reports completed for Phase One: 'Review of Current Literature on IF' and 'Current Practices in other Jurisdisctions' (Stainton et al., 2024a; 2024b).

Future reports will include data and results from Phase Three: 'User Experience Surveys', Phase Four: 'Qualitative Individual Interviews', and Phase Five: 'Summary Analysis of Data and Proposed Directions' (2025). Funding for this report was provided by Community Living British Columbia (CLBC).

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Executive Summary

The current report presents findings based on key informant interviews and participants' observations about individualized funding (IF) as it pertains to funding offered through CLBC to eligible individuals, and their families and carers. In addition, findings include key informant insights into their experiences with CLBC's services, other professionals, and general observations about the community living sector in BC. IF is defined as funding allocated directly to an individual or, in the case of adults under guardianship, their parent or legal guardian. Funding is meant to provide the support necessary to meet disability related needs, in which the amount of funding is determined by direct reference to the individual and/or family's specific needs and aspirations, while the individual and/or family retain choice and control in how funds are used to meet those needs (Stainton 2009).

This report relies in part on information sessions with CLBC leadership to gain insight into the operational structure and IF policies. Insights into these policies informed semi-structured interviews with key informants to identify best practices, strengths, and challenges of current CLBC IF funding models in British Columbia. Findings from key informant interviews, presenting professional experiences within and outside of CLBC's organization, provide a rich account of the various strengths, challenges, financial implications, and policy considerations associated with CLBC's IF options. In addition, findings from the current study align with strengths, challenges, implications, and considerations identified in the international literature on IF (Stainton et al. 2024b).

Strengths of IF

The strengths of IF options lie in the ability to empower families, provide personalized support, and foster strong, collaborative relationships. Key informants stressed that families value the flexibility and control over services offered through IF, and how the reduction of administrative tasks offered by agencies (e.g., Host Agency agreements) helps reduce barriers. However, most informants cautioned that as demand for services has grown, maintaining this balance of flexibility, personalization, and support presents a challenge that requires attention and potential systemic adjustments to address evolving person-centered support needs.

Challenges of IF

While CLBC's IF programming was intended to provide greater choice and control for individuals with disabilities, key informants identified that its current implementation is marred by systemic inefficiencies, lack of flexibility, and inadequate support structures. Several informants indicated that addressing these issues will require streamlining or limiting of bureaucratic processes, while improving communication, accessibility, and the level of true choice in personalized supports available to individuals and families.

Financial Constraints

The financial and budgetary constraints identified by the key informants paint a social

support system marked by rigidity, resource scarcity, and a lack of flexibility, which in turn affects the quality and availability of services. These constraints were seen to place significant burden on individuals and families, CLBC employees, and service providers. Specifically, reduced funding was seen to carry an emotional toll, presenting uncertainty of funding and complicating efforts to deliver appropriate, self-determined supports.

Policy Considerations

While key informants acknowledged the initial promise and success of IF options, particularly in giving individuals and families more choice and control, several systemic barriers persist. These include bureaucratic complexity, inconsistent communication, and regional disparities, all of which hinder the CLBC's effectiveness and IF uptake, especially among rural, Indigenous, and marginalized communities.

Key informants called for more transparency, better training, and a focus on community-based individualized care to improve the reach and impact of CLBC's IF. Almost all key informants specifically stressed the need for better training of CLBC staff to improve communication about IF, making IF more accessible and flexible for families. Additionally, improved training and communication between CLBC and individuals and families were considered important in an effort to foster a change in negative sentiment about CLBC among service providers and eligible individuals and families. Informants emphasized systemic flaws in person-centered service delivery through a disconnect between policy instruments and needs. Informants indicated the importance of community-based hiring and leadership positions for self-advocates to better deal with organizational challenges in balancing IF ideals with collectivist community values. Key informants highlighted clear frustration with bureaucratic processes that hinder person-centered support.

Moving Forward

Key informants emphasized the need for better training, more awareness of IF as an option, improved transitions for aging caregivers, more efficient resource allocation, and clearer communication to strengthen both IF options and the support of families. A synthesis of key informant interviews foregrounded a deep need for reform within CLBC, with an emphasis on community involvement, cultural sensitivity, better support for families, and a restructuring of leadership and communication strategies to make both the system and IF more inclusive, flexible, and led by the diverse communities' needs.

Introduction

Research indicates that individualized funding (IF) leads to more positive outcomes for individuals receiving disability supports compared to traditional funding models (Stainton & Askerova, 2013). Despite its implementation and initial intent as a cornerstone for CLBC services, barriers to effective IF utilization persist. Through interviews with key informants, including CLBC employees and community-based service providers and professionals, this report identifies strengths and challenges associated with CLBC's IF options.

This report is part of a multi-method study that seeks to understand how CLBC can better support individuals and families' consideration of IF as a viable and sustainable option for meeting their service and support needs. Utilizing a comprehensive approach, the broader proposed research project includes a review of current literature on IF and practices in other jurisdictions, along with consultations with a wide range of stakeholders. The aim of the research is to identify ways to improve the experience of IF users in BC[2] and to enhance the accessibility of IF for individuals and families eligible for CLBC funding and/or receiving supports through other means. The project involves multiple phases:

Phase 1 – Complete a jurisdictional scan of current IF practices in Canada (Stainton et al., 2024a). Complete an international scoping review of the literature on IF (Stainton et al., 2024b).

COMPLETED

Phase 2 – Review past and current CLBC research, policy and practice guidelines related to IF. Identify current utilization numbers. Conduct qualitative interviews with key informants (e.g., professionals, CLBC staff/employees, IF experts).

CURRENT

Phase 3 – Conduct a survey of current IF users and eligible individuals and families to explore experiences with IF, reasons for not taking up IF, and what would encourage users to consider IF.

FUTURE

Phase 4 – Conduct qualitative interviews with IF users and eligible individuals and families with a focus on Indigenous users and families and people in rural and remote locations to explore experiences with IF, reasons for not taking up IF, and what would encourage users to consider IF.

FUTURE

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[2] As of June 2024, CLBC reported 4,137 Simplified Agreements, 705 Standard Agreements, 246 Host Agency Agreements, and 358 Person-Centered Societies, including Microboards.

1. Methods

Researchers at the Canadian Institute for Inclusion and Citizenship (CIIC) conducted semi-structured interviews with ten key informants, which included CLBC employees and community-based professionals.[3] Prior to these interviews, during the months of February and March of 2024, researchers were part of various information sessions with CLBC leadership that informed the creation of a semi-structured interview guide (Appendix A). Researchers relied on CLBC's network and snowball sampling methods to recruit key informants, who were asked to complete a Qualtrics XM Survey consent form (Table 1). Key informant participants had the opportunity to offer direct feedback on their experiences with IF, which is crucial to enhancing understanding of the strengths and challenges associated with CLBC's IF options. The semi-structured interview approach allowed for the free flow of ideas and sharing of opinions while also garnering responses in the specific areas of professional experience and policy understanding (Appendix A). Ethics approval was granted by the UBC Behavioural Research Ethics Board [H24-00004].

1.1 Procedure

Participants accessed the Qualtrics survey form outlining the study and consent process through an invitation email. Individuals were prompted to indicate their willingness to participate and their consent (or lack of consent) to have their interview audio recorded. Once the consent form was completed, a CIIC researcher contacted individuals via email to schedule an interview. To allow in-depth insights, we conducted two paired interviews with four key informants. This approach was chosen by those participants and facilitated dialogue and sharing of complementary expertise between participants and the interviewer. Both pairs were together based on their professional roles and shared involvement in the disability sector. All voices were equally important and the interviewer encouraged the sharing of individual perspectives and respond to each other's contributions. All key informant interviews lasted between one to two hours approximately and were audio-recorded with participants' consent for subsequent transcription and analysis. Before commencing the interview, the researcher reviewed the consent process with the participant(s). Any questions or concerns of the participants were addressed prior to the start of the recording in order to promote a clear understanding and resolution of any concerns before the interview and its recording. This report addresses the data shared with the researchers during interviews using a UBC-licensed Zoom account.

