Social Enterprises
Knowledgeable Economies
and Sustainable Communities

Exploring Key Informants' Experiences with Self-Directed Funding

A Research Report

Nicola S. Chopin
Isobel M. Findlay

A research report prepared for the Northern Ontario, Manitoba, and Saskatchewan Regional Node of the Social Economy Suite

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Entreprises sociales
économies intelligentes
et communautés durables

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List of Acronyms

ACL — Associations for Community Living

CDS — Cognitive Disabilities Strategy (SK)

CILT — Centre for Independent Living in Toronto

CLBC — Community Living British Columbia

CLD — Community Living Division (SK)

CUISR — Community-University Institute for Social Research

DDS — Department of Developmental Services (California)

DLSA — Daily Living Skills Assessment (SK)

DSSS — Department of Social Services and Seniors (PEI)

DFSA — Direct Family Support for Adults (NS)

DFSC — Direct Family Support for Children (NS)

DSP — Disability Support Program (NB)

ILSP — Independent Living Support Program (NS)

IF — Individualized Funding

ICOF — In the Company of Friends (MB)

IQOL — Individualized Quality of Life (ON)

LIFE — Living in Friendship Everyday (MB)

PDD — Persons with Developmental Disabilities (AB)

PSW — Personal Support Worker

SACL — Saskatchewan Association for Community Living

SAID — Saskatchewan Assured Income for Disability

SDF — Self-Directed Funding

SSAH — Special Services at Home (ON)

VPA — Vulnerable Persons Living with a Mental Disability Act (MB)

Executive Summary

Self-directed funding (SDF) models provide public funds to individuals with intellectual disabilities to help them fulfil their unmet needs and allow them to reach their goals. SDF is based on principles of self-determination, choice, and equality. In a more functional sense, SDF allows persons with disabilities to choose and purchase which programs and services will support them. With these principles in mind, this report seeks to examine the complexities, challenges, and strengths associated with SDF models.

The literature review and interviews focus on:

- sustainability of SDF
- accountability measures related to the allocation of funds, including the design of appropriate reporting requirements
- quality and risk management to ensure clients' funds are managed properly
- labour market and staffing issues related to the availability and retention of personal support workers
- equity among different user groups

Research Methods

This research builds upon previous research by Lynch and Findlay (2007) investigating funding models for persons with disabilities. For the current project, the literature review of SDF programs in Canada, California, the United Kingdom, and Australia was based largely on reports and websites on SDF programs in the selected geographic areas.

In addition to the review of programs, researchers conducted key informant interviews with eight service provider and Associations for Community Living representatives, seven government representatives, and two consultants with international expertise on programs for individuals with disabilities. The key informants were from Newfoundland (n=1), Prince Edward Island (n=1), Nova Scotia (n=1), New Brunswick (n=2), Ontario (n=3), Manitoba (n=3), Saskatchewan (n=3), and British Columbia (n=3).

Brief Summary of Funding Models

The review of seventeen funding models in Canada (in order, west to east), California, the United Kingdom, and Australia identified several commonalities:

- Funding was most often based on identified needs (thirteen programs) rather than income level (one program); three programs used a combination of needs and income to determine funding levels. Individuals were often involved in identifying their needs and goals during the planning process.
- Because funding was most often based on identified needs and personal goals, there was a wide variety of funding uses.
- Funding may be managed directly by the client, a person appointed by the client (e.g., family, friend, public trustee), or a service provider. Many programs provide clients with several options for fund managers.
- There was a great deal of variability among and within programs in the frequency of budget revisions. Six programs conducted annual reviews. All programs allowed revisions to occur as needed (particularly due to crises, changing needs, or changes in income).
- A wide variety of reporting tools included monthly invoices (the most commonly used), tracking forms, formal reports from clients and/or service providers (quarterly or annual), and government reviews of staff and families. Measures for safeguarding clients' funding included direct deposits, cheques, and accounts dedicated to receiving funding.

Key Findings

Program Design and Accountability Measures

- The goal of individualized approaches is to empower, build capacity, and respond to individuals' needs. This may be accomplished not only by meeting medical or living supports but also by enhancing individuals' personal networks.

- Because of the lack of standardization within and between provinces, there are challenges in providing individualized approaches while maintaining accountability.
- SDF models do not automatically produce individualized services, which require sufficient infrastructure to build operational capacity.

Labour Market and Staffing Issues

- Staffing issues, including high turnover rates, low wages, and varying availability of staff in rural and urban areas, are a prominent concern. In addition, clients can find the responsibility of hiring and firing staff overwhelming.
- Staffing difficulties are related to inequities. Clients in some jurisdictions, for example, are allowed to top up staff wages, resulting in socioeconomic differences in clients' abilities to locate quality staff.

Funding Sustainability

- Despite some initial concerns, issues around sustainability and abuse of the system are not common. Individualized approaches tend to be more cost-effective than traditional approaches and many programs have developed policies (such as ceilings) to overcome sustainability problems.

Client Equity

- Client equity emerged as a complex theme. First, there are regional differences in available supports and services. In addition, SDF must balance the recognition that disabilities impact individuals differently with the need to justify and apply guidelines consistently.

Outcomes and Challenges

- Program evaluations and anecdotal accounts showed that the individualized approach improves quality of life. However, this model is more difficult for clients because of their involvement in making decisions, hiring staff, and reporting on fund use. Interviewees identified complex reporting that can result in fund management taking over their lives as a key reason they chose to remain with block-funded services.

Innovation

- The literature review and interviews highlighted SDF's ability to address client needs

in innovative ways and the importance of social networks in improving the lives of individuals with disabilities.

Suggestions for Future Examination

- Separate funding decisions from planning to avoid placing staff in conflict with families. Key informants identified independent brokerage as an important part of providing support to participants.
- Balance accountability and individuals' control over funding while still accounting for public funds. Key informants linked complicated reporting requirements with a lack of trust that funding will be spent properly.
- Address reporting complexity, which can result in recipients' lives being taken over by fund management. Fund manager training tends to be provided informally.
- Ensure individuals are supported in planning and carrying out plans. Programs should offer varying levels of support to respond to different levels of need.
- Alleviate staffing difficulties by developing a roster of recommended staff; creating staffing agencies; providing clients with educational tools to assist with staffing issues; reviewing wages and benefits for workers; and developing strong family groups, which was identified by interviewees as another solution for staffing problems.
- Communicate the sustainability of individualized approaches to policy makers and decision makers.
- Fund people on an individualized basis as a powerful way to enable them to secure the services and supports they require. Without the capacity to respond to needs in an individualized manner, participants will likely opt for block-funded services.

Limitations and Areas for Further Study

The open-ended nature of the interview questions led to the identification of several common themes surrounding the difficulties and strengths associated with SDF models. Future research should investigate these themes in greater depth by interviewing individuals with disabilities (to determine if they experience the challenges and strengths identified in this study) and government representatives and community-based organizations (to collect more detailed information on program development, implementation, and documentation). Finally, careful planning and implementation should ensure that future SDF programs take advantage of the strengths and address the challenges identified in this research so that individuals with disabilities are able to participate fully in the community.

Plain Language Summary

In Saskatchewan, the government usually gives money to agencies so that agencies can give services to people with disabilities. Agencies decide what programs to offer, and then people can sometimes choose which services and programs they want to use. That kind of funding is called "block funding." Sometimes, however, the government gives money to people with disabilities so that they can buy their own services, programs, and supports. When government gives money directly to people with disabilities, it is called "Self-Directed Funding" or SDF. This report is about Self-Directed Funding or SDF.

The people who wrote this report looked at SDF programs all over the world to see what works about SDF, and what causes issues. They had interviews with people who work with SDF every day. Because of everyone they talked to, and everything they read, they were able to find out what was good about SDF, and what may cause issues for people on SDF. They also learned some things that help some programs work better than others. Remember that SDF stands for Self-Directed Funding.

Issues

- It is sometimes hard for government to know how much money to give people. They worry that if they give them too much it wastes tax money, but if they don't give enough money to people with disabilities, they may not be able to meet their needs.
- Sometimes even when people are given money to buy their own services, they buy the same services they always had — other kinds of services are not always available, and sometimes people find it easier to do the same things they always did.
- Sometimes people need training to know how to use the money and how to look at new ways to solve problems.
- SDF takes more paperwork than the block funding system; paperwork can be difficult.
- When someone is funded through SDF, they actually hire other people. It can be

hard to hire other people and be the employer because there are lots of rules and regulations that need to be learned.

- It is difficult to find people to hire to help you do the things you want to do — that kind of work doesn't pay as much as other jobs do, and it can be hard to find someone who wants to work weekends and evenings.
- Not everyone can get SDF even if they want SDF.
- People are not always happy with the services they get — even when they paid for them.
- Sometimes people spend money on things that are not in their plan; that leaves them short of money for other things. Some people need help to learn how to manage their money.
- Sometimes there is not enough money available for a person to get all the support they need. That means some people have to wait, or go without some supports.

Good Things

- SDF is seen as a more flexible system. That means you can do things with the money that you cannot do under "block funding." People on SDF say they are more independent.
- You can decide who gives you help and when.
- Many programs let you hire family members or friends.
- Some people really like being the employer and hiring their own staff.
- You can sometimes apply for money other than the money the government gives you.
- People on SDF get more power and control over their lives than people who are funded through block funding. Quality of life is seen as better for people on SDF.
- SDF is based on a person's need, so even if two people have the same disability they may get different amounts of money depending on what they need it for.
- Most people on SDF say they do better on SDF than they did without it.
- Some people say they have more friends and they get along better with their families once they are on SDF.
- Some people say their health is better, and they do more things in the community now that they are on SDF.
- Staff who work for people on SDF were found not to have as many problems on the

job — they are sick less, and were happier in their jobs than people who worked for people who were not on SDF.

Learnings

- It is important that there be someone to help you make plans, get supports, and manage money. It is important that this person is a different person than the one who decides how much money you get.
- Teaching people how to do paperwork is very important.
- Everyone agrees that there should be a way for people who get SDF to show that the money is being used the right way.
- Good communication is very important.
- People with good social networks (that means people who know a lot of people) have an easier time finding staff, and getting their needs met.
- Agency support can help people with disabilities find staff.
- Sometimes too many staff can get in the way of people with disabilities getting what they want. Sometimes there are other ways to get needs met besides hiring staff.
- People do not agree on which one (SDF or block funding) is more expensive.
- In order to make it work, SDF has to keep within a budget and there need to be rules. Right now each place has different rules about how much you can get and where you can spend it.
- It is important that there is a way to prove that the money goes where it is supposed to go if SDF is going to work correctly.
- Block funding is seen as easier for families.
- The system is not set up for SDF. Services that people want are not always available.
- People do not usually use the money in the wrong way.

Introduction

This report on self-directed funding (SDF) for persons living with disabilities explores the *sustainability* of SDF; *accountability* measures related to the allocation of funds, including the design of appropriate reporting requirements; *quality and risk management* to ensure clients' funds are managed properly; and *labour market* and *staffing* issues related to the availability and retention of personal support workers. In addition, the report addresses issues of *equity* among different user groups. The current project builds on previous research investigating funding models for persons with disabilities (Lynch and Findlay 2007).

Lynch and Findlay (2007) define Self-Directed Funding as models where "public (government) monies (funds) are given to individuals with intellectual disabilities to fulfill the individuals' unmet needs and to allow them to reach their goals" (Lynch and Findlay 2007, viii). Lynch and Findlay distinguish between two types of Self-Directed Funding: under an *Individualized Funding* model, the individual with a disability, his or her family, or support network, administers the funds themselves. *Individually Funded Services* is similar to Individualized Funding. In this case, however, funds are administered by a service provider, broker, or facilitator rather than the individual with a disability or his or her network (Lynch and Findlay 2007).

SDF usually includes the development of an individual plan (often based on a needs assessment) that includes the person's goals and a plan to fulfil them (Lynch and Findlay 2007). For example, if the individual would like to secure employment and requires training to attain this goal, the plan would include an objective to attend courses or training to develop the skills needed to obtain employment. Individual plans are submitted to a government official for approval. Once approved, the individual is provided with money for basic living requirements, expenses related to the disability, and costs related to attaining their goals as outlined in their individual plan.