1.2 Eligibility Criteria

Any potential key informants had to conform to the following eligibility criteria. CLBC employees had to be 18 years of age or older, currently or previously employed by CLBC with

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[3] A key informant here refers to a person who is knowledgeable about IF and CLBC's role in providing IF as a support option. All key informants in this report had a professional or practice-related perspective of CLBC's IF. Several key informants also expressed lived experience in caring for a person or being a parent of an adult with disabilities, eligible for CLBC's IF.

knowledge of IF, and able to agree to participate. Similarly, IF experts or professionals working in the field of disability supports had to be 18 years of age or older, currently or previously working at community-based agencies or service provider supporting individuals and families receiving IF, and able to agree to participate. CLBC, Vela, Inclusion BC, and BC People First supported the recruitment.

1.3 Confidentiality

The confidentiality of key informant participants was secured through the online consent form and the secure storing of interview records in a research folder on a UBC Secure Research Drive. Participants' personal information is protected through the use of pseudonyms. Table 1 presents an overview of the key informants involved in the study, their pseudonym, role, and region of employment (Figure 1). In any dissemination activities, these pseudonyms and limited demographic data are used to avoid identification of participants. Names used are assigned to each informant for the sake of confidentiality. Due to familiarity within the sector, all professional roles outside of CLBC are referred to as 'Community'. Roles assigned to key participants refer to their more recent connection to either CLBC or community-based services. Most key informants have held multiple positions within and outside of CLBC and community-living sectors. Participants also spoke to perspectives of IF in relation to family members with disabilities.

Table 1: Key Informants, Age, Role, and Region

Informant	Pseudonym	Role	Region (Figure 1)
1	Ally[1]	Community	2
2	Ellis[1]	Community	2
3	Andy[2]	Community	2
4	Stan[2]	Community	2
5	Devin	CLBC	1*
6	Kate	CLBC	1
7	Robin	CLBC	1
8	Mark	Community	1
9	Jane	CLBC	1*
10	Jody	CLBC	3

* Identified as rural or remote within this region; [1,2] Key informants completed interview together.

Figure 1: British Columbia Service Regions

Figure 1: Region 1: Vancouver Island and Coast; 2: Vancouver Metropolitan Area; 3: Thompson Okanagan Cariboo; 4: Kootenay Area; 5: Cariboo; 6: North Coast Nechako; 7: Northeast (source: https://selfadvocatenet.com/bc-self-advocate-organizations/)

1.4 Data Extraction Process and Synthesis

The semi-structured interview guide supported the extraction of information from the key informant interviews in a relatively consistent manner (Appendix A). Themes were identified based on answers to those questions and informed by previous meetings with CLBC leadership as well as insights from a review of relevant IF documents. The results of the key informant interviews presented in this report are based on the participants' professional and personal experiences with IF and/or observations about IF. The findings and discussion speak to five levels of engagement: strengths of IF, challenges of IF, financial and budgetary constraints, policy considerations, and suggestions for moving forward. The discussion section connects the findings to the international literature on IF (Stainton et al., 2024b) to compare the key informant takeaways regarding CLBC's IF program options and practices with IF research from international jurisdictions.

2. Findings

The findings presented here are based on the analysis of the data gathered from ten key informants in eight interviews exploring CLBC IF policies and practices. The results need to be considered in the historical context of CLBC's organization and the various community-based agencies or service providers supporting IF-eligible individuals and their families. CLBC as the provincial Crown agency is mandated to deliver supports and services to adults with developmental disabilities and their families in BC since 2005. CLBC as an organization is connected to years of development by self advocacy leadership and families as well as professional and academic expertise. Key informants recalled the shift in authority from the Ministry of Child and Family Development (MCFD) to CLBC in an "effort to create a community-based, consumer-driven and responsive system of supports for adults with developmental disabilities" (Stainton & Askerova, 2013). Since 2007, CLBC introduced IF into its community-based and consumer-driven model. Principles guiding IF are to improve individuals' capacity for self-determination, autonomy, and community inclusion. Figure 2 provides some information about the various IF models available in BC.

Figure 2: IF Models in British Columbia

What is individualized funding?
Community Living British Columbia (**CLBC**) provides individualized funding that lets you or the person you assign (the Agent) manage the money and hours of service you get for your disability-related needs. Individualized funding gives you more choice in the support decisions that affect your life. You can choose who you work with and how you manage your supports.
CLBC's individualized funding has two levels:

→ The **Direct Funding Simplified Agreement** for $10,000 a year or less

→ The **Direct Funding Standard Agreement** for more than $10,000 a year

You can manage your individualized funding in different ways:
1. Direct Funding (Self-Managed**)**:
Money from **CLBC** to buy supports is paid directly to you or the person you assigned (the Agent). You or your Agent handle the money and manage the supports and hours of service for your disability-related needs.
2. Host Agency Funding:
Money from **CLBC** to buy supports is paid to a **Host Agency** that you or you and your Agent choose. Depending on your **Host Agency**, you can choose your own support workers or get offered support workers that will be trained to support your needs. The **Host Agency** handles the money for you for funding over $6,600 a year.
3. Person Centred Society:
A **Person Centred Society** is a small, not-for-profit organization that supports an individual (or sometimes two siblings or a couple). These societies are registered with the *BC Societies Act*. The society is led by a board of directors that forms a circle of support to oversee the delivery of services using both **CLBC** and other funding. Some individuals choose a **Person Centred Society** because it creates a circle of support to distribute the work of support to more than a single person or Agent.
4. Microboard:
A **Microboard** is a small group of family and friends (a minimum of 5 people) who join together with a person with a disability to create a not-for-profit society (board). **Microboards** are supported by [Vela Canada]. **Microboards** help the person plan their life, advocate for what they need, monitor services ensuring they are safe, connect to their community, and do fun things together. A **Microboard** can access funding and deliver the services in a creative and flexible way, with funding coming from the Ministry of Children and Family Development, **CLBC**, the Ministry of Health, and/or a trust or a settlement (i.e., ICBC or WorkSafeBC).
5. Family Governance:
Family Governance is a person-based initiative where a group of parents, carers, or Agents work together to pool their funding and organize their own society or agency to support their people with disabilities. **Family Governance** is often driven by family members that all support a person with disabilities. It often refers to a closed group of about 7 to 12 families that work together to ensure the funding received for all individuals is spent on the delivery services and supports that benefits everyone. People in **Family Governance** set up their values and goals as a group and have control over hiring workers and signing agreements with **CLBC** and other sources of funding.

*** Important to note ***
Individual and Family Wellness Support is a type of individualized funding that refers to **CLBC** funding given to a family to support that family with caring for a person with disabilities. This *Individual and Family Wellness Support* funding used to be called *Family Respite*. The funding can be used to organize or pay for supports to help make daily life more comfortable, healthy, and happy. The support may be provided in the individual's home or at another location. For example, the funding can be used for day camps, therapy, and counseling to directly support the carers of a person with a disability.

In an earlier study regarding cost comparisons with block funding models, Stainton and Askerova (2013) suggested that for the 2010 programming "there is ample evidence to suggest that the values espoused by CLBC matches the principles IF modes were built upon" (p. 45). The authors concluded in favour of promoting a further expansion of IF in the province. Nine out of ten key informants, in the present research, have been involved with CLBC and/or community living organizations and service provision in BC for at least the last fifteen years and have been part of, or witness to, that expansion of IF for eligible adults and their families. Key informant insights included references to different periods in CLBC's organization and comparisons between periods in terms of the organization's growth, leadership, and restructuring.[4] Informant framed their experiences with IF and CLBC according to the following approximate periods:

Early Days (2007 – 2012)
Review and Improvement (2013 – 2017)
New Strategies (2018 – 2020)
COVID-19 Pandemic and After (2021 – 2024)

2.1 Strengths of IF

Several themes emerged when comparing the responses from key informants asked to identify the strengths of IF and its contributions to better support outcomes for individuals and families: 1) family-centered control and flexibility, 2) tailored and person-centered services, 3) collaborative relationships, 4) ability to adapt to changing needs, 5) simplification of processes, 6) social networks and community connections, and 7) evolving challenges.