SDF is based on the principles of self-determination, choice, and equality (Lord et al. 2000). Under SDF, funding is attached to the individual, who chooses which programs and

services will meet his or her needs (Lynch and Findlay 2007). These funding models are based on the philosophy that when persons with disabilities are empowered to make decisions about their life, their quality of life improves (Lynch and Findlay 2007; Lord et al. 2000).

Traditionally, funding for individuals with disabilities is provided under a *block funding model.* Under this model, government funds are allocated to agencies that provide services for individuals with disabilities (Lynch and Findlay 2007). The service provider determines which programs and services to offer and community members choose from the available programs. Because block funding tends to be more uniform and is offered by established service providers, programming may be easier to obtain and more stable than programming that is obtained through SDF.

Research Methods

Building on a previous review of Individualized Funding and Individually Funded Services models conducted by Lynch and Findlay (2007), the current project comprises a review of SDF programs across Canada (in order, west to east), California, the United Kingdom, and Australia. It focuses particularly on client outcomes, sustainability, accountability, quality and risk management, client equity, and labour market and staffing issues related to SDF.

First, we consulted reports and websites on SDF programs in Canada, California, the United Kingdom, and Australia, reviewing them for content related to the priority areas. Second, we conducted key informant interviews with representatives of Associations for Community Living (ACL) and provincial governments across Canada. The key informants represented a range of perspectives, particularly those critical of SDF. Researchers developed a conversation guide exploring information parallel to that covered in the document review (see Appendix A for the conversation guide). We conducted eight interviews with key informants from service providers and ACLs and seven interviews with government representa-

tives. In addition, we interviewed two consultants with international expertise on programs for individuals with disabilities. The key informants were from Newfoundland (n=1), Prince Edward Island (n=1), Nova Scotia (n=1), New Brunswick (n=2), Ontario (n=3), Manitoba (n=3), Saskatchewan (n=3), and British Columbia (n=3).

We obtained key informants' contact information through the Saskatchewan Association for Community Living (SACL). Judy Hannah, Grassroots Alliance Project Co-ordinator for SACL, sent out a call for contact information through SACL's network. Individuals interested in participating provided their contact information and also that for other potential participants. The Community-University Institute for Social Research (CUISR) then contacted individuals via email and phone to arrange interview times.

We conducted semi-structured interviews by phone, tape recording them with assurances that participant names would not be reported. Participants received a copy of the conversation guide ahead of time to allow them to formulate their responses in advance, which made good use of their time. Interviews ranged from approximately twenty to sixty minutes. In some cases, the participant was unable to answer the questions in the conversation guide. In those cases, we asked the participant to discuss SDF with regard to the priority areas. In two cases, it was not possible to interview the informants; however, they provided written feedback by inserting their comments into the conversation guide.

We transcribed the interviews and analyzed their content to identify key themes. The results of the document review and key informant interviews are presented below. Program descriptions are provided first, followed by the results of the priority area investigation.

Funding Model Descriptions

We devote a significant portion of the document review to compiling comprehensive descriptions of the funding models in Canada, California, the United Kingdom, and Australia. In addition, during the key informant interviews, we asked participants to describe their funding models. Wherever possible,

descriptions draw on the document review supplemented by interview information. For an overview of program features across jurisdictions, please see the Program Features Table in Appendix B.

BRITISH COLUMBIA

Government Policies and Legislation

- Guidance Support Allocation
- Individual and Family Support Policy
- Individualized Funding Policy
- Direct Funding Policy
- Host Agency Funding Policy

Program Missions and Objectives

Community Living British Columbia (CLBC) delivers supports and services for individuals with disabilities in British Columbia (CLBC 2008). According to its "Individual and Family Support Policy" (CLBC 2008), its vision is "one of full citizenship in which people with developmental disabilities lead good lives in welcoming communities." CLBC's mission is to "respond to the life-long needs and goals of individuals and families by recognizing their abilities and contributions, sharing leadership with communities, and funding supports that honour individual choice" (CLBC n.d.). To further these goals, "CLBC is committed to fostering the growth of inclusive, supportive communities" (CLBC n.d.).

Microboards — nonprofit societies established solely to support one person — provide a way to manage individualized funding in British Columbia. The Vela Microboard Association supports individuals with disabilities, their families, and friends to create a small nonprofit society (a microboard) that addresses planning, supports, and fund management for the individual (Vela Microboard Association n.d.). The association's mission is "to promote and secure innovative and individualized community options and supports for people with disabilities or chronic illness" (Vela Microboard Association n.d.). Vela's overarching philosophy is to honour the rights of individuals with disabilities and to eliminate barriers. Part of this philosophy is the recognition that individuals with disabilities have the "right to free-

dom, equality, control over their own lives, and to be fully included as valued citizens in the relationships and the opportunities of community life" (Vela Microboard Association n.d.). Vela's objectives include developing living options that facilitate interdependence, integration, and membership in communities.

Program Description

CLBC is guided by policy foundation statements that emphasize five areas of concern:

- creating inclusive communities
- putting individuals first
- working together to build capacity
- nurturing a culture of change and learning
- maintaining accountability (CLBC 2009e)

In CLBC's individualized funding program, participants may choose a direct funding option where they self-administer their funds, or they may choose to have their money flow through an agency that works on their behalf (CLBC 2009a). If individuals are unable or choose not to self-administer their funding, they enter into a representation agreement to allow an agent to act on their behalf (CLBC n.d.). Allocations are based on the individualized support plans through consultation with the Guidance Support Allocation, which takes into account individual needs. According to a key informant, CLBC is "very public in saying IF is just a way to pay for stuff."

Microboards, "a very popular way of bridging between IF and more traditional contracted services," are typically comprised of the individual's social network (Vela Microboard Association n.d.). A microboard requires at least five people, including a president, vice-president, secretary, and treasurer; the microboard is the fund administrator. If the microboard wishes to hire staff directly, it appoints a staff liaison (Vela Microboard Association n.d.).

Funding Eligibility Criteria

According to a key informant, clients must be nineteen years or older and have an IQ of 70 or below to be eligible. The BC Association for Community Living issued a press release on 23 July 2008 stating that the Order in Council of 18 July 2008 which limited CLBC services to those with an IQ of 70 or below came "without any community consultation or notice" and

against community advocate advice "to move away from traditional psychological assessment tools that focus on IQ and to develop mechanisms that effectively and equitably assess individual needs." The effect, according to the news release, was to leave young adults with Fetal Alcohol Spectrum Disorder or autism and with an IQ over 70 "to fend for themselves" (BC Association for Community Living 2008). In addition, the IQ requirement often forces families to take responsibility for fund management.

Funding Uses

Allocations are based on an individualized support plan. Under CLBC, individuals may purchase supports for home living, transition, community inclusion, education and employment, professionals, behavioural interventions, health care planning and medical, family, and crisis situations (CLBC n.d.). According to a key informant, if the individual is eligible for services that are the responsibility of another ministry or government body (e.g., housing or education), then CLBC attempts to secure funding from those sources.

Fund Management

Under CLBC's Individualized Funding Policy, individuals, their families, or agent are provided with two self-directed payment options: Direct Funding and Host Agency Funding (CLBC 2009a). Through Direct Funding, CLBC provides funding to the individual, family member, or agent, who then purchases supports and services directly (CLBC 2009b). Under Host Agency Funding, an agency administers funding with, or on behalf of, the individual to manage supports and services (CLBC 2009c). According to a key informant, fund managers are more likely to be family members. Under the microboard model, the individual and family members manage funds together.

Budget Revisions

Budgets are reviewed annually in British Columbia, on a crisis basis, or as needs change.

Reporting Requirements and Safeguards

Every six months, clients (or their legal agent) provide Compliance Reports, or statements describing how they have used their funding (CLBC 2009d). According to a key informant, if

the individual has funding channelled through an agency, host agencies have a three-way contract with the individual (or agent) and the Government of British Columbia.

In the case of British Columbia's microboard program, microboards have the same reporting requirements as a nonprofit agency, including the requirements for reporting to the Canada Revenue Agency (Vela Microboard Association n.d.). According to a key informant, host agencies that work with microboards report on a quarterly basis to the government and the individual. CLBC is currently undergoing a rigorous contract monitoring and accountability process.

CLBC uses direct deposits for client funds (CLBC 2009d). There is also online financial reporting to track how funding is spent. Clients use cheques to purchase services and are dissuaded from using cash (CLBC 2009d).

Alberta*

Government Policies and Legislation

- Social Development Act
- Persons with Developmental Disabilities Act
- Community Inclusion Supports Framework
- Family-Managed Supports Policy

Program Missions and Objectives

The Government of Alberta's Seniors and Community Supports ministry has a program titled Persons with Developmental Disabilities (PDD) that manages funding for individuals with disabilities in Alberta. The PDD program's mission is "to create a province where adults with developmental disabilities are included in community life" (Alberta PDD 2007a, 01–2). The program operates under the founding principle that "individuals, with the assistance of their families and friends, are the primary source for identifying what is best for themselves and what kinds of support they require" (Alberta PDD 2007a, 01–4). The Community

* A key informant from Alberta was unavailable for an interview. All the information on Alberta's Persons with Developmental Disabilities program is based on the document and website review.

Inclusion Supports Framework outlines the following principles of service: inclusion, equality, empowerment, equity, supports, and innovation and quality (Alberta PDD 2007a).

Program Description

PDD provides direct funding for individuals with developmental disabilities to purchase the supports they require to live, work, and participate in the community (Alberta PDD 2007a, 01–4). The Family-Managed Supports Policy was implemented in April 2006 (Alberta PDD 2006). Under the policy, families use funds to hire supports according to the individual's determination of his or her support needs (Alberta PDD n.d.). Individual needs are determined via a person-centred, comprehensive assessment process that includes the collection of information from multiple information sources (Alberta PDD 2007a).

It should be noted that Alberta began modifying its Individualized Funding program as of 31 March 2009, although the precise reason for the change remains unknown (Auditor General of Alberta 2009). In addition, the exact structure of the modified program is currently unclear.

Under the new policy, clients may opt to transfer to flexible funding arrangements, notably "family managed supports," where families are directly responsible for their funds, or they may choose to contract an agency to manage funds on their behalf (Alberta PDD 2009a, 2009b). A summary of key stakeholder consultations reported that, under the previous funding model, agencies used — even overused — all funding provided for clients, regardless of their level of need — an arrangement that could lead to "over-servicing" clients, which is a possible reason for the policy change (Alberta PDD 2009b). Providing block funded services was mentioned in the consultation report as a way to avoid "over-servicing" (Alberta PDD 2009b).

Funding Eligibility Criteria

Before the changes to Alberta's IF program, the eligibility requirements to receive supports from PDD were:

- onset of disability prior to adulthood (i.e., the disability is developmental)
- intellectual capacity that is significantly below average
- limitations in two or more adaptive skill areas (adaptive skill areas include communi-

cations, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, work, and leisure) (Persons with Developmental Disabilities Program Website n.d.).

Officials also took income levels into account (Alberta PDD 2007a). It is unclear whether or not eligibility criteria have changed since the program modifications.

Funding Uses

Funding was portable and could be used for community living supports (including up to twenty-four-hour support, respite, and supported independent living), preparation for and placement with employment supports, community access supports, and specialized community supports (including behavioural support, professional services, start-up community living supports, and transportation; Alberta PDD 2007a).

Fund Management

Prior to the modification of Alberta's program in 2009, clients chose either to self-manage or pay a fiscal intermediary to manage funds on their behalf (Alberta PDD 2007a). Funding was provided directly to the individual who was identified as the funds administrator.

Budget Revisions

Financial and program reviews were required under the Operational Program Policy (Alberta PDD 2007a). Prior to the program modification, plans and budgets could be revised to adapt to changing needs.

Reporting Requirements and Safeguards

Invoices were submitted monthly, after which payments were provided (Alberta PDD 2007a). Invoices were submitted after services were provided, although requests for advance payments were considered on a case-by-case basis (Alberta PDD 2007a).

SASKATCHEWAN

Government Policies and Legislation

- At the time of data collection, there was no official policy governing direct payments and direct support payments in Saskatchewan.
- Saskatchewan Assured Income for Disability (SAID) became available in late 2009. SAID decouples funding for individuals with disabilities from social assistance (Saskatchewan Community Living Division 2009).
- In November 2009, officials announced a new funding standard for day programs for people with intellectual disabilities. The funding model is no longer based on cost-per-space but on the assessed needs of individuals and the organization's capacity to support them. While full implementation across the province is expected for 2010–11, funding is underway for up to 170 jobs in community-based organizations (CBOs), a $588,000 six-month pilot involving eight CBOs delivering day programs. The pilot will test the new Day Program Support Assessment tool and new accountability reporting and data collection template (Government of Saskatchewan 2009; Snider 2009).

Program Missions and Objectives

The Community Living Division's (CLD) primary objective is "to ensure physical, emotional, and social needs are met and that people with intellectual disabilities live and function as independently as possible within their own communities" (Saskatchewan CLD 2007).

Cognitive Disabilities Strategy

The objectives of the Saskatchewan Cognitive Disabilities Strategy (CDS) include the following:

- improving the availability of assessment and diagnostic services
- providing services to address the unmet needs of people with cognitive disabilities and their families
- providing training opportunities for individuals with cognitive disabilities
- enhancing provincial Fetal Alcohol Spectrum Disorder prevention and intervention initiatives (Saskatchewan Ministry of Health 2007)

Program Description

According to a key informant, the Government of Saskatchewan provides "individually funded services." One key informant noted that this funding method tends to be provided to individuals who have families that are "well connected" and are willing and able to advocate for their family member. However, another key informant reported that "everybody is entitled equally to individualized supports based on either what they tell us they want or what we can see might fit best for them."

Cognitive Disabilities Strategy

A key informant discussed "CDS benefits" as "the closest thing that we (the Province of Saskatchewan) have to IF." CDS is a province-wide strategy, based on an integrated planning model, to fund service or support needs that cannot be met by existing services or supports. Application, plan, and invoice forms must be completed. In Saskatoon, additional documentation includes a list of individuals involved with the plan development, goals, strategies for meeting the individual's goals, information about other funding sources that are being accessed, and letters from funding providers indicating why they are unable to meet the client's need. Benefits are based on a support plan that identifies the individual's goals and strategy for accomplishing those goals. The planning process is different in each of the province's regions, which allows a better fit for individual communities but may lead to differences in the ease with which plans are approved in different areas.

Funding Eligibility Criteria

According to key informants in Saskatchewan, clients must be eligible to receive service from the Community Living Division. The Daily Living Skills Assessment (DLSA) is conducted with the individual or the people closest to the person (most often family members). The DLSA assesses the individual's strengths and challenges to determine the necessary supports. Information from the individual, significant others, school reports, health reports, psychologists, psychiatrists, medical doctors, and social workers may also be used. The majority of participants have a diagnosis of mental retardation.

Cognitive Disabilities Strategy

For the CDS program, participants must meet five criteria to be considered to have a cognitive disability:

- significant limitations in learning and processing information
- behavioural challenges that limit interpersonal, social, and emotional functioning
- developmental challenges that limit daily living
- unmet needs
- persistent and long-term limitations and impairments

It is preferred that a team be involved in the development of the individual's plan to ensure the individual has effective supports. The funding allocation for the Cognitive Disabilities Strategy is based on the Daily Living Skills Assessment and family income.

Funding Uses

Key informants related that funding may be used for a variety of purposes including residence, quality of life needs, emotional needs, and one-on-one support for complex needs. If the Community Living Division does not provide the support directly, it may act as an intermediary, helping the individual access a particular support. Funding must be spent on items that are approved by the Province of Saskatchewan.

Fund Management

According to key informants, families sometimes manage their own funds but often prefer a community-based organization to manage funds on their behalf.

Cognitive Disabilities Strategy

For CDS, a team member is identified as the fund manager. Families have three options for fund management:

- receive the funds directly and act as payees
- have a service provider invoice the government and receive funding
- contract a third party to manage the funds; the third party is paid for this service through the support funding

Budget Revisions

Key informants in Saskatchewan stated that budget revisions for direct support contracts that depend on the individual's situation are conducted at least every two years. Many budgets are reviewed annually or as needs change.

Cognitive Disabilities Strategy

For CDS, a committee reviews the individual's budget annually, although changes may occur during the year as needed. A renewal letter is sent to the team leader, family, and fund manager outlining requirements for continued benefits and requesting an accounting.

Reporting Requirements and Safeguards

Key informants reported that contracts lay out how much funding will be provided over the period of the contract. Clients complete and submit invoices to the funder, who then provides payments as long as the amount invoiced is within the terms of the contract. Officials conduct regular audits. A key informant reported that, for direct support contracts, CLD relies on self-reporting, does not use direct deposits, and has no banking controls in place. The system is based on trust that funding will be used responsibly, with the annual review being the only safeguard.

Cognitive Disabilities Strategy

For CDS, clients report annually, completing a bookkeeping sheet that outlines how funds were spent and the dates. Receipts are not required but should be kept in case more detailed accounting is requested during reviews. Service providers are also required to report.

Manitoba

Government Policies and Legislation

- The Vulnerable Persons Living with a Mental Disability Act (VPA)
- Policy on Management of Personal Funds

Program Missions and Objectives

In the Company of Friends (ICOF) is a province-wide program funded by Manitoba Family Services and Housing (ICOF 2009). Its mission is "to enhance the quality of life for the participants involved" (ICOF 2009). Its philosophy is built on creating social networks. ICOF aims to empower participants to be involved in decision making or, ideally, to be primary decision makers (ICOF 2009).

Living in Friendship Everyday (LIFE), a nonprofit organization founded in 2000, is contracted by Manitoba's Department of Family Services and Housing to support ICOF program participants by providing resources, training, information, and case management (ICOF 2009). LIFE's mission is "to provide high-quality resources responsive to the needs of participants of In the Company of Friends." The organization assists ICOF participants to be fully integrated into ordinary community life to enable them to become "valued and contributing members of society" (LIFE 2009).

Program Description

One key informant described Manitoba's Supported Living Program as "Individually Funded Services." Caseworkers develop a "person-centred holistic plan" that identifies the supports and services required to meet individuals' needs in order to help them live as independently as possible. ICOF is a program option that allows individuals to purchase services directly (ICOF 2009). LIFE oversees and monitors budgets and ensures quality service on behalf of the government and ICOF participants. Caseworkers conduct a support needs assessment to assist in determining the level of funding. In order to be approved for In the Company of Friends, individuals must have an active, viable, support network or be willing to have a support network built as part of their participation. Caseworkers assist individuals in planning their lives and develop budgets that reflects individual plans.

Funding Eligibility Criteria

Eligibility requires a mental disability, which is defined by the VPA as "significantly impaired intellectual functioning existing concurrently with impaired adaptive behaviour and manifested prior to the age of 18 years" (Government of Manitoba 2009). Participants must also be Canadian citizens or legally entitled to remain permanently in Canada, resident in Manitoba, and eighteen years of age (Manitoba Supported Living n.d.). According to key informants, a clinical assessment is required to confirm that the individual has a full scale IQ of approximately 70 to 75 or below. ICOF participants must be willing to accept input from other people in their lives.

Funding Uses

Clients receive cheques monthly. One key informant explained that "their money is for life." Funding is used to purchase whatever supports the individual requires to be most successful

as outlined in the individual's plan and budget; for example, basic living expenses (food, rent) and supports (staff).

Fund Management

Individuals self-manage their funds with the assistance of their social network (LIFE 2009).

Budget Revisions

According to key informants, financial plans are reviewed annually in accordance with the Manitoba government's "Policy on Management of Personal Funds." Because program participants (particularly those in rural areas) may have difficulties finding staff and consequently may be unable to spend all of their funding, they can keep up to three months' budget in their savings account before it is taken away.

Reporting Requirements and Safeguards

Key informants related that LIFE clients complete monthly reports that are submitted quarterly. LIFE also conducts an in-depth report that reviews clients' progress, including the strength of their relationships, accomplishments in the previous six months, and staffing. Clients' plans and budgets are reviewed periodically to ensure that budgets match clients' needs. In addition, when the Government of Manitoba enters into contracts with external agencies, those agencies are required to submit annual audited financial statements.

Our key informants described several safeguards in place to protect clients:

- financial transaction records are retained for seven years
- documents are tracked to keep a record of individuals' accounts
- staff's personal fund management is reviewed periodically

Ontario

Government Policies and Legislation

- Ontario Disability Support Program Act
- Special Services at Home Policy Changes

Program Missions and Objectives

In Ontario, Developmental Services falls under the Ministry of Community and Social Services (Ontario Developmental Services 2006). The mission of Developmental Services is "to support the realization of the goal of being fully included in society, and for people who have a developmental disability to have the same opportunities as other Ontarians to participate in the life of the community" (Ontario Developmental Services 2006, 1). The goal is to promote greater social inclusion, based on six principles: citizenship, fairness and equity, accessibility and portability, safety and security, accountability, and sustainability (Ontario Developmental Services 2006, 1).

Program Description

Centre for Independent Living (CILT) Direct Funding Program

There are several individualized funding options in Ontario. Funded by the Ontario Ministry of Health, the Direct Funding Program is administered by the Centre for Independent Living in Toronto, or CILT (CILT 2000). The program provides monthly funds that enable clients to hire, train, and schedule their own attendants (CILT 2000). Participants become employers and are responsible for determining how and when their services are provided (CILT 2000).

Special Services at Home

According to one key informant, individualized pilot projects in Ontario have been generally well received, with the most successful one being Special Services at Home (SSAH). Originally for children's families to purchase respite services in the home, the program has since expanded to adults, while providing the ability to access services outside the home, including personal growth and development and/or family relief and support (Ontario Ministry of Community and Social Services 2008). Under the program, individuals decide what their needs are and families use their funding directly, self-direct their funding, and self-manage the process (Ontario Developmental Services 2005).

Individualized Quality of Life

The Individualized Quality of Life (IQOL) project was a Toronto-based initiative funded from 1997 to 2000 by the Ontario Ministry of Community and Social Services (Roeher

Institute 2000). The IQOL was hosted by the Family Service Association of Toronto and provided individualized planning support; assistance developing support networks; funding approvals; individualized financial tracking, banking, administration, and reporting; and information sessions for participants and their families (Roeher Institute 2000).

New Funding Framework

Ontario is currently developing a new funding framework in which the individual applying for funding will be assessed for support needs. An allocation mechanism will determine the individual level of funding based on support needs. Participants will be able to choose to have their funding directed to a service agency, to receive direct payments, or a combination. It is anticipated that the various individualized projects around the province will be absorbed into this initiative. Intense twenty-four-hour residential supports will continue to be provided through block funding.

Funding Eligibility Criteria

CILT Direct Funding Program

Clients in Ontario are eligible for the program if they

- are sixteen years of age or older
- are an Ontario resident
- require attendant services for a permanent physical disability
- are able to complete the application on their own
- have the capacity to meet with the selection panel to discuss their needs
- are able to schedule attendances
- are capable of managing attendant workers
- meet the legal criteria for being an employer
- are able to manage and account for their own funds (CILT 2000)

Special Services at Home

The individual must be living with a family member to access funding. It is possible this requirement may be reviewed because of the large numbers of individuals who would like to live independently.

Individualized Quality of Life

Target groups for the IQOL pilot project were Ontario families with children aged zero to six years at risk for or diagnosed with a developmental disability; young adults with a developmental disability who left school and were transitioning to work, education, or community activities; and adults with a developmental disability who had parents over sixty-fuve years of age (Roeher Institute 2000; Vincente 2000).

New Funding Framework

This new program in Ontario will use a modified version of the Support Intensity Scale, a tool that evaluates support needs. Although allocation tools have not yet been developed, they will use the needs assessment to determine the individual's funding level.

Funding Uses

CILT Direct Funding Program

Clients must use their funding to purchase attendant services; a maximum of six hours a day (on average) is permitted (CILT 2000).

Special Services at Home

Clients may use the funding for a variety of supports that fall broadly under two categories: (1) personal growth and development; and (2) family relief and support (Ontario Ministry of Community and Social Services 2008). According to one key informant, funding has been used for "very extensive supports" in the past.

Individualized Quality of Life

Clients used their funding on a variety of supports including equipment purchases, housing, community participation, employment, community living supports, respite services, professional services, transportation, and behaviour management services (Roeher Institute 2000).

Fund Management

CILT Direct Funding Program

Direct funding participants must manage their own funds; funding is available for individuals who would like assistance with payroll and bookkeeping (CILT 2000).