Family-Centered Control and Flexibility

In the 'Early Days (2007 – 2012)' most key informants remembered a sense of optimism: "I remember being more excited about individualized spending before" (Jane). According to Jody, "Initially, it was extremely collaborative and collegial. And there was a real optimism … about empowering people and families and maybe looking towards best practice." Most informants emphasized the flexibility and control that IF offered individuals and families, allowing them to tailor services to their needs, as "[with IF] you have the control and flexibility" (Ally).

Robin mentioned how families appreciate having the ability to make decisions about their care with IF. This was echoed during interviews with Andy and Mark. Mark spoke to the importance of giving families the option for complete oversight and control over their supports.

They'd like to have more of a say in how they are involved or included, or, or have shared responsibilities. [T]here have been times where people have … felt that they

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[4] To promote a critical, yet respectful engagement with statements, informants' mention of names is omitted, and, at times, paraphrasing is used to convey the sentiment expressed.

weren't heard, and that the Host Agency agreement might give them a bit more involvement. (Andy)

The overarching strength voiced among informants was that IF options can empower families by giving them autonomy in decision-making, especially in choosing services and managing funding. This led to a more individualized, person-centered approach in support that was highly valued by families.

Tailored and Person-Centered Services

Several respondents emphasized how early on, the introduction of IF fostered more opportunities for person-centered planning and customized care. "[It represented a push] to make [support] person-centered rather than science-centered or biomedically-centered" (Jody). According to Robin and Mark, IF through Host Agency agreements enabled families to select service providers and adjust services based on their unique circumstances.

> We decided to offer [IF] because we thought it was one of those innovations that are important that allow individuals and families to control their services. It ensures individualization of service or person-centeredness more than the global contracts do. (Andy)

As Robin indicated, "[families] get to help set the goals, the deliverables. They get to be in the know with pretty much anything they want to." The ability to individualize services to match personal needs was seen as a critical benefit of IF. By making the funding more flexible and personalized, families could address the specific needs of their loved ones, which was especially important in cases where traditional service models may have fallen short.

Collaborative Relationships

Several interviewees, including Robin and Kate, discussed the importance of building strong, collaborative relationships between individuals and families, CLBC facilitators, and service providers. Robin, as a CLBC employee, observed the importance of consistency in relationship building among individuals and families that expressed positive experiences with their IF. Collaboration was also identified as central to IF success among families who were using a Family Governance model as "individualized and tailored to the families, and there is a level of control … to make sure everybody gets pretty much what they need. Um, and that they're happy" (Kate). These collaborative relationships were characterized by regular communication, co-planning, and shared responsibilities. Strong, consistent relationships between service providers, families, and CLBC, such as facilitators and analysts, were seen as crucial for the successful implementation of, and experiences with IF.

> [Host Agency agreements involve] working closely with all parties, in order to make sure that the services are in line with the individuals' goals and support needs … [and] each Host Agency agreement that we have is tailored to the wishes of the individuals

and families …, basically giving complete choice and oversight over the services without having to deal with the administrative burdens. … That true partnership that individuals and families enjoy as a part of being here; they really do get to choose how supports happen. (Mark)

Mark emphasized the importance of the "long term relationships with care providers," and whether the individual and their family have found their match in a support worker:

You know we've got some contractors who have just essentially become part of the family. And you know they're working in the individual's home; they know Mom and Dad. They know the brother, or whatever um, and they really are immersed into the family situation. And so, it's not necessarily just about the funding. Specifically, it's more about the relationship. (Mark)

Collaboration helped tailor services and made families feel supported in managing their IF.

Ability to Adapt to Changing Needs

The importance of IF ability to adapt services and funding to meet evolving needs was mentioned in general and in connection to the 'COVID-19 Pandemic and After (2021 – 2024)' period. Robin and Jody mentioned that the flexibility that was re-introduced during the COVID-19 pandemic allowed for more adaptive uses of funding received as Individual and Family Wellness Support (formerly respite funding).

I think what's working well for families is … having that new flexibility. … I've seen a lot of people come through, families, and they're like, 'Oh, I have to do these reports, and I have to, you know, sign these invoices and receipts with the respite providers', and it was very intimidating for a lot of folks … so, I love that these new flexible options are in. They still have to report. But it's not insane like it used to be. (Robin)

Kate and Jody mentioned IF allowed families to adjust services as circumstances changed, especially in the Microboard and Family Governance options of IF. Both IF models were seen as responsive to changes, such as when children transition out of school environments or when there were unexpected costs. Funding flexibility—whether in the form of financial management, service adaptation, or even through the pooling of funding—allowed families to remain in control while meeting dynamic needs. This adaptability was particularly important in the context of shifting life stages and crises like the pandemic.

Simplification of Processes

A recurring point mentioned as a potential strength in IF was the reduction of the administrative burden through updates to the process. Robin mentioned how the creation of simplified agreements and clearer materials have made IF more accessible. Jane also noted the importance of providing families with easy-to-understand materials and videos that helped

demystify the process of obtaining IF. The simplification of administrative tasks made IF more accessible to families, particularly those who might otherwise be overwhelmed by paperwork. This streamlining allowed families to focus more on care and less on navigating complex bureaucratic requirements.

Social Networks and Community Connections

Mark noted IF works particularly well for individuals and families with strong social capital or support networks, and "mostly people that are … potentially higher educated, or have more time" (Mark). Kate pointed out the importance of community-based supports, especially in the context of Family Governance. The pooling of service hours and resources among families or members on a Microboard strengthened the sense of age-appropriate, community-based, and shared responsibilities. Another mechanism for community connection with families and the promotion of IF was mentioned by Jane, who praised instructional videos offered through Vela:

> There's videos [for families to understand the process better]. Like the videos, are super easy, and it's Vela who has them all on their site. I feel like these videos are a good step cause my initial gut reaction was like; 'I don't want to do this'. If I was a family; the administrative burden; I would be like 'No, thank you.' (Jane)

In addition, IF was described as more effective when people could still rely on a robust support network, either through Family Governance models or pre-existing community connections. Jody emphasized the power of social capital retention in Microboards that Kate associated with the pooling of resources within Family Governance to enhance outcomes and ensure that families are not isolated.

Evolving Challenges

Jody and Jane observed that despite the early optimism about IF, already challenges arose during the 'Early Days (2007 – 2012)' period as funding demands increased and resources were tight. Jody highlighted how the program started with a more collaborative approach but faced strains with the demand for services and reduced funding availability.

> There was real support around the front-end development … it was right at the beginning of CLBC, they had money. They actually had budget if you had a kiddo that had really high needs. They were talking about this wonderful process of person-centered planning and workbooks and the facilitators and the analysts were copasetic but already … as soon as the money started to tighten, that relationship started to strain. (Jody)

Mark touched on the balance between personalization and administrative burdens, noting that families need to feel supported in the process. While IF offers significant benefits, there were challenges related to balancing the demand for services with the need to maintain flexibility

and personalization. These identified challenges suggest that ongoing improvements in communication, funding allocation, and resource management were seen as necessary to maintaining the values espoused in the principles of IF.

2.2 Challenges of IF

According to the key informant insights, there are various challenges with CLBC's IF These insights presented recurring themes and patterns impacting IF and CLBC's image: 1) systemic and bureaucratic barriers, 2) eligibility and access to services, 3) impact on families and individuals, 4) technological barriers, 5) organizational and governance challenges, and 6) crisis and flexibility gaps.

Systemic and Bureaucratic Barriers

There was strong sentiment that IF and funding has become overly bureaucratic, focusing more on standardized processes and accounting metrics than on creative, individualized services. According to Ally and Ellis, "up until the last few years, it felt like we were making positive impacts in families lives. And now those are harder to come by just because there's so many systematic barriers." According to Jody, the system, initially designed to offer flexibility, veered away from its innovative roots due to economic pressures and institutionalization. What was initiated as a more flexible system turned into a rigid, bureaucratic one that hindered creative solutions for individuals.

> This shift to community living was not really organic … families were agitating against institutionalization. And [when IF] became an option … unfortunately, what happened out the gate was that money went to what existed. Community living organizations, which in and of themselves [were a] wonderful forefront in the early days, but were also holders of older practices. And they received huge bumps in their funding. So, they hired people and they started running really great day programs. But then there's … this many seats. They need those seats. They have huge demand on the volume. And they don't have any more money And so it's really advantageous economically … to keep funneling to these certain key players. It meant that there weren't as many options within community living as it would seem externally …. Because the little guys have burnt out or they gave up. They weren't really supported by individualized funding because the local CLBC offices didn't recommend it. (Jody)

As the excerpt from Jody's interview shows, in the early days of organizing individualized supports, smaller service providers struggled to offer a diverse range of services based on individual need and IF, while larger organizations, despite their historical importance, did not necessarily choose to offer specialist, creative, or innovative individualized support options; instead sticking to more standard and mainstream support options for individuals to spend their IF on, like day programs. In connection to day programs in the early 2010s, Kate identified a lack of openings in the traditional service or day programs, despite those existing service types being predominant in offering options to spend IF.

According to most key informants, access to tailored services, using IF has furthermore become increasingly complex, with administrative responsibilities overwhelming individuals, families, and service providers. Ally and Ellis mentioned this difficulty, as families often feel overwhelmed by the detailed reporting requirements, which detracts from their ability to focus on the needs of their loved ones.

> They don't know how to be an employer. They don't want to take on the paperwork involved in the contracts. I mean, CLBC also isn't telling them about the options, which isn't helping. But when they are, they're, often presented in a very negative light and you know, 'This is so much work.' (Ally & Ellis)

Robin described how increased administrative requirements have made the process of setting up IF more cumbersome over time:

> [Burden] went up over the years than when it was when I first started. It was basically; they gave us their name, and we set up the agreement and gave them a package of information, and that was it. It was easy. Now they have to set up like their account, which is with their criminal record check review program, account number, and there's a lot more steps that they have to go through to get that agreement signed and in place. (Robin)

According to Andy, burden was ascribed to different reasons, ranging from managing employees, where being an agent and hiring yourself is cumbersome compared to an agency who "has an HR department and can be continually screening and hiring", to difficulty working with CLBC as "the other reason that families have said that IF is just too much paperwork and complex reporting." Similarly, Jane commented seeing more hardship: "because that's what I'm doing, supporting families who find IF challenging to get through the paperwork and the barriers to get there."

Eligibility and Access to Services
Multiple informants, including Ally and Robin, mentioned a lack of communication from CLBC staff, resulting in families feeling unsupported and isolated. Devin spoke to a disconnect between policy and real-world needs, where CLBC's decisions do not necessarily align with the realities individuals and families face on the ground: "sometimes what happens in government is, you're just so removed. It's really easy to say; 'Well, the policy says this, so let's do it this way,' or 'This is what makes sense on paper.'"
IF policy itself was mentioned as unsupportive of individuals without family or a community-based support network. A lack of family, or appointed agent, can mean that 'family' served as a gatekeeper. Several informants pointed out the reliance on families to advocate for services. Robin and Mark posited that a families' lack of knowledge or understanding about their responsibilities and the IF system created an additional barrier for both individuals and service providers. According to Mark, individuals without family or a potential agent are

not considered eligible for IF. It all "relies on the level of understanding and knowledge from the family" (Robin). Mark and Robin emphasized that individuals without a family agent are often ineligible for IF, which excludes some individuals who could benefit from or wanted IF. Mark explained how individuals transitioning out of foster care are particularly disadvantaged and that the system's assumption that every individual needs a capable relative to manage their IF is problematic. In addition, Jane argued that even families with PhDs, "they're like super brainiacs … but even those families assert 'This is insane. There's nothing fluid about this.'"

Some informants reflected on the intersection of health care and IF as a contentious issue. According to Ellis and Ally, the collaborative care guideline between BC Health and CLBC means funding gets lumped into a single pot, leading to a lack of clarity and transparency. At times, this created suspicion about the amount of funds that CLBC is contributing in addition to the allocated BC Health funds. According to Ellis and Ally,

> We used to get CSIL[5] funding. Now it's added care, which again is very minimal compared to the needs. … Health goes; 'Here is your $3,000,' to CLBC and then CLBC gives it all to the family in one pot. You know, CLBC has used this as an opportunity to often not fund extra supports on top of the health. And that's another battle; there's very little transparency between those [funding streams] and then to families.

Ally added that this makes the process of funding and support hour allocation muddled, where CLBC was seen as using that as an opportunity "to reduce what they would have given if health wasn't involved". They do "a lot of finger-pointing as far as; 'You're supposed to be funding this', … and it also leaves a black hole for things like bathing toilets and feeding because neither of them will touch that" (Ally). The collaborative care guideline was seen as inadequate rather than as a collaboration between health and disability support.

Impact on Families and Individuals
As also noted above, informants talked about the strain and pressure on families to navigate the IF system. Jane specified the difficulty for families already struggling with the demands of caregiving, who may require a high level of hand-holding to navigate the process. It is "hugely dependent on the resiliency and work of the people involved" (Kate). Both Jane and Kate pointed out that transitioning from child to adult services was complicated.

> As a parent, I didn't want traditional day programs for my [child], I mean, in in all these situations our kids had been fairly included in schools. And so why would you go from inclusive education to segregated day programs? (Kate)

Transitions were seen as especially challenging for families who are not prepared for the increased complexity and reduced support as their children aged out of child-focused

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[5] CSIL stands for Choices in Support for Independent Living the IF program available through the health authorities.

services. The shift to adult services often lacked the same level of support and guidance, leading to confusion and added stress. Jane added that

> Most of the families that are doing individualized funding, they're already overwhelmed. With a very complex child or two children, or three, for that matter. They have not had success with service providers, because they feel that their voices haven't been heard. Their sons and daughters are not being served. So, they're not doing IF because they think; 'Oh, sign me up. This is fun'. No, they're doing it on a necessity … the stress level is right here [gestures above head].

Technological Barriers

Key informants highlighted the problematic reliance on technology for managing IF. Both in the periods before COVID-19, during, and after, informants addressed a digital divide between access to IF and service provision and the individuals and families CLBC is meant to serve. This was especially felt outside of urban areas and by folks without digital literacy or higher levels of education. Ally and Ellis noted that the system's increasing reliance on online forms, electronic signatures, and digital reporting creates a barrier for individuals in rural or remote areas, or those without adequate access to technology. Robin mentioned that some families do not have computers, further complicating their ability to engage with the system. According to Jane, "people don't use computers very well. So, you know, you even almost have to coach them on their own computer, like how to log on and how to make the printer work, and how to print this, and how to put it in". According to Ally and Ellis,

> Another barrier to the system is that we're very technology reliant now and a lot of our families aren't literate on technology. So that's another huge barrier for individualized funding options because really if you can't do online forms, you're not going to be able to manage IF currently because they don't have paper options.

When Robin reflected on the available paper options in the Vancouver Island region, this did not appear to be an adequate alternative to online forms. Paper reporting presented "a significant delay in payment to them by the time it goes through the mail, and then we get it, sign it, send it up to CLBC Accounts for processing". According to Jane, paper forms still relied on technological hardware that might also not be available.

Rural and remote communities were reported to experience greater digital access barriers, not having access to the internet, fax machines, and instead, relying on phone-based connection.