Special Services at Home

Individuals or their family can self-manage the funding. Participants may also choose to have their funding paid directly to an agency. One key informant noted that support for building infrastructure for facilitation is emerging as a strong movement in Ontario.

Individualized Quality of Life

The Ministry of Community and Social Services funded the community-based Family Services Association (Vincente 2000), which then provided funding to the individual or their family based on the individual's support plan (Roeher Institute 2000). According to Vincente (2000), funding approval was based on clear guidelines and there was a clear appeal process in place.

Budget Revisions

Special Services at Home

Participants apply for funding annually, although if no changes are desired, the individual submits a form to that effect. Budgets are revised every three years.

Individualized Quality of Life

Participants were monitored every three months or as new needs emerged; caseworkers also conducted a six-month review of the individual's plan and budget (Vincente 2000).

Reporting Requirements and Safeguards

CILT Direct Funding Program

Participants receive funds on a monthly basis and report quarterly (CILT 2000). Participants must apply for a business number from the Canada Revenue Agency, a process that is explained in detail during the application process (CILT 2000).

Special Services at Home

According to a key informant, clients who self-manage their funds are required to submit invoices at the end of each month. More formal reporting, conducted annually, includes an evaluation of the clients' progress. One key informant reported that Ontario's auditor gen-

eral has been positive about this process. Although the reporting assumes that clients and families are trustworthy, many clients ask agencies to manage their funds to avoid having to do reporting. Periodic government reviews with workers and families have led to the auditor general reporting very little abuse.

Individualized Quality of Life

The individual or family submitted invoices on a bi-weekly or monthly basis (Roeher Institute 2000). Monthly financial statements were prepared for individuals and families outlining supports purchased (Roeher Institute 2000).

New Brunswick

Government Policies and Legislation

- Disability Action Plan Strategy
- Financial Contribution Policy
- New Brunswick Human Rights Act

Program Missions and Objectives

Provided by the Department of Social Development, New Brunswick's Disability Support Program (DSP) pilot project aims to develop and test new means of providing personalized, flexible, disability support plans. According to the Government of New Brunswick's DSP Fact Sheet, the aim of the DSP is to provide "personalized, flexible disability supports for persons with disabilities in the development of their personal disability support plans" (Government of New Brunswick n.d., 1). The program's overarching goal is the full participation of persons with intellectual disabilities in all aspects of society (NB Premier's Council on the Status of Disabled Persons 2007).

Program Description

Until the pilot project is expanded, the rest of the province receives the Long Term Care Program (Government of New Brunswick n.d.). Under this program, individuals residing in

residential facilities are assessed according to their level of need and then placed in one of four levels, receiving appropriate funding for their basic living and support. For individuals living outside residential facilities in New Brunswick, there are two funding ceilings expressed as maximum hours of support depending on level of need. Some of the funding can be direct, so that if individuals opt to hire their own supports, they are eligible for reimbursement. Advance payments can be arranged for individuals who do not have the income to pay in advance. Funding can also be provided to agencies on behalf of the individual.

New Brunswick's Disability Support Program is a long-term program for seniors and adults with disabilities. It began as a two-site pilot project and will be expanded to the whole province by March 2011 (NB Premier's Council on the Status of Disabled Persons 2008). The program "allows for the provision of independent facilitation and the use of person centered approaches to planning and designing disability supports" (Government of New Brunswick n.d., 1).

Funding Eligibility Criteria

Both key informants reported that New Brunswick's funding is not disability-specific; i.e., individuals with intellectual disabilities or mental health issues do not receive separate programming. The current Long Term Care Program conducts a "very traditional" assessment that identifies needs to determine individuals' eligibility. Direct funding is currently usually provided only in high-cost cases. In both the Disability Support Program and the Long Term Care Program, participants are required to have a long-term disability and unmet needs. A financial income test determines how much the government and individual pay towards disability supports.

To be eligible for the Disability Support Program, clients must be residents of New Brunswick, living in one of the two pilot test service regions, be between nineteen and sixty-four years of age, have a long-term disability, and require disability-related supports to address unmet needs (Government of New Brunswick n.d.). The DSP pilot program does not use a formal functional assessment, but rather employs a person-centred planning process that looks at the person's life, goals, and supports.

Funding Uses

A government caseworker helps individuals to identify their key needs and determine how they could enhance their participation in their community. Individuals can purchase per-

sonal care services privately (anyone other than a family member may be hired as a personal support worker). Funding can be spent in a variety of ways, including home worker supports, respite, skill enhancement, transportation, equipment, and increasing participation in the community (Government of New Brunswick n.d., 1). Because other government programs in New Brunswick cover some supports and services, clients cannot spend their funding on services such as addictions services, vehicle retrofitting, mental health services, employment services, medical services, or prescription drugs (Government of New Brunswick n.d., 1). According to one informant, "People have been able to access funding for different kinds of things that made sense in their lives. There was one young man who was able to attend a leadership program outside the province because it would enhance his potential for the future so he identified that as a need for himself."

Fund Management

Individuals can self-manage or a trustee can be appointed when individuals cannot do it themselves. Individuals can also choose to have the money go directly to an agency.

Budget Revisions

According to one key informant, there is limited flexibility in New Brunswick for moving funds from one category to another (for example, from home support to community participation) or from one month to another. However, budgets are revisited every two years or as individuals' needs or financial situations change. The status of individuals is not reviewed if they are on a fixed income (e.g., social assistance).

Reporting Requirements and Safeguards

Clients are provided with a form to fill out monthly and are expected to include monthly invoices. Invoices are reviewed to determine that clients are spending their funding appropriately. One key informant finds this method too restrictive and suggests that reporting should occur less frequently (perhaps every six months).

Key informants reported that there are few safeguards for clients in New Brunswick. Workers suggest that clients not purchase services until they receive their money, while those clients receiving direct funding are advised on general safeguards, including hiring staff (e.g., conducting criminal records checks).

Nova Scotia

Government Policies and Legislation

- Independent Living Support Policy
- Direct Family Support Policy

Program Missions and Objectives

Nova Scotia's Department of Community Service is "committed to a sustainable social service system that promotes the independence, self-reliance, and security of the people we serve" (Nova Scotia Department of Community Services 2008). The department's goals are self-reliant people, strong families, and inclusive communities; a strong, responsive, and sustainable social service system; an integrated, quality, service delivery system; strong provider relationships and collaboration; leadership and the continuous pursuit of excellence; and a skilled, flexible workforce (Nova Scotia Department of Community Services 2008).

Program Description

Nova Scotia's Direct Family Support program is available to children (Direct Family Support for Children, DFSC) and adults (Direct Family Support for Adults, DFSA; Nova Scotia Department of Community Services 2006a). The amount of the funding is negotiated with the Department of Community Services, after which the funding is paid directly to the family. According to the key informant, Nova Scotia began providing direct support for adults within the last two or three years and "the children's program has morphed over into an adult program. It used to end when the son or daughter reached eighteen … and now it can go on as long as the adult son or daughter lives in the family home." The DFSC program is based on the premise that while families are responsible for supporting their children, funding may be required to support "assessed unmet needs associated with the child's disability, such as respite, medications, transportation to medical related appointments, and equipment" (Nova Scotia Department of Community Services 2006a, 2). The DFSA program acknowledges that families who support an adult with a disability have different responsibilities and support needs; assessed unmet needs for adults with disabilities include shelter, food, clothing, prescriptions, transportation, and a personal use allowance (Nova Scotia Department of Community Services 2006a).

Nova Scotia also has an Independent Living Support Program (ILSP) that allows individuals to self-manage funding to provide up to twenty-one hours a week of supports and services (Nova Scotia Department of Community Services 2006b). The ILSP program is intended for individuals who are semi-independent and have unmet needs as determined by a functional and financial assessment (Nova Scotia Department of Community Services 2006b).

A key informant related that Nova Scotia also has a Support Services Group Co-operative. This program tends to be accessed by individuals who do not fit well into other models in the province. Members of the co-op are provided with support to live in the community. Clients pay a participation fee and their cheques go directly to the co-operative (individuals can then receive their cheques from the co-op if they choose). The co-operative's client coordinators assess the level of funding based on the support services the individual needs, helping the individual or family develop a plan. There are ceilings in certain categories, although they can be negotiated.

Funding Eligibility Criteria

Participants in Nova Scotia must have a disability, defined as a "severe and persistent restriction or impairment that results in an inability to perform an activity within the range considered normal" (Nova Scotia Department of Community Services 2006a, 2006b). To be eligible, individuals must have a mental health issue, developmental disability, intellectual disability, or physical disability (Nova Scotia Department of Community Services 2006a, 2006b). Participants' income is also assessed. Funding allotment is based on the types of support services required.

Funding Uses

Funding is used in way specified in the Individual Support Plan, which identifies unmet needs, goals, choices, and outcomes (Nova Scotia Department of Community Services 2006a, 2006b). According to the key informant, children's funding may be used for respite, recreation, and other family needs. Adults may use the funding to live more independently or for self-support or employment supports.

Fund Management

According to the key informant, Nova Scotia does not have brokerage facilities; funding goes to the family or the co-operative. Individuals participating in the Independent Living Support Program are "encouraged and entitled to participate in the management of their finances to the greatest extent of their ability" (Nova Scotia Department of Community Services 2006b).

Budget Revisions

Budgets are reviewed three months after admission and then annually or as circumstances warrant (Nova Scotia Department of Community Services 2006b).

Reporting Requirements and Safeguards

Clients complete monthly invoices (Nova Scotia Department of Community Services 2006b). According to a key informant, many clients ask their co-ordinator to complete their monthly billing forms on their behalf. Cheques go to the family or the co-operative. In the case of co-op participants, the individual has his or her own bank account but has a co-signer when writing cheques.

Prince Edward Island

Government Policies and Legislation

- Rehabilitation of Disabled Persons Act
- Social Assistance Act
- Social Assistance Policy Manual
- Disability Support Program

Program Missions and Objectives

Prince Edward Island's Disability Support Program was the first one in Canada to separate disability support from income support (PEI DSSS 2009). The purpose of the Disability Support Program is to "assist with the personal planning and help meet the needs related to an

individual's disability" (PEI DSSS 2009). Prince Edward Island's program is administered by the Department of Social Services and Seniors (PEI DSSS 2009). The department's mission is "to support social and economic prosperity for individuals, families and communities" (PEI DSSS 2009, 1). The framework of core values that drives the development of social programs and services includes inclusion, non-coercion, respect, equality, and diversity (PEI Disability Services Review Committee 2009).

Program Description

A key informant provided the majority of the information about Prince Edward Island's program, which is "person-centred." Under this program, funding is provided to the client directly or the client's agent, trustee, or parent is responsible for paying for services outlined in the individual's plan. Caseworkers do not provide services or manage resources in the client's home. Rather, they facilitate the development of the case plan with the individual, help cost out those services, and help the individual identify where the necessary services may be purchased.

Funding Eligibility Criteria

The key informant described PEI's program as needs based rather than income based. There are "eligibility criteria around intellectual disability, physical disabilities, and neurological disabilities." The caseworker conducts an assessment to determine the person's natural supports and his or her unmet needs. The program distinguishes between "basic needs such as shelter, food, clothing, and so forth" and disability needs.

Funding Uses

The Government of Prince Edward Island does not offer programming, but rather, contracts with ACLs, community services, community-based organizations/nongovernmental organizations that offer supports. Clients use their funding to address the needs identified in their assessment.

Fund Management

Clients decide who they would like to manage their funds. According to the key informant, fund managers should have a "logical connection" to the client (e.g., spouse, parent, sibling,

friend, public trustee). The key informant did not discuss whether clients are provided with money to pay fund managers.

Budget Revisions

Budgets are revisited annually. Clients can ask their worker if they would like their plan changed.

Reporting Requirements and Safeguards

Clients (or their agents) complete support logs (which verify that the individual purchased and received the services they claim to receive) and sign a form saying that they will use their funds as outlined in the case plan, although this is not monitored. The government also conducts internal audits of files and casework to ensure staff is conforming to policies. Caseworkers also make visits to ensure the clients are using their funds appropriately. PEI is moving towards direct deposits but currently still uses cheques.