> Some of the people we support don't have computers. … It was really frustrating. I heard a lot from families trying to get that set up. Everything's like electronic. The contract [that] clerks send out to the families ask them for their electronic signature. Most people don't know how to do that. (Robin)

Devin and Jane described how rural and remote communities face unique challenges due to the lack of available infrastructure and services. The shortage of available staff and services in these areas made it difficult to maintain consistent programs and meet individuals' needs where online access was unavailable as well. Moreover, Devin added that "what works in cities, what works in urban areas, doesn't always work in rural and remote areas… Their life is very different in rural and remote areas".

Organizational and Governance Challenges

Some challenges related specifically to issues with governance and community engagement due to overburdened staff. According to Ally and Ellis, CLBC facilitators appeared both overworked and undertrained. This resulted in families not receiving the support they need and was compounded by higher staff turnover and a lack of familiarity with the intricacies of IF. In turn, according to Mark, the lack of knowledge translated into a lack of IF referrals.

> I think that the barrier is [that] I don't think that CLBC really talks to individuals and families about the level of responsibility that might be included in being an agent for a Host Agency contract. … So, the facilitators who are doing the planning. I don't think that they necessarily have a lot of knowledge or understanding of Host Agency or Individualized Funding. And, so they're not promoting it.

According to Jane, some issues existed with the requirements of completing GSA and priority tools when CLBC facilitators have just met the individual and the family without knowing, or being able to get to know, the people. In turn, "if you have a misguided or misinterpreted GSA, then everything else is going to be building on that" (Jane). According to Jody, CLBC staff were required to act as gatekeepers: "They can only say, 'No, not now,' or 'No, never.' And can you imagine how that must wear on them? Do you think they're going to start phoning people and having coffees in their kitchen if that's what they're going to have to say?". Ally and Ellis also mentioned how a lack of resources in CLBC makes the facilitator job "a hard job because they're having to say no so often."

Crisis and Flexibility Gaps

Ellis, Ally, and Jody reflected on the lack of support for families in crisis and the failure of the system to respond appropriately to people heading for a crisis due to aging of carers. There might be a discrepancy in language and terminology as Ally asserted, "CLBC likes to call complex needs like folks that are unhoused and on the streets." According to Jody, more crises were expected to occur due to a lack of legacy planning for aging carers that no longer have social capital to rely on. In fact, according to Jody's personal experience, when in a state of crisis, despite following all the necessary procedures to request additional support, the system failed to provide timely assistance during a critical period. This highlighted the rigidity and lack of flexibility in the IF process, particularly during times of urgent need.

Another flexibility gap in relation to service provision and IF was addressed by Devin.

Service provision and availability in cities,

> can count on numbers. And it does make sense for people to just have money
> attached to them so they can go wherever they want, because there's lots of
> programming … whereas in the rural and remote areas that's by definition the
> opposite, there's not many people, and there's not many services and so, being able to
> pay staff to be there, no matter who shows up is the only way to keep a program
> running. Because if you can't pay staff for the days when only one person shows up, if
> that program ends, the next day, when 5 people show up, well, there's no program.
> And I saw that happen in a lot of communities where if you couldn't pay staff to be
> there during the quiet times, then you lose the programming.

Common threads addressed in these observed challenges from the ten key informants were the excessive bureaucracy and administrative burden, lack of clear communication and collaboration, burden on individuals and families without (community) support or resources, technological barriers in rural areas, and gaps in service for individuals with complex health needs or those from more marginalized communities. These challenges were also addressed in the international literature that will be briefly commented on in section 3 of this report.

2.3 Financial and Budgetary Constraints

Key informants' narratives revealed recurring financial and budgetary constraints within the provincial social care system. Particularly in the context of IF offered through CLBC, this pointed to higher level constraints affecting CLBC and having a trickle-down effect for CLBC employees, service providers, support workers, individuals and their families. "We all know that what's creative and innovative takes a while. ... I don't think government is inherently very tolerant of that. [In the end] everyone had the scarcity mindset" (Jody).

Underfunding and resource scarcity was mentioned by Kate, Ally, Ellis, Jody, Andy, Stan, Jane, and Mark. Kate highlighted that from 2010 to 2012 CLBC was significantly underfunding, requiring families to seek resources from various other streams. This echoed throughout other accounts, as Ally and Ellis mentioned that recent funding levels (e.g., $350 or $700 per month) are insufficient to meet the needs of families, especially for individuals with higher support requirements.

> The other barrier, certainly in the last year and a half, two years, is that there's just not
> the funding available to families to make it worth it. Like, when you're saying, you know,
> 'Welcome to the system. Here's your $700 a month for your person who's a level 5 and
> has 4 flags.' Of course, they're not gonna choose IF, you know, like it's not helpful at
> that point. (Ally)

The idea of scarce resources was mentioned repeatedly. Ally and Ellis noted the lack of resources in CLBC and the impact on support workers, who frequently had to say no to

families due to insufficient funding. Andy and Stan further emphasized the tight budgets and lack of flexibility in CLBC funding, which restricted the amount of support that can be offered. From a service provision perspective, Andy and Stan said that for "this year, they're very tight. [There is not] much flexibility at all. And people are referred as GSA 4 and 17 hours … but CLBC only funds 12 hours, because they don't have enough money."

This leads to observed economic and administrative rigidities. Mark and Jody commented on the financial rigidity within the system. Jody critiqued the reliance on an economic lens for decision-making, which does not align with the individualized and person-centered approach needed. The system's strict adherence to data and budgetary limitations was seen as stifling innovation and flexibility. Mark described the challenges of navigating bureaucratic structures that limit the ability to adjust contracts based on actual needs, particularly when funding rates for support hours vary, depending on unionized workers or contracted workers.

Rigidities in turn were faulted for the impact on service delivery and self-determination. Ally, Ellis, Jody, and Mark asserted that financial limitations lead to significant challenges in delivering self-determined supports, which is essential for families and individuals relying on CLBC IF. Ally and Ellis stressed that the amount of funding was insufficient for families to make meaningful choices or to facilitate self-determined support options. This limitation has direct implications for the quality and scope of services available. Jody and Mark further suggested that these financial constraints prevent the flexibility and creativity needed to deliver more personalized care.

Scarcity of resources seemed to be offloaded onto service provision and families through accountability concerns and safeguarding of spending funds. Mark explained that there is an ongoing focus on proving that the money allocated is being spent properly: "I think it's safeguarding - where the money goes. … Maybe the pull federally is to be accountable, to, like, 'We've given this money to this organization, and we can prove that that was a valid thing to do'" (Mark). This highlights a financial safeguarding mechanism that, while important, contributes to rigidity and a narrow focus on cost-effectiveness over service quality. Mark's assessment reflected a concern brought up by Jody that CLBC's policies as part of a system prioritized financial reporting over the actual needs of individuals and families.

This priority and financial strain lead to emotional and practical burdens on families and workers that were brought up by Jane, Ally, and Ellis. Jane reflected on trying to provide support by helping families find resources or pathways, even when unable to deliver the desired outcomes due to funding limitations. Emotional toll was seen to be compounded by the isolation that families experienced in the face of bureaucratic and financial obstacles. Ally and Ellis mentioned the burden on families, noting that inadequate financial support often meant that families are left to pull together resources from different sources. This uncertainty and instability of funding was also noted by Jody and Devin. Both informants assessed that the inherent instability of funding for services, particularly in the context of government priorities, meant funding can change unpredictably. Devin stated, "I'm conscious of the fact that we are being funded right now, and that could change anytime …. Governments are fickle, and you know. Things can change. Things can change. Priorities can change." The

volatility of funding was a concern that affects long-term planning and the ability to maintain consistent support services, as funding can be reduced based on shifting political or economic priorities.

In summary, comments about financial constraints revealed a chronic underfunding that was identified by all, particularly in 2010 to 2012 and since 2022, leading to resource limitations in terms of financial support and available services, where CLBC facilitators were appointed as gatekeepers having to turn families away. These constraints have created a rigid system, where CLBC's administrative and economic frameworks for allocating funds do not align with the needs of individuals and families. This affected families and support workers who were reportedly bearing the emotional consequences of financial constraints, including feelings of isolation and frustration due to the instability and unpredictability of funding sources, which complicated long-term planning and service delivery.

2.4 Policy Considerations

Informants were asked to reflect on IF and CLBC policies. Their responses highlighted both supportive policies and processes, as well as significant barriers in the uptake of IF.

Policies and Processes Supporting Success

Both Kate and Jody emphasized the promise of innovative policy in the early stages of the IF program, when "the ministry was giving out money for innovation" (Kate). Early grassroots activism and support in IF according to Jody were marked by forward-thinking but lacked financial support from CLBC. With more resources and clearer communication, these efforts could have gone further. In later periods of IF, changes in service provision included increased choice and control for selecting support workers. According to Mark, the move toward a contractor model, away from unionized positions, was crucial for ensuring families and individuals could choose their support workers, based on availability and funding, where unionized positions had seniority rules, limiting choice:

> We decided that we needed to go to contractor route. … In order to really give choice to individuals and families, we needed to move away from the union for these specific IF services. Because otherwise it would have been seniority lists, and it would have been, you know, people wouldn't have necessarily had the say in who was providing the supports.

This connected to Robin's comments about the flexibility offered by some service providers with Host Agency agreements. Andy, Mark, Stan, and Robin promoted Host Agency agreements with contractors for support workers for providing more control to families, allowing them to choose their support workers; these were seen as more individualized. Though the process could be intimidating due to multiple contracts and was identified as not referred enough by CLBC staff (Mark), it allowed families more input and choice.

Both Jody and Robin applauded the flexibility in funding introduced by pandemic-driven

changes. Jody reflected on a brief period during the pandemic when there was more flexibility in funding use where families had better access to support. However, according to Jody, after the pandemic, changes reverted where the system returned to its old methods, which Jody saw as a missed opportunity for more person-centered approaches to be permanently adopted. According to Robin, some of this much-needed flexibility remained in the flexibility offered in Individual and Family Wellness Support (formerly respite).

Barriers to Uptake and Current Policy Challenges

One barrier to IF uptake that was considered a policy challenge was a lack of attention to cultural and regional differences. According to Devin, programming in rural and Indigenous communities should look different from urban centers to address the disparities experienced by marginalized communities. Policy should address disparities from the perspectives of specific communities to steer away from ineffective programming, designed from an urban perspective. Settler-colonial systems and individualization, according to Devin, also presented challenges in terms of nation-to-nation relationships. Offering external funding to Indigenous communities can reinforce colonial rhetoric in assuming the needs of these communities or imposing individualistic models of support in collectivist cultures. While IF might work in some contexts, in others it may not align with the values or structure of that specific community. Policy should consider First Nations and communities on a case-by-case basis that first focuses on building trust. Devin advocated for hiring within community to foster trust and provide employment opportunities to local individuals, many of whom may not have formal qualifications. In small, Indigenous, or rural communities, family ties often influenced hiring decisions, which complicated the existing workforce policy dynamics. IF should be community-based, avoiding a top-down approach, recognizing that the introduction of external funding and power can be a colonial practice.

Informants noted the complexity and lack of transparency within CLBC, leading to strained relationships with service providers and limited collaboration. According to Mark, the bureaucracy and lack of transparency affected service provision and families. For CLBC facilitators, a lack of clear policy and knowledge about IF combined with high caseloads led to unresponsive and insufficient support for individuals and families. This understaffing also impacted families' awareness of about IF options. Robin, Mark, Ellis, Ally, Jody, and Jane indicated that facilitators are overburdened which discouraged both staff and the families they support from pursuing IF options. The IF process was seen as overly complicated, with frequent staff turnover. According to Devin, the role of analyst was "really overly complicated".

IF use and reporting of that use by individuals and families at times was reported inaccurately, only to be discovered much later. According to Jane, some families have been underreporting for years, and when discrepancies were discovered, these were often blamed on the family rather than on the forms, staff, or inaccessibility of online reporting. Jane emphasized that this oversight is a systemic issue, as the reporting system has not been effectively monitored. This was in a different way visible for service providers who are not consistently monitored and deal with different rules of engagement with their Host Agency

agreements and CLBC depending on the region, as confirmed by Mark, Andy, Stan, and Robin.

Policy appeared most bogged down by an inconsistency in operational knowledge of IF. Mark expressed concern about the inconsistency in understanding and promoting IF across regions and among CLBC facilitators, leading to families being unaware of IF as an option. What is more, Host Agency agreements, Person Centered Societies, and Microboards appeared even less accessible with some CLBC facilitators telling families those options no longer existed (Ellis & Ally). As Robin, Jane, and Mark also pointed out, CLBC did not provide adequate training to address knowledge gaps, where online information and modules did not reflect real-world interactions with individuals and families, nor teach facilitators how to inform their clients about IF. Most informants expressed empathy for CLBC facilitators and their position as for instance Jody and Jane expressed, they could imagine how staff must feel intimidated by IF processes and lack the necessary confidence to inform families. Robin asserted that training programs are either insufficient or non-existent, leaving staff with little guidance, which can hinder the promotion of IF options.

Strain on CLBC facilitators and analysts intersected with the lack of resources and lack of a funding budget. According to Jody, this has meant a departure of person-centered care.

> You have people speaking person-centered [without] practice …. CLBC is saying, 'Oh, families are so difficult', and they don't understand how [as a Crown agency] they get farther and farther removed from the personhood …. [Facilitators and analysts], they're scared to death of upping their numbers or having to spread their money further. And so, they're just keeping you, [in] the parking lot. … So, facilitators and analysts just spent all their time out in the parking lot fending off people to come in. Keeping them in a holding pattern so that people only get funding when they're in acute crisis.

The lack of confidence and knowledge about IF added to the reported lack of transparency in CLBC's procedural processes, with families facing inconsistent information or conflicting information across different regions. According to Ally and Ellis, "we get lots of families that come to us and go, 'Oh, my facilitator didn't even tell me I could run my funding through these options'". Inconsistencies made it difficult for families to navigate the system. Jane pointed out that this has resulted in CLBC leadership and staff actively discouraging IF. Similarly, Ally and Ellis indicated some families were actively discouraged from pursuing self-directed IF options in favour of block funding, which was presented as simpler, even though it may not align with families' desire for greater control and choice. This ableist and at times negative attitude about IF did not present room for promoting the idea that individuals and their families can learn and become more knowledgeable about the system and their funding. According to Jane, current attitudes within CLBC leadership presented the view that IF is complex or overly burdensome, which affects how it is communicated. Furthermore, direction was given that when families do not understand the forms, they should be considered ineligible for IF.

Mark, Stan, Andy, and Robin addressed some Host Agency policy challenges.

According to Mark, CLBC "[hasn't] been working very collaboratively with service providers throughout the province. Of course, each region is different. But it [is] a challenge." While service providers see the value and importance of Host Agency agreements in providing more options for choice and control of support workers, CLBC analysts may perceive the agreements and contracts as complicated and time-consuming:

> Analysts always come to me and be like, 'Oh, my gosh! I have a Host Agency, and I looked on our system, and there's like 5 different contracts that need to be done', and they immediately get a little bit worked up and scared about setting those ones up. (Robin)

Some families also faced challenges when wanting to hire specific workers due to some service providers only having unionized support workers on their payroll. Jane emphasized the importance of building strong relationships with service providers, ensuring they can meet the specific goals of individuals. She noted that there is often turnover among intake staff, which can lead to miscommunication and misalignment of services with the families' needs. She also highlighted the difficulty in working with agencies that cannot provide the necessary individualized services, particularly when union regulations imposed constraints on service delivery times.

According to Ally and Ellis, the provincial systems operate in silos. There was a lack of communication between the different provincial systems (health, social care, education), leading to inefficiencies and missed opportunities for integrated support. In turn, siloed systems also reflected a lack of flexibility in policy and supporting individual and family needs that are prone to change and fluctuate. Some families were discouraged from accessing IF options due to the rigid structure of the system. For example, families may have been discouraged from pursuing non-agency managed funding or were told that specific types of support services (such as purchasing external services like cooking classes) are no longer allowed, thus reducing autonomy.