Newfoundland and Labrador

Government Policies and Legislation

- Self-Managed Home Support Services Act

Program Missions and Objectives

The Government of Newfoundland and Labrador is committed to ensuring that individuals with disabilities are included in all aspects of society (NL Disability Policy Office 2009). In Newfoundland, disability-related programs and services are delivered by six regional Health and Community Services/Integrated Boards, which fall under the Department of Health and Community Services (NL Program Development Division n.d.).

Program Description

The Newfoundland key informant provided the majority of the information on programs in the province. He did not consider Newfoundland's model to be "true traditional individual-

ized funding." Rather, individuals with physical disabilities, intellectual disabilities, or mental health issues are eligible to receive "direct funding." Under this model, individuals with disabilities may directly manage their own funds or the government may purchase services from an agency directly on their behalf (in this case, the agency bills the government directly and the individual is a support recipient). Newfoundland does not operate group homes, although private homes are approved by the Department of Health and Community Services (NL Program Development Division n.d.). The key informant explained that the options available to clients have recently been reduced and ceilings have been imposed on the amount of funding available. During its development, there was an intention to make the program as "individualized as possible," although it lacks the flexibility "one would expect in a truly individualized funding model."

Funding Eligibility Criteria

An individual must have a physical disability, intellectual disability, or a mental health issue to be eligible for funding. Seniors also receive home support funding. Access to funding is income-based; recipients must demonstrate a financial need for the services they would like to purchase.

Funding Uses

The key informant reported that Newfoundland has a basic living income support program. Individuals participating in the direct funding model who have additional needs may purchase further supports (including home support, attendant care, and support for independent living) through the Department of Health and Community Services' Home Support Services Program. The Government of Newfoundland has several types of funding available (NL Program Development Division n.d.):

- the Special Needs Board and Lodging Supplement, which is combined with funding provided by the Department of Human Resources and Employment for monthly room and lodging for adults living with non-relatives
- the Flat Rate Allowance for adults with disabilities who require home support services
- other Special Needs Funding, which covers "minor expenses" for community access activities, repairing furniture/appliances, or increasing the accessibility of clients' homes

Fund Management

According to the key informant, individuals may self-manage their funds, or services may be purchased directly from an agency by the Department of Health and Community Services, with the agency billing the government directly.

Budget Revisions

The key informant did not discuss the frequency with which budgets are revisited and no other documentation could be located.

Reporting Requirements and Safeguards

The key informant reported that once individuals' budgets are approved, reconciliations are conducted quarterly or biannually to ensure the funds are being used properly.

Department of Health and Community Services staff may suggest direct deposits. Funding goes to individuals or their family. To ensure the funding is being spent according to the approved budget, government staff monitor expenditures on an ongoing basis, although the frequency of monitoring and the amount of assistance provided to individuals to manage their funding was not mentioned. Newfoundland's key informant felt that "the direct deposit system is in some levels, in some cases, insulting to individuals" — a consideration that led to the development of a system that assumes individuals "can manage their own money until proven otherwise."

CALIFORNIA

Government Policies and Legislation

- California Welfare and Institutions Code
- Early Intervention Services Act
- Lanternmen Development Disabilities Services Act

Program Missions and Objectives

In California, the Department of Developmental Services (DDS) is responsible for ensuring that individuals with developmental disabilities receive services and supports to enable them

to lead independent, productive lives (California DSS 2009). The department is "committed to providing leadership that results in quality services to the people of California and assures the opportunity for individuals with developmental disabilities to exercise their right to make choices" (California DSS 2008, 1). DSS is working to establish a state-wide Self-Directed Services program, expanding on pilot projects conducted in the Eastern Los Angeles, Redwood Coast, Tri-Counties, Kern, and San Diego Regional Centers (California Community Development Branch 2002; California DSS 2008). The program is based on the principles of freedom, authority, support, responsibility, and confirmation.

Program Description

Self-Directed Services program participants have enhanced control over the decisions and resources necessary to implement their Individual Program Plan (California DSS 2008). Plans are developed with the assistance of a supports broker in a person-centred planning process, which includes the creation of an individualized budget to purchase required services and supports (California DSS 2008). Services and supports must be purchased in a community setting; funding may not be used for day programs, sheltered workshops, and residential facilities (California DSS 2008). Participants are actively involved in choosing their service providers, supports broker, and financial management service (California DSS 2008).

Funding Eligibility Criteria

To be eligible for services, the individual's disability must be present before his or her eighteenth birthday and be expected to last indefinitely (California DSS 2008). According to the "California Welfare and Institutions Code," the term "developmental disability" includes mental retardation, cerebral palsy, epilepsy, and autism (California DSS 2008). Participants must be over the age of three years, be willing to undergo an in-depth program orientation, agree to use only the program's services and supports, accept and manage their individualized budget, hire or designate financial management services of their choice for disbursement of funds, and hire or designate a supports broker in implementing their Individual Program Plan (California DSS 2008). Eligibility is determined via diagnosis and assessment at one of the state's regional centers (California DSS 2008).

Funding Uses

Funding is used to purchase community-based services and supports as specified in Individual Program Plans (California DSS 2008). Self-Directed Services funding does not

cover "congregate" settings such as day programs, sheltered workshops, and residentia facilities.

Fund Management

Individuals self-manage their funds, often with the assistance of a support broker (California DSS 2008).

Budget Revisions

According to California's "Individual Program Plan Resource Manual," plans that result from the person-centred planning process are dynamic; progress is monitored and adjustments are made to the plan as required (California DSS n.d.).

Reporting Requirements and Safeguards

Participants are required to report their expenditures and budget balance monthly (California DSS 2008).

United Kingdom

Government Policies and Legislation

- Health and Social Care Act
- National Health Service and Community Care Act
- Carers and Disabled Children Act
- Children Act
- Community Care, Services for Carers, and Children's Services (Direct Payments) Regulations

Program Missions and Objectives

The purpose of the UK's Direct Payments is "to give recipients control over their own life by providing an alternative to social care services" (DoH 2003). Funding is administered by

local government social services departments, which make payments to the individual with a disability (DoH 2003). The individual then uses the funding to purchase required services and supports (DoH 2003).

Program Description

Direct Payments in the UK are seen as "a different way of delivering certain existing social services responsibilities" (DoH 2003, 4). The local council assesses clients' needs and develops their care plan (DoH 2003). Individuals choose services and supports that they feel best meet their needs (DoH 2005). The Department of Health reasoned that individualized budgets should increase the quality of services by giving individuals the opportunity to stop receiving low-quality services and supports (DoH 2005). Direct Payments are flexible and individuals can adjust the amount of money they use from week to week as long as the objectives of their care plan are being carried out; moreover, spare money can be banked and used when needed (DoH 2003).

Funding Eligibility Criteria

There are several criteria for eligibility. Participants must be

- "older people" (under sixty) who have been assessed as requiring community care services
- a person with a disability aged sixteen and over
- a person with parental responsibility for a child with a disability
- an individual with a disability who is responsible for a child
- a caregiver sixteen years of age or over (DoH 2003)

Funding Uses

Funding may be used to purchase a broad range of supports, services, and equipment (e.g., personal care, community access, mental health, food preparation) as outlined in the individual's care plan (DoH 2007). Certain regulations restrict the use of Direct Payment funding, which may not be used to pay for residential care or to employ relatives (DoH 2008). Services may be purchased as outlined in section 46 of the National Health Service and Community Care Act 1990, section 2 of the Carers and Disabled Children Act 2000, or section 17 of the Children Act 1989 (DoH 2003).

Fund Management

Individuals may self-manage their funding or they may ask others to assist them in managing it. In the case of children under sixteen, families make payments on behalf of the client (DoH 2003).

Budget Revisions

The frequency of monitoring in the UK is determined by how long clients have self-directed their funding, and their individual situation (DoH 2003).

Reporting Requirements and Safeguards

Individuals must account for their funding separately from other funding used for similar purposes (DoH 2003). A dedicated bank account for funding may be recommended.

Western Australia

Government Policies and Legislation

- Western Australian Disability Services Act

Program Missions and Objectives

In Western Australia, the Disability Services Commission (DSC) is responsible for "advancing opportunities, community participation and quality of life for people with disabilities" (Australia DWA 2009, 1). The DSC offers Intensive Family Support Funding, which provides flexible assistance to individuals and their families to support persons with disabilities (Australia DSC 2009). The Intensive Family Support Funding program is intended to:

- support, develop, and enhance existing and new relationships, community connections, and support networks
- promote the individual, family, and/or carer's capacity to maintain a positive home environment
- facilitate, maintain, and enhance the individual's independence

- engage individuals, families, and/or carers in community activities
- increase access to and inclusion in the community (Australia DSC 2009).

Program Description

Western Australia's Disability Services Commission provides Local Area Co-ordination, a form of service brokerage which ensures that support for individuals with disabilities is personalized, flexible, and responsible (Stehlik and Chenoweth 2001). Local Area Co-ordinators (LACs) help individuals and their families plan, select, and receive supports and services identified as necessary (Australia DWA 2009). The Intensive Family Support program "aims to supplement and complement the natural supports and other available resources provided by the individual, family, and/or carer" (Australia DWA 2009, 1). The program provides a range of flexible, tailored, household supports recognizing the strengths, aspirations, needs, preferences, values, and cultural identity of the individual with a disability (Australia DWA 2009).

Funding Eligibility Criteria

Families in Western Australia are eligible for the program if a member of their household has a disability that impacts the functioning of the household and that meets the Disability Services Commission's eligibility criteria (Australia DSC 2009). The individual must be under sixty years of age and have a disability as defined by the Disability Services Act: intellectual, psychiatric, cognitive, neurological, sensory, or physical impairment (or combination of impairments) that is permanent or likely to be permanent (Australia DWA 2009). Disabilities may be episodic or chronic, must result in a need for continued support services, and must result in significantly reduced capacity for communicating, social interaction, learning, or mobility (Australia DWA 2009).

Funding Uses

Funding may be used for assistance with

- developing and maintaining new relationships, community connections, and support networks
- strengthening family or carer capacity to promote a positive home environment
- enhancing the well-being of the individual with a disability

- building positive relationships among all household members
- supplying personal care
- providing support to siblings (Australia DSC 2009)

Fund Management

Individuals or a family member may manage the funding with support from a brokerage organization (Australia DSC n.d., a).

Budget Revisions

Clients wishing to modify their application may speak with their service provider or LAC, who will submit a new funding plan on their behalf (Australia DSC n.d., b).

Reporting Requirements and Safeguards

Researchers could not locate information about reporting requirements or safeguards.

Priority Area Results

The priority area results are presented by theme. Under each theme, we give the document review results first, followed by the results of the key informant interviews. It should be noted that many interviewees used the term "individualized funding" to describe Self-Directed Funding (SDF).

Interestingly, many of the responses from government and ACL (Associations for Community Living) key informants were consistent with one another, suggesting that the challenges and strengths associated with SDF are acknowledged by stakeholders at many levels. In addition, similar themes emerged from interviewees across the country, regardless of the philosophy and history of their province's funding model.

Program Design and Accountability Measures

The literature review and key informant interviews converged on several common themes, including program design considerations, the importance of brokerage systems that are separate from budgeting, and reporting complexity. The key informants discussed these themes in greater detail.

Literature Review Results

Policy and Program Design Commonalities

It is evident from the program descriptions above that, from a policy and design standpoint, the goal of individualized approaches is to **empower** individuals and their families to be involved in making decisions about their lives. Legislation, policy statements, and department missions all reflect to some degree the need to **build capacity** within individuals with disabilities so they can enjoy a full life. In all of the cases reviewed, supports and services are based upon an individualized plan, which is commonly developed with the individuals and/or their family and personal network.

It is also common for funding programs to be **needs-based**, rather than relying solely on income criteria, which allows individuals experiencing similar disability-related impacts to receive similar levels of funding. This tends to be accomplished with a formalized needs-assessment process, with guidelines written into policy for allocating money based on assessed level of need. Plan and budget revisions generally appear to occur on a regular as well as an as-needed basis, which ensures that plans continue to meet the individual's needs — a policy that conforms to the underlying philosophy of individualized approaches.

Finally, accountability tends to be formally mapped out in terms of (often monthly) **invoicing** to account for expenses incurred, and reporting that requires individuals to **follow their personalized plans** when purchasing services and supports. Individuals and their caseworkers commonly identify where services and supports will be purchased and what they will cost during the **budgeting** process, which likely assists with program accountability.