There appeared to be tension in balancing equity with nuanced care. The challenge of maintaining fairness in the allocation of resources while addressing the unique needs of each family and individual was a key concern for service providers. On the resource allocation side of things, this meant CLBC facilitators and analysts sometimes act as gatekeepers, making decisions on behalf of families. Jody highlighted the gap between the rhetoric of person-centered practices and their actual implementation. Facilitators and analysts could limit access to funding and services unless individuals were in acute crisis. Jody also mentioned that the system, initially rooted in grassroots efforts, has become heavily bureaucratized, with decision-making power largely held by government officials rather than those directly impacted by the policies.

> Ultimately, it's strict data through an economic lens. And when they first set up CLBC, they hired the software company I guess the platform was essentially just for a hospital or something, so it was totally based on accounting principles. (Jody)

These bureaucratic-centered policies have had an impact on time management, at the detriment of relationship building. According to Jane and Jody, facilitators were often caught up in paperwork and forms, leaving little time to build meaningful relationships with individuals and families, which limited the effectiveness of the support provided. According to Jane, a lack of direct interaction and visitation with families led to ineffective use of the Guide to Support Allocation (GSA) and Priority Ranking Tool (PRT). The PRT and GSA are deficit-based, asking individuals to describe their worst-case scenarios to secure funding. Jane believed this approach is flawed, especially for individuals with invisible disabilities or non-verbal conditions. The assessment does not capture the complexity of certain disabilities and may overlook the unique needs of those with conditions like autism.

In summary, the key informants emphasized systemic flaws in policy and execution, reporting strained IF service delivery, a disconnect between policy tools and individual needs, the importance of community-based hiring and leadership, and the challenges of balancing IF with collectivist community values. There was a clear frustration with bureaucratic processes that hinder the person-centered support intended by the policies.

2.5 Moving Forward

Informants highlighted several areas where IF policies and programming by CLBC could be improved to better meet the needs of individuals and families. Their responses are organized according to four themes: 1) training and confidence building, 2) transition planning, 3) funding and resource allocation, and 4) addressing bureaucratic and logistical challenges.

Training and Confidence Building

Robin emphasized the need for more training for staff to increase their confidence and knowledge about IF policies. This would help staff better support families and offer IF as an option. According to Robin, with more training, facilitators would be more comfortable discussing IF with families, leading to better outcomes. Robin further suggested procedure manuals and improved knowledge about IF across the board would help families make informed decisions about utilizing IF. Many families may not be aware that IF is an option, and providing more information could lead to more families choosing this funding model.
Jody and Devin highlighted the importance of involving communities in a meaningful, culturally relevant way, especially with regard to Indigenous populations, and the need to create systems that are truly reflective of community values, not just individualistic approaches. Devin pointed out the importance of cultural sensitivity when working with Indigenous communities, emphasizing the need to remove barriers and create a safe space for engagement. Devin also advocated for a complete rethinking of IF in terms of cultural values, moving away from colonial, individualistic frameworks. Mark also noted the need for more community-based approaches to IF, with a focus on understanding families' needs and building trust, especially within Indigenous communities. Robin and Jody highlighted the importance of accessible knowledge bases for families, such as short videos on IF, families' best practices, and support for families to navigate the system. Jane called for better

scaffolding of family support, suggesting mentorship and shadowing for new staff to ensure they understand the IF process from the ground up.

Transition Planning

Ally and Ellis highlighted the issue of transitioning from child-specific funding (CYSN by MCFD) to adult funding under CLBC. They described this transition as a "funding cliff," where families face underfunded and less supportive systems when moving to adult services. There was growing concern about aging parents who have been the primary caregivers for individuals with disabilities. Ally described how many families have not adequately planned for the future, which leads to a crisis when parents can no longer care for their loved ones. This results in more families turning to agencies or long-term care facilities for support. Jody and Jane emphasized the lack of training and preparation for transitions, particularly for aging parents. Jane shared the example of a family that had been doing well with IF, but where the aging mother was increasingly unable to manage the funding. Without adequate planning and support, this family presented an example of how families might face significant challenges, without a clear process for transitioning IF responsibilities to a service provider.

Funding and Resource Allocation

Jody and other informants pointed out that provincial funding for IF is subpar, with there being insufficient resource allocation at both the provincial and organizational levels. They described how the allocation process was inefficient, with some funds mismanaged or not distributed effectively. This lack of proper funding and resource distribution negatively impacted the families who rely on IF. Informants also suggested that CLBC could improve communication with families by being more transparent about available resources and what they can realistically expect. This would help manage families' expectations and improve their overall experience with the system. Jody pointed out the lack of communication and shared stories about IF, which could help families and individuals understand its potential and limitations. The *Incommon TV* project, aimed at sharing such stories, was an example of how information sharing could be more effective but has been underfunded and left behind.

Addressing Bureaucratic and Logistical Challenges

Ally and Ellis highlighted bureaucratic issues within CLBC, such as the lack of a system to replace an IF agent when they pass away. They stressed the need for improved logistical support, better communication, and more efficient resource allocation. They also advocated for reducing paperwork to make the process less cumbersome for families and staff alike. Jane and Jody stressed the need for leadership to actively listen to families and individuals with lived experience to comprehend the impact of the policies they create on those families and individuals. Jody suggested that executives and board members should spend time with individuals with lived experience to better understand their needs. Jody further criticized the tokenization of self-advocate advisors, stating that these individuals should be treated as real leaders with the capacity to influence change. Several informants expressed their frustration with the current system. Ally suggested that the system may need

to be completely restructured to meet its original goals. Devin criticized the bureaucratic nature of the system, noting that the community focus seems lost, and Jane was concerned about the overall direction, particularly the increased business-like approach within leadership. Jody criticized the lack of diversity and creativity within the leadership and executive teams, observing that the system has become self-preserving and disconnected from the needs of the community. Robin and Mark both reflected on the lack of flexibility in IF policies, with some families facing barriers to accessing the full support they need due to budget constraints or restrictive bureaucratic processes. Ally and Ellis advocated for offering full-time employment with benefits to improve retention of community-based workers. Robin emphasized the need to streamline policies and reduce bureaucratic hurdles to make the system more accessible.

Based on the above, we can surmise recommendations and paths forward to enhance the effectiveness and uptake of IF:

- Training and transparency: Invest in comprehensive training for CLBC staff and improve communication to promote awareness and understanding of IF.
- Simplification and flexibility: Streamline bureaucratic processes, reduce administrative burdens, and offer individuals families more control over their funding use.
- Culturally appropriate models: Adapt funding models to reflect the values and structures of rural and Indigenous communities, avoiding one-size-fits-all approaches.
- Person-centered practices: Shift focus from crisis-driven to proactive, individualized care, ensuring policies genuinely empower families and individuals.
- Sustained grassroots engagement: Leverage community-led innovations and lessons learned from the pandemic to create a more adaptable and inclusive system.

By addressing these systemic flaws and fostering collaboration, CLBC's IF can better achieve its goal of empowering individuals and families with choice and control over their care.

3. Discussion and Conclusions

Key informant interviews provided a rich account of IF that was at once varied, based on individual perspectives, yet comparable in their observations about CLBC's IF options and the strengths, challenges, financial, and policy-based considerations. Many elements brought up by informants were reflected in research about IF programs in other jurisdictions. Based on the international scoping review prepared for CLBC in March of 2024, the next sections will integrate key informant findings with academic research and perspectives about IF and self-direction.

3.1 Strengths of IF

Identified strengths of IF options lie in its ability to empower families, provide

personalized support, and foster strong, collaborative relationships. The international literature reviewed in Stainton et al. (2024b), similarly contained the overarching positive outcome of IF as a person-centered alternative to block funding that provides greater choice and control leading to a stronger sense of self-determination among disabled individuals and their families and carers. Key informants in the context of BC, stressed that families value the flexibility and control over services offered through IF, and how the reduction of administrative tasks offered by for instance Host Agency agreements, helped reduce barriers. However, most informants cautioned that as demand for services has grown, maintaining this balance of flexibility, personalization, and support presented a challenge that requires attention and potential systemic adjustments to address evolving person-centered support needs. Various academic sources indicated that the research evidence on the strengths of IF indicates that disabled adults from the dominant cultural group with less complex disability needs benefitted most (e.g., Boschen et al. 2022; Crozier et al., 2013; Friedman & VanPuymbrouck 2019; Welch et al. 2012). Families that can rely on support networks and community integration apart from being well resourced and capable of advocating and providing support benefitted most from IF and increased self-direction.

3.2 Challenges of IF

Key informants identified that CLBC's current implementation of IF is marred by systemic inefficiencies, lack of flexibility, and inadequate support structures. Several informants indicated that addressing these issues will require streamlining or limiting of bureaucratic processes, while improving communication, accessibility, and the level of true choice in personalized supports available to individuals and families. Similarly, the international academic literature presented common barriers associated with IF, including administrative burden, a lack of accessible and accurate information, an increase in existing inequities, geographic constraints, a lack of available services, and a lack of available skilled workers. For example, Alexander et al. (2019), Carey et al. (2018), and Dickinson and Yates (2023) argued that challenges navigating supports due to financial and administrative burden increased experiences of pre-existing inequity, limiting access to services for groups with potentially the highest need. This was echoed by Jane, Jody, and Mark. Other challenges identified by Jane and Devin included contextual barriers based on sociocultural factors and availability of appropriate human resources due rural and remote factors (see also Ettelt et al. 2018; Pattyn et al. 2023; Simpson & Douglas 2016). Rural and remote factors compounded barriers to IF, with less culturally sensitive service options being available in some regions (e.g., Dinan & Boucher 2023; Layton et al. 2023; Slasberg 2013). In addition, the shifting to an IF model meant that agencies needed to adopt a different service delivery model and not all support types or innovative therapy options were equally supported according to Jody (e.g., Dew et al. 2016; Dintino et al. 2019; Hamin et al. 2022).

3.3 Financial and Budgetary Constraints

Key informants painted a social support system marked by rigidity, resource scarcity,

and a lack of flexibility, which affects the quality and availability of services. These constraints were seen to place significant burden on individuals and families, CLBC employees, and service providers. Specifically, reduced funding was seen to carry an emotional toll, presenting uncertainty of funding and complicating efforts to deliver appropriate, self-determined supports. Financial and budgetary constraints reported in the academic literature also referenced austerity and funding cuts affecting the IF model. The majority of peer-reviewed research made some reference to financial and budgetary constraints (Stainton et al. 2024b). Austerity measures and the impact of such measures on the financial landscape and availability of needs-based funding was found in the context of Australia (e.g., Edwards 2019; Miller & Hayward 2017), the United Kingdom (e.g., Aspinal et al. 2019; Manthorpe et al. 2015; Norrie et al. 2014), the United States (e.g., Simon-Rusinowitz et al. 2014, and Canada (e.g., Hande & Kelly 2015; Kelly et al. 2021). According to Power (2014), a comparative policy analysis of IF in the Canadian provinces of Ontario and British Columbia, the American region of Washington DC, and London, England revealed opposing forces of the increasing spread of personalisation and austerity within neo-liberal countries.

3.4 Policy Considerations

Key informants acknowledged that despite the initial promise and success of IF options, several systemic barriers persist. These included bureaucratic complexity, inconsistent communication, and regional disparities, all of which hinder the CLBC's effectiveness and IF uptake, especially among rural, Indigenous, and marginalized communities. Academics in various jurisdictions similarly identified 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 (e.g., Dew et al. 2016; Dintino et al. 2019; Pattyn et al. 2023). Another important policy consideration related to the role of facilitators/navigators to address the importance of clear and transparent communication and the administrative burden that families experience. Key informants called for more transparency, better training, and a focus on community-based individualized care to improve the IF's reach and impact. Almost all key informants specifically stressed the need for better training of CLBC staff to improve communication about IF, making IF more accessible and flexible for families. Additionally, improved training and communication between CLBC and individuals and families were considered important in an effort to foster a change in negative sentiment about CLBC among service providers and eligible individuals and families. Many of the communicated barriers currently associated with IF impact the image of the Crown agency in the communities it is meant to serve. Informants emphasized systemic flaws in person-centered service delivery through a disconnect between policy instruments and needs. Informants indicated the importance of community-based hiring and leadership positions for self-advocates to better deal with organizational challenges in balancing individualized funding ideals with collectivist community values. There was clear frustration with bureaucratic processes that hinder person-centered support (see also Nevile 2019). Both the international literature and the key informants in the current study communicated the need for policy adaptation and development of culturally safe materials and communications (e.g.,

Ferdinand et al. 2021; Gilroy et al. 2017). Equity considerations in IF policies and practices can help to address socio-cultural-economic inequities of equity deserving groups in the implementation of IF.

3.5 Moving Forward

Key informants emphasized the need for better training, more awareness of IF as an option, improved transitions for aging caregivers, more efficient resource allocation, and clearer communication to strengthen both IF options and the support of families. Needs and IF recipients are unique individuals requiring local frameworks for development and implementation of needs-based funding for services and supports. A synthesis of key informant interviews foregrounded a deep need for reform within CLBC, with an emphasis on community involvement, cultural sensitivity, better support for families, and a restructuring of leadership and communication strategies to make both the system and IF more inclusive, flexible, and led by the community's needs. All in all, IF options require a thoughtful and family-driven approach to evolving needs and challenges.

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Appendix A: Semi-structured Interview Guide

Individualized Funding – Key Informant Interview Guide

Preamble:
- Welcome
- Review consent to participate and to record the session
- Ask for any question prior to commencing and prior to recording

➔ Start recording

Opening questions:

1. Could you please tell us where you work and describe your role?
2. Which geographical are does your role primarily cover? (North-Thompson-Cariboo, Southern Interior, South Fraser, Vancouver Island or Vancouver Costal)

Questions about experience with supporting individuals and families receiving IF:

1. Can you share your experience or involvement with IF?
2. From your perspective, how does IF contribute to better outcomes for individuals and families?
3. From your perspective, what are the aspects of the IF program that are working well?
4. From your perspective, what are the aspects of the IF program that are not working well?

Questions about perceived challenges and barriers with the IF program:

1. Can you share any challenges you or the clients you work with have encountered in relation to IF?
   a. How do you think this challenge(s) could have been mitigated?
2. Based on your interactions with individuals and families who are not currently receiving IF, what perceived barriers or obstacles have they expressed as reasons for not taking up IF?
3. What barriers do you believe contribute to individuals and families choosing not to opt for IF?
4. From your perspective, are there certain populations who appear more likely to adopt IF?
   a. If so, why do you think this is the case?

Questions about current IF policy:

1. From your perspective, what policies and processes have supported the success of the IF program?
2. In your opinion, how do current policies and processes contribute to barriers for uptake?
    a. Are there specific policies and processes that you perceive as serving as barriers to the uptake and accessibility of IF?
3. Are there any procedural challenges you encounter in managing the implementation of IF?
    a. How have you navigated these challenges?
    b. How do you think these challenges could be mitigated?
4. What changes do you believe are necessary in current policies, procedures, and processes to better support individuals and families currently receiving IF or those eligible but not currently utilizing it?

Questions about enhancing the IF program:

1. Are there aspects of the IF program that you believe could be enhanced to better meet the needs of individuals and families?
2. From your perspective, are there additional resources or supports that could be provided to overcome barriers associated with IF?
3. In what ways can collaboration between CLBC, community agencies, and service users be strengthened to make IF more successful?
4. Is there anything else you would like to share about your experiences with IF that we haven't talked about?