Other Program Design Considerations

Evaluations have highlighted several things to take into consideration when designing programs. First, several individual program evaluations and larger reviews have underlined the importance of **separating the planning process from decisions about funding alloca-**

tions. Requiring caseworkers to conduct assessments and assist with planning while they are also responsible for allocating budget amounts may create a conflict of interest that strains their relationships with clients. One of the key lessons learned from the final report on Ontario's Individualized Quality of Life project, for example, was the importance of separating allocation and administration from planning (Roeher Institute 2000). Similarly, in a large review of promising individualized approaches in Canada, the United States, the United Kingdom, and Australia, Lord et al. (2000) highlighted the key lesson that it is "essential" that funding decisions be separated from planning and service delivery.

Second, evaluations have also found difficulties with designing policy, which affects accountability measures and program flexibility. In British Columbia, for example, Lord et al. (2000) found that it has been **difficult to develop clear policy statements** around the microboard approach. This was attributed to the individualized nature of microboards and it was suggested that monitoring frameworks guided by a strong, well-laid-out philosophy are more effective in terms of accountability than a detailed policy. Walker et al. (2009) noted that programs that have expanded pilot and demonstration projects into state-wide plans have experienced a **loss of flexibility** as the checks and balances required of larger programs are imposed. In British Columbia, a review of the Choices in Supports for Independent Living program noted a province-wide need for **standardization** due to regional variations in how policies were interpreted (Gauthier 2006).

Finally, some evaluations also noted difficulties with monitoring. In the US, Walker et al. (2009) recommended emphasizing accountability in a manner that **balances the individual's control with accountability for the disbursement of public funds**. Accountability measures can be cumbersome. In the UK, participants in the Direct Payment program reported issues around unnecessary and overly bureaucratic paperwork to the Commission of Social Care Inspection (2007). Difficulties with monitoring are not limited to accounting for funds. In their review of Ontario's Choices program, Lord et al. (2000) found a concern that the project's brokers did not adequately monitor participants' support arrangements.

Interview Results

Several important themes emerged from the key informant interviews regarding program design and accountability, including reporting complexity, fund manager training, and accountability measures.

Program Design

Key informants noted difficulties associated with a **needs-based system** for determining funding levels. A government representative felt that systems where the caseworker is responsible for **conducting assessments and for allocating the budget** put front line staff in a difficult position. This person also cautioned anecdotally that **reassessment** may produce a vicious cycle in which client funding is consistently reduced. Moreover, programs tend to be structured so that individuals with the **highest needs receive the most funding**. However, higher levels of funding (at least initially) may be particularly helpful for providing "greater opportunities for inclusion or self-determination or self-efficacy for those with lower support needs."

Providing **independent brokerage** to support clients in developing plans, acquiring supports, and managing money is an extremely important option for individualized funding approaches. Difficulty with fund management was a common thread throughout the interviews, attributed particularly to difficulties navigating bureaucracy and staffing arrangements. A key informant from Saskatchewan stressed the importance of identifying a team to support families. However, family members often take on the role of team lead, and depending on the family's skill level, this may produce difficulties with managing funding and reporting.

Finally, one key informant noted a common perception that **direct funding models will automatically produce individualized service**. This may not be the case. A key informant from British Columbia observed that direct funding is often spent on "off-the-shelf products" such as slots in existing programs rather than on individualized services: "When you combine the workload pressures and the intimidation of trying to do something new and different, a lot of people will simply do the easiest thing, which is simply to join an existing, already established service. So what you are seeing is individualized funding is being used essentially to do the same old same old."

Reporting Complexity

Many interviewees (both government and ACL representatives) felt that complexity in reporting was an increasing concern. Several interviewees identified complex reporting requirements as a **key reason that individuals opt for a traditional approach over a SDF approach**. One ACL key informant felt that one reason for complexity was government's need to be accountable for public monies: "One of the great problems with IF is that systems

tend to be driven by bureaucratic needs and often put up onerous reporting requirements. So I think that is one of the reasons people are opting for the host agencies route."

Several key informants felt that simplicity in reporting should be a desired goal for accountability processes. **Complex reporting was attributed to mistrust** of individuals or families within the system. According to one informant, "If you trust families, then [reporting] can become simplified and elegant, not highly complex." According to many of the interviewees, abuse of the system does not occur enough to warrant an assumption of misuse. One informant from Saskatchewan has found that "there are many people upset with the detail we are asking and are upset with having to answer to how the money is spent; we often hear that we should just trust that the money is being spent appropriately."

Interviewees raised additional concerns about complexity. One informant was concerned that complex reporting impinged on clients' **privacy** as increasing amounts of personal information are shared. Another key informant felt that complex reporting is not a concern as long as clients are provided with **assistance**. Another key informant related that individuals who participate in British Columbia's microboard program are **well informed** about the reporting requirements before they establish a microboard. One government informant stated that officials simplified reporting procedures in the province by **providing invoice forms and templates**, which help clients fill out the required information.

Fund Manager Training

The key informants related that fund manager training tends to be done **informally**. In cases where clients self-manage their funds and where reporting requirements are not complex, agency staff often do not provide training other than to simply show clients or provide written instructions on how to fill out the forms. In Ontario's CILT program, self-managing clients are not trained but they are connected with other self-managers and have access to online training. Fund managers in Saskatchewan are not provided with training as frontline workers lack the expertise themselves, although they do get information around income tax and labour laws. If clients request information about fund management, frontline workers do their best to help or refer the client to someone able to help.

In the case of New Brunswick's Disability Support Program, agency workers are trained in fund management as part of their orientation and caseworkers **complete the paperwork on behalf of the client**. Caseworkers in Prince Edward Island sign a form that says they will

use clients' funds according to the case-plan requirements, although this is not monitored. In Manitoba, agencies are responsible for ensuring their staff are properly trained and must also maintain policies to prevent financial management irregularities. British Columbia has a training program for staff, and the microboard association offers workshops on employer-director issues and individualized funding.

In addition to educating them about reporting requirements, training has **other benefits** for individuals who are managing funds. One key informant from Ontario suggested that training could inform clients about the values and philosophy behind individualized approaches, introducing them to ideas such as citizenship and self-determination. Key informants in Ontario and British Columbia also claimed that fund manager training would be useful to help families **"expand their vision"** in order to use their funds innovatively: "A lot of family members who are raising a son or daughter with a disability have sort of bought into — perhaps unintentionally — but they have bought into a more traditional model of disability supports. And we want families to know how to be creative."

Characteristics of Strong Accountability Measures

Interviewees discussed several strengths of SDF programs. Key informants in New Brunswick and Ontario identified **flexibility** as beneficial, although the latter cautioned that flexibility must be attached to a strong brokerage system.

Several key informants mentioned **periodic reviews** as being important to the success of SDF programs. A New Brunswick key informant felt that the current system, in which clients submit their receipts monthly, is highly accountable. A key informant in British Columbia argued that clients' plans should be reviewed to determine which approaches are effective and which are not. An interviewee in Manitoba said that the strengths of his province's program lay in the financial reporting requirements and regular reviews of clients' financial care plans. Another Manitoba key informant felt that her program had no challenges with reporting requirements: "We work closely with people. Our staff, my staff, is involved. We meet with their support networks three or four times a year to see how things are going. We or our staff are not seen as social workers that come in and go through. They are very much seen as part of teams that are constantly helping in terms of resources… Our staff are helpers. We don't do — we help, we connect, provide resources."

Finally, interviewees in British Columbia and Saskatchewan identified **simplicity** and **clarity** of expectations and guidelines as strengths in their provinces.

Gaps and Challenges Related to Accountability

Several government interviewees identified challenges with SDF models. One informant cited difficulties with clients' interpretations and **understanding of how funding should be spent**. For example, "Approval for therapeutic swimming does not mean that the money can be spent on purchasing a swimming pool, but the family interpreted it as such."

One interviewee suggested that his province's program could "probably strengthen their controls around **verification** … there is more accountability on all parties with IF." A key informant from Saskatchewan related that it may be difficult to have clients provide enough information during year end to properly account for funding that is spent. In addition, clients may forget the requirement to track expenses, which affects the accuracy of reporting.

Another representative thought that extremely **strict accountability measures** become a deterrent for participants. Related to this, one interviewee felt it desirable to have "a fair way of responding to the process of what happens when money is misspent."

Finally, one interviewee reported that his government was currently facing issues around "sufficient funding to **support the administrative capacity** of the agency and improved training for executives of these agencies."

Labour Market and Staffing Issues

Evidence in the literature and reports from interviewees noted staffing issues as ongoing and serious concerns.

Literature Review Results

Evaluations consistently identify difficulties **recruiting, developing, and retaining** appropriate staff (Lord et al. 2000). Shortages exist in both **personal support workers** and **caseworkers**. British Columbians engaged in microboards, for example, often have difficulties finding staff able to work in their unique support environment (Lord et al. 2000). The Commission of Social Care Inspection (2004) in the United Kingdom also noted problems recruiting, employing, retaining, and developing quality personal assistants. Staff are often located through personal networks, including friends and relatives (Lord et al. 2000). In New Brunswick, a human resources shortfall exacerbated backlogs in intake, reviews, and client care when its Disability Support Program was expanded (Orion Marketing Research 2007).

Evaluations have attributed staffing issues to **low wages**, which contributes to high turnover (Lord et al. 2000).

Solutions

Evaluators have suggested several solutions to staffing difficulties. Those assessing Ontario's Centre for Independent Living program recommended maintaining a **roster** of recommended staff (Roeher Institute 1997 as cited in Lord et al. 2000). The Individualized Quality of Life project evaluation report suggested developing a **staffing agency** to alleviate issues related to locating suitable employees (Roeher Institute 2000). Some agencies have developed tools to assist clients with staffing issues. The Arizona Department of Economic Security, for example, has a tool box with suggestions on how to locate appropriate staff and establish good working relationships (Division of Disabilities n.d.).

Interview Results

We asked key informants about common staffing challenges, including difficulties and innovations regarding finding, retaining, and training qualified personal support staff. We also discussed performance management.

All of the key informants but one reported that finding and retaining qualified staff to support individuals with disabilities remains a struggle. This appears to be a worldwide phenomenon that occurs regardless of whether organizations use block funding or individualized funding.

Responding to Low Wages

According to the interviewees, labour and staffing issues for support programs for individuals with disabilities are highly related to the level of pay. Because the funding for individuals with disabilities is public, there are **limited financial resources** available to pay staff, with governments often setting restrictions on hourly wages. Some key informants mentioned the option for clients to offer a **top-up** to staff, which enables some individuals to offer higher pay and thus attract higher-quality employees. This may set up a dynamic where individuals and families of higher socioeconomic status are more likely to locate staff and receive quality care, resulting in differential treatment of clients.

The low income for staff is particularly relevant when considering the **workload** of many employees. One government key informant related that their workers might have "tremendous caseloads" of up to two hundred clients. Another government representative mentioned the high needs of clients and their families: "I can tell you that staff does struggle with the everyday **weight of dealing with families with need**. You know it can wear on you is one way to put it. I mean our workers are very committed to their clients and case loads, they are very committed to the work they do, but they're only human too."

In addition to being paid low wages, workers may be employed on a contract basis, which has the advantage of creating **flexibility** for the client, who then have more control over when staff work with them or come into their home. However, **workers on contract** do not receive **benefits** or **pensions**. One key informant from Ontario whose child was a direct payment recipient discussed his daughter's support worker: "She's on contract with us so she only gets paid for the hours she works, without any benefits. So that's one of the downsides. I mean it has flexibility but there are no real benefits for the workers." And finding workers with the desired level of flexibility can be challenging: "It's difficult. On the one hand, the individualized funding allows the family to have control over when the person comes into the home or when a person works with the individual. So that's beautiful. But the dilemma is finding workers who have that kind of flexibility."

"[There's] not enough hours in the week, [pay is] low and there are no health benefits. They're on payroll but only have about seven hours a week at a certain rate of pay — and when you consider that we're competing for staff with long term care homes and other service providers…"

Dealing with Limited Worker Pools

In general, our key informants reported that there are **limited** numbers of people working in the disability supports area. Locating sufficient staff is particularly difficult when hiring for nights and weekends. Moreover, clients who are attempting to locate and hire support staff under an SDF model may be **competing** for staff with agencies and service providers who are having difficulties finding sufficient staff for themselves. One key informant succinctly captured the difficulties associated with limited financial and staff resources: "[There's] not enough hours in the week, [pay is] low and there are no health benefits. They're on payroll but only have about seven hours a week at a certain rate of pay—and when you consider that we're competing for staff with long term care homes and other service providers …"

One government key informant noted that this problem is not unique to individualized

funding schemes: "I think the issue around staffing is bigger in that it certainly doesn't have a lot to do with IF, but I guess clients who want to hire people are in effect having difficulties with agencies who are struggling to get enough staff themselves."

Because of problems locating staff through formal channels, some clients may opt to find workers through their **informal networks**. Many funding programs allow clients to hire friends or relatives (although not parents or relatives who reside with the client). Unfortunately, this may lead to inequities among clients, as those who are well connected may be better able to find staff.

Finally, there may be differences in staff limitation in **rural and urban areas**. In rural areas, clients may have difficulty finding staff who are not attached to traditional, block-funded services, which reduces the pool of workers available for innovative, individualized approaches. In urban areas, the potential pool of workers has greater access to employment opportunities in general. Thus, there may be smaller numbers of disability support workers available, particularly when the economy is "hot" and wages are higher for work outside the disabilities field. One key informant related that limited service availability is a general problem and that even where an individualized approach is offered, the services to meet individuals' needs may not be available.

"Most of the issues in terms of being competitive in the marketplace and competitive with people that have the values and the skills and the experiences you would want for someone who might be vulnerable are just very challenging."

Finding Qualified and Trained Staff

Low wages and limited availability also affect the likelihood of locating quality staff. Without the ability to offer higher wages, clients may be forced to hire **untrained** and/or **unqualified** staff. As one key informant stated: "Most of the issues in terms of being competitive in the marketplace and competitive with people that have the values and the skills and the experiences you would want for someone who might be vulnerable are just very challenging."

Disability support worker positions may be perceived by some as temporary jobs, attracting students and others who will soon move on to different careers. This leads to **high turnover**, which negatively affects clients' quality of life as they establish a rapport with support workers who will eventually leave. As one key informant from Ontario related: "People don't stay a long time; they might stay for a couple of years. But I think the people over the years are … moving on to other things — grad school or other things. It's sort of a temporary job and that's a bit of a problem."

One ACL representative stated that individuals with degrees or diplomas in an appropriate field are paid the same wages as those who have no education. Moreover, there is often little in the budget for training staff, which exacerbates problems associated with hiring staff with little or no experience. This problem may be particularly relevant for individuals with **high needs**. As one government informant stated: "Something that would come up over and over again for those children with extreme behavioural or health issues or needs, the families, even though they were receiving funding, a modest amount of funding, weren't able to hire people that were skilled to handle their son or daughter."

Hiring issues are primarily about finding staff who are a good fit for the client and his or her needs. As one government interviewee stated, **"it is not only finding people but finding the right people."** Thus, possessing the right values and having experience with vulnerable people is often essential. Indeed, experience or knowledge of legislation related to vulnerable persons may be a requirement for securing employment at some agencies that offer brokerage or facilitator services. However, it may not always be desirable for staff to possess formal qualifications as Personal Support Workers (PSWs). One service provider commented: "We find that in general people don't like people who are formal PSW trained because they may not be as flexible. I mean the most successful, I think, types of people that they employ are students or, you know, someone just looking for part time. Or even someone to get him or her out of the house for a few hours."

Becoming an Employer

One theme that many key informants discussed was the difficulty of having to become an employer. Individuals receiving SDF are responsible for **hiring** and **firing**, which can be overwhelming. Clients must establish an employer/employee relationship with their workers and are required to learn about relevant regulations. One key informant from Saskatchewan offered the following observations:

> In these particular areas, there has been extensive discussion about families who are hiring personal support workers for their son or daughter and the obligation for them to work as an employer, to establish an employer relationship with these workers. It goes beyond what most families are willing to do for one. Those who take it on find themselves hit with various regulations. All of a sudden Worker's Compensation applies, Canadian Revenue Agency applies, deductions, occupational health and safety applies, because

> now you are an employer. Also the Criminal Code applying that if one of your workers injures himself on the job, you have liability for it. There are a number of variables that complicate the whole process.

Many of the key informants who raised this issue suggested that becoming an employer was undesirable for the majority of individuals receiving SDF because of the amount of work involved for themselves and/or their families. However, deciding to become an employer may be an opportunity for the individual to participate more fully in the community and is related to the philosophy of **empowerment** upon which individualized approaches are based. As one interviewee stated, "For a lot of them it is [overwhelming]. For some people, there are some people out there who, believe it or not, actually like being employers."

Conducting **performance reviews** is another issue related to becoming an employer. In our discussions with the key informants, performance reviews, though not mandatory, tend to be suggested by agencies that support individuals with disabilities. Performance reviews do occur but tend to be informal. Some ACLs and other agencies undergo an education process (such as a booklet or discussion) with clients as they become funding recipients. One interviewee noted that performance reviews are particularly important as the worker pool has a propensity to be young and inexperienced.

Solutions

Many key informants provided information on initiatives seeking to address staffing issues. Manitoba and Nova Scotia are in the process of **reviewing the wage and benefits** structures for their disability support workers, not only examining the level of pay but also considering how to provide workers with benefits and pensions. One key informant from British Columbia mentioned that **unionization** of workers has increased staff retention.

Interviewees also discussed **facilitating the development of strong family groups and access to staff**. Some key informants noted that families with larger social networks are better able to find staff. One interviewee noted that infrastructure should be in place to allow families to support one another. In British Columbia, the Family Support Institute offers parent support, including access to a "Resource Parent" who also has a child with a disability. In addition, the Family Support Institute is developing a web resource to connect people with individualized funding and staff. In Saskatchewan, the Cognitive Disability Strategy is initiating a project to connect all support workers who are hired privately. A key informant

said that "the reason for this will be to provide support to the workers and to provide some assistance in helping them understand what the expectations are for the work they do."

Difficulties encountered by clients when searching for staff may also be alleviated through **agency support**. One key Ontario informant noted that, while SDF schemes should include facilitation infrastructure to support clients' planning and budgeting, clients and their families should also be provided with "human resource support" (e.g., by supporting a pool of workers).

Training is also required on both sides of the employer/employee structure. Clients entering into SDF arrangements should be provided with information about their responsibilities as an employer, including regulations, how to hire staff with strong skills, the importance of performance reviews, and labour standards for terminating staff. Employees should receive training that is general to the disabilities field, including legislation and policies, as well as specific training about their new client. In a related area, Saskatchewan's Cognitive Disabilities Strategy asks service providers to provide a letter outlining their plan for clients, which is reviewed annually as part of the strategy to track clients' progress.

Finally, at its core, SDF is related to **innovative approaches** that maximize the ability of clients to participate in society. Many of the programs reviewed here focus on developing and maintaining a **strong social network** for participants. One consultant reported:

> In many cases, the individuals often do better by having less staff than more staff. This seems counter-intuitive but I see individuals and families give money back because they don't want so many staff in their life. So the staff isn't necessarily the best way to meet individual needs because you get people coming and going in your life and your life can become then almost dominated by the staff coming and going. In many cases, it may be developing alternatives to staff.

Funding Sustainability

Sustainability is an ongoing concern. The literature review discusses how organizations ensure sustainability and the outcomes of several cost-effectiveness studies. The interviews expand considerably on issues related to sustainability, including common perceptions and informants' suggestions for ensuring that programs are sustainable.

Literature Review Results

As evident in the program descriptions above, **budgets are often developed within set parameters** to ensure allocation amounts are sustainable. Alberta's Community Inclusion Supports Framework, for example, has a policy to ensure that services and supports meet the individuals' needs and that budgets are within available resources (Persons with Developmental Disabilities 2007). Community Living British Columbia has quality service analysts who review individualized plans to determine the level and availability of funding (CLBC 2009a). Planning also may involve attempts to **locate other funds and in-kind resources** in addition to disability support funding (Lord et al. 2000). It is also common for accountability measures to be in place to **ensure funds are used as described in the plan**.

Evaluations have found that Canadian individualized approaches are **cost-effective** relative to traditional block funding. Manitoba Family Services (1996 as cited in Lord et al. 2000) evaluated the In the Company of Friends pilot project. In addition to improving participants' quality of life, community living options were less expensive by 8.3 percent for twelve of the fifteen participants in the study, although the evaluators noted that staffing costs were more expensive than traditional approaches. The evaluation of the Centre for Independent Living pilot project found that the cost per client was lower; the evaluators concluded that the project represented a cost-effective alternative to block-funded services and that the benefits outweighed the challenges (Roeher Institute 1997 as cited in Lord et al. 2000). The New Brunswick Disability Support Program was also found to be more cost-effective overall, although there were regional differences: while the individualized program was 8 percent more expensive than the traditional program in one pilot study region (an approximate annual increase of $381,000), the program was 42 percent less expensive in the second pilot study region (Orion Marketing Research 2007).

> "People are assuming that if everyone has staff all the time it wouldn't be financially feasible but, in fact, most individualized funding schemes have a wide range of level of funding from very little to a lot."

Finally, American individualized programs have been found to be cost-effective relative to traditional funding approaches (Conroy et al. 2002). In Michigan and New Hampshire, average expenditures were between 7 percent and 15 percent lower. In California, costs increased, although they did not increase as much as costs for the control group, indicating a cost savings relative to the traditional program.

Interview Results

We asked interviewees about common perceptions regarding SDF as well as how their experience confirmed or challenged those perceptions.

Common Perceptions about SDF Approaches

Interviewees reported an overriding perception that SDF schemes are **unsustainable**. Several key informants mentioned the commonly held view that clients would be **overfunded** under an SDF model, which was attributed to requests for more money than would be provided under other funding models. One key informant observed, "People are assuming that if everyone has staff all the time it wouldn't be financially feasible but, in fact, most individualized funding schemes have a wide range of level of funding from very little to a lot." Another key informant reflected, "If I were on a Treasury Board, I would have the same concerns: am I about to fund a payment mechanism that is going to lead to increased inflated demand on the state?" The outcomes of overfunding included further strain on the already small budgets provided by the government and reduced supports for funding recipients. According to one government informant, another concern regarding sustainability was that SDF would cause **service-providing agencies to collapse**. It was also commonly reported that funding recipients themselves may believe that SDF means **"24/7 funding."**

Interviewees reported another common concern that **recipients would use their funding improperly**, resulting in abuse of the system. One government informant reported that this perception applied particularly to individuals with intellectual disabilities, who are perceived not to have the capacity to manage their own funds. As a result of this perception, individualized approaches are offered only to individuals with physical disabilities in his province. However, the overwhelming majority of respondents reported that SDF funding systems are remarkably abuse-free. One government representative stated: "There is always this fear that families are going to diddle the state and use it for personal gain. There is no evidence at all internationally that families do that. Yes, there may be the occasional person that does, but you know, quite frankly, the service providers do the same thing when they move budgets from one line to another."

Many interviewees noted the perception that **everyone would want SDF** if it was offered. In practice, because of the effort required to manage one's own funds, few recipients opt for more individualized funding options. One government informant stated that, in his

experience, no more than 20 percent of eligible participants opt for an individualized approach.

Experience with Sustainability

The interviewees reported a range of experiences with the sustainability of SDF approaches. One government representative stressed that this approach to funding is "simply about creating a new way of paying for something that gives people a little bit more control and power."

Interviewees reported difficulties around tracking and allocating funding. One ACL informant reported they have had **difficulties tracking** how funding is allocated and spent. As discussed earlier, there has been a national struggle to develop criteria for **allocating funding**. According to this key informant:

> There has never been a great deal of clarity of what that funding is based on and therefore our government has never had very good statistics about what the money is being used for, has never been able to account very effectively for that money to our provincial auditor, and therefore has never been able to make a very strong case to the funder or the Minister of Finance for what the financial needs are of the sector.

Several interviewees (primarily government representatives) reported that **block funding is more sustainable** in the long term. One informant described Manitoba's In the Care of Friends as "cost prohibitive" if it was applied to everyone. One government informant commented that block-funded programs are **more visible** and are perceived by local politicians and neighbourhoods to have a **larger impact** than individual approaches. One ACL informant observed that individual approaches are "undeniably more expensive" but that "ultimately, quality of life is better" with SDF.

> "It's pretty clear that for a dollar that goes into a block funded program, a dollar in IF buys you $1.08 to a $1.15 of service."

While several interviewees reported that block-funding schemes are the more sustainable option, many others claimed that SDF is no more expensive. In fact, interviewees often related that **SDF approaches are less expensive than block funding**. One key informant, for example, stated, "It's pretty clear that for a dollar that goes into a block funded program, a dollar in IF buys you $1.08 to a $1.15 of service." One ACL representative reported that a cost comparison be-

tween his province's old block-funded program and the new individualized program found no differences in the cost per case. One region's costs were actually significantly lower under the new individualized program. Another government representative stated:

> It's been shown that individualized funding in the longer term — not in the short term, not in the first one to three years, but in the longer term — individualized funding is used to create and sustain more innovative but less costly solutions.… None of the literature I've read indicates that the individualized funding model is more expensive.

One key informant noted that people who are overfunded in an individualized system are a symptom of lack of innovation. He stated that overfunded clients are

> …a crisis for the system. They don't know what to do with them so they throw a lot of staff at them.… If everyone was getting this there would be no money left, but these [cases] are more a sign of a failure to come up with the right thing to spend the money on. Once you get the things that people really need, they may be cheaper than 24/7 staff.

Policies and Program Development

Many key informants spoke of the importance of having **strong policies** for allocating funds to ensure client budgets, and thus funding programs, are sustainable. The interviewees discussed several policies, suggesting that strong policies and multiple levels reinforce program sustainability.

At the individual level, allocation based on **eligibility requirements** and needs assessments contributes to sustainable programs. Some provinces have strict **budget parameters** and costing guidelines within which services purchased by clients should fall. As one government representative from British Columbia stated, "We have what is called a catalogue of service where we have costing guidelines, we have the guide to support allocation. These are all tools that are used to ensure [sustainability]." One program in Ontario funds clients on an annual basis, so that contracts are no longer than one year in duration and clients' budgets cannot exceed the **annual amount**.

At a broader level, one key informant stressed the importance of building **accountability measures** and **infrastructure supports** into programs at the development stage. Key infor-

mants in both Manitoba and Ontario suggested that the sustainability of direct funding programs is ensured by **strong government commitment** to support programs on an ongoing basis. To ensure the government is informed enough to commit to a direct funding model, one ACL interviewee underlined the importance of educating the government about how many individuals will need support, what supports they will need, and how much they will cost. Finally, in provinces such as Ontario, the funding program is embedded into the province's long-term care **legislation**. Legislation is not easily changed, which builds sustainability into the program.

Innovation and Leadership

Individualized approaches are funding models, but many key informants stated that, at their core, direct funding models are about **addressing needs in innovative ways**. According to an ACL representative, "When you move to an IF approach, you can focus on the real needs of people. When you're able to do that, I think most people will be honest about the kind of supports they'll need." Providing clients with more money may not be the most effective solution. One government interviewee pointed out, "It's not always about more money; it may be about doing things differently." Several key informants argued that **innovation and commitment to innovation arise out of strong leadership**: "When you have strong leadership — if you have champions of something — it really helps sustainability because there is some continuity of ideas, continuity of values." Strong leaders were noted to have come from advocacy groups, families, and government representatives.

"When you have strong leadership — if you have champions of something — it really helps sustainability because there is some continuity of ideas, continuity of values."

Client Equity

Equity is a complex issue. While the literature focuses on differences in supports by region, the key informants' discussions were much more broad ranging, including how to balance recognizing individuality with equity, group differences, and solutions.

Literature Review Results

Although the majority of policies regarding individualized approaches emphasize equity, evaluations tend to focus on **regional differences in supports**. In Alberta, evaluations found

regional differences in infrastructure for providing information and planning to clients (Lord et al. 2000). In New Brunswick, the pilot study's evaluation revealed a lack of standardization in services between the two pilot regions (Orion Marketing Research 2007).

There may also be **differences in what services and supports are approved**. In New Brunswick, for example, the evaluation found differences in the two pilot regions' approval of support services, although the reason was unclear (Orion Marketing Research 2007). The evaluators recommended training staff in the philosophy of the Disability Supports Program to ensure that the "spirit" of the program was upheld (Orion Marketing Research 2007). In the United Kingdom, some local councils had stricter and more rigid policies than others, which resulted in regional differences in approval of budgets (Commission of Social Care Inspection 2004). Participants attributed these differences to a lack of trust in their ability to spend funding properly (Commission of Social Care Inspection 2004).

"You can't have a person-centred program and not have differences… We try to recognize 'This is what you need.' Well, sometimes people say, 'Well, I want what he has.' Well, you might not need what he has or your disability doesn't require you to have that."

Interview Results

Interviewees discussed a number of equity issues under SDF models. As one interviewee stated, "Equity doesn't just mean equality; equity means figuring out what requirements make sense in that particular context." Interviewees generally reported that while their systems attempted to ensure equity among clients, there were often differences in practice: "The more supports a person has, the better, but are they treated equally? We try to treat everyone as equally as we can, but there are definite differences."

Recognizing Individuality

Equality is a central challenge when developing an individualized system. Many of the key informants stated that funding is allocated according to the **impact** of the individual's disability on his or her life. In this manner, two individuals with the same disability may have very different supports because their **unmet needs** are different: "You can't have a person-centred program and not have differences… We try to recognize 'This is what you need.' Well, sometimes people say, 'Well, I want what he has.' Well, you might not need what he has or your disability doesn't require you to have that."

According to one ACL interviewee, these differences create a form of inequality that may also be difficult to justify: "There has always been a question as to why, you know, the person who appears to have the particular degree of disability and someone who looks to have a similar [degree of disability]… why those two individuals might receive very different amounts of supports."

> "The more supports a person has, the better, but are they treated equally? We try to treat everyone as equally as we can but there are definite differences."

Because funding tends to be allocated based on an assessment of unmet needs (perhaps on the assumption that funding should not be required for needs that are being met by other means), the interviewees emphasized that it is important to **apply guidelines consistently** and in a **justifiable** manner. However, the interviewees related some challenges associated with offering funding based on needs assessment. One government informant noted that it is important that **individuals have a say** in what they would like in terms of supports and goals. Another government informant noted that while providing individuals with greater needs with more funding "makes sense," providing less funding to someone with fewer barriers can create a barrier: "It creates a barrier for someone who is near independence and could be totally independent from any form of governments — or in other words — if they need job training or some skill sets developed towards the payment of independent work, they are not funded at a level which would enable them to choose that."

Social Inequities

Many of the key informants confirmed that individuals with **stronger social networks** tend to be more successful. Key informants in Ontario, British Columbia, and Saskatchewan reported that individuals whose families are well connected or highly engaged are more able to find supports and workers because of their larger networks and ability to advocate more strongly. An interviewee from Manitoba commented that the lack of a strong family is not an insurmountable obstacle as some participants with no family supports have been "extremely successful." However, in cases where individuals are less well connected, staff must focus on **building a strong support network** for them. One key informant noted that strong family ties may be a hindrance when the client and family members disagree about the types of support that are needed.

> "Equity doesn't just mean equality; equity means figuring out what requirements make sense in that particular context."

Financial Inequities

Several interviewees pointed to financial inequalities as another important issue sometimes associated with SDF models. Several noted that individuals with **lower socioeconomic status**, those who are less educated, and those from minority backgrounds also tend to experience difficulties with an individualized supports system. Informants commented that individuals with lower incomes may be at a particular disadvantage when hiring workers. Key informants in New Brunswick reported that participants in their program are free to top up their support workers' wages if they have the financial means.

Geographic Inequities

Prairie region interviewees pointed out geographic inequalities in access to individualized supports. In Saskatchewan, the only organizations in the province willing to act as financial intermediaries are in Saskatoon and Regina, which means that **individuals living in rural and remote areas cannot access SDF**. In addition, funding is not transportable, so if individuals move from Saskatoon or Regina, they lose their supports. In Manitoba, key informants noted that not all rural or remote labour markets are able to accommodate increased demand for services, which reduces the program's ability to operate in those areas.

Group Inequities

Two interviewees noted differences in funding for **disability programs**. The British Columbia government, for example, has recently expanded eligibility to the program, which now includes individuals with Autism Spectrum Disorder and Fetal Alcohol Spectrum Disorder. But because of the history of disability support funding in British Columbia, individuals with long-term disabilities are much better funded than those with Autism Spectrum Disorder because the former program has been in place for longer. In Ontario, **support workers** for the Direct Funding Project for individuals with physical disabilities receive higher wages than those who work for the Special Services at Home program for individuals with developmental disabilities. The wage differences affect the care clients receive, creating a form of inequity.

Solutions

Many of the interviewees felt that equality should be addressed by **basing funding allotments on needs** rather than on standardized funding levels. One key informant from British Columbia suggested that there should be variation in funding levels to address differences in

needs. However, this solution is complex. Flexible systems may create variability, which may impact on the system's ability to treat clients equitably.

A significant portion of interviewees felt that equity could be addressed more effectively. One key informant said, "Equality is not addressed very well in any funding models that I have seen. It's something that needs a lot more attention and part of that probably relates to figuring out at the front end how you assess people's needs and how you assess people's requirements and part of that is a tough thing to do."

Many provinces are dealing with the matter of assessments. A key informant in Manitoba reported that the government is currently investigating **standardized assessment tools** to "bring about fair and equitable funding to all individuals." The Ontario government is also conducting a system-wide initiative to determine all their clients' needs in order to inform a more individualized approach in the future.

The interviewees also provided some considerations for needs assessment. A British Columbia key informant suggested that needs assessments should "do some triaging in terms of what's a **real need for support** as opposed to the advocacy or support behind it," a problem she described as an "age-old problem" in the system that can only be addressed by strong planning. One Ontario ACL representative cautioned that determining needs is complex and a **simple assessment** is unlikely to be adequate for determining needs. And an informant from Saskatchewan reported that a lot of work is being done "to connect with agencies that work with people who have no system connection." However, agencies in her province often do not have the resources to connect clients and **build support networks**. Social support was a strong theme throughout the interviews and interviewees often identified the importance of building strong social networks as vital to the success of clients.

Outcomes and Challenges

Both the literature and interviews outlined a variety of positive impacts on clients' quality of life, while noting some benefits for staff and some ongoing challenges.

Literature Review Results

Improved Client Outcomes

Self-directed funding has been found to improve participants' **quality of life**. In New Brunswick, the Disability Services Program found significant positive impacts on clients'

quality of life (Orion Marketing Research 2007). In addition to high client satisfaction (89 percent), 94 percent of participants said they were receiving the supports they wanted and 86 percent were making progress towards their goals.

In Ontario, the Choices project evaluation found that the program assisted individuals in developing personal networks and relationships (Lord et al. 2000). Participants reported stronger relationships with family and friends as well as more friendships with individuals who were not paid supports. The Centre for Independent Living Toronto's pilot project evaluation found several positive outcomes for participants including greater self-determination, management skills, independence, and relationships. Finally, the Windsor-Essex Brokerage for Personal Supports (2009) found that their clients experienced a sense of empowerment when planning supports were provided.

Manitoba's In the Company of Friends pilot project evaluation found improved quality of life for fourteen of the fifteen participants (Lord et al. 2000). Although no percentages were reported by the authors, Lord et al. (2000) report these positive outcomes:

- improved material well-being
- increased satisfaction with life
- increased self-determination
- improved social interaction
- increased community participation
- personal development
- improved health

Prior to the cancellation of Alberta's Individualized Funding program, Persons with Developmental Disabilities found extremely high satisfaction rates with its individualized funding model. The 2006–2007 client satisfaction survey found respondents (who included clients and their families) had an overall satisfaction rating of 83.4 percent (Alberta PDD 2007b). In addition, overall staff responsiveness received a 88.5 percent satisfaction rating (Alberta PDD 2007b). Respondents reported that they were participating in community activities as much as they wanted (81.0 percent), living where they wanted (91.0 percent), living with the people they wanted (89.8 percent), and involved with service planning as much as they would like (83.8 percent; Alberta PDD 2007b).

In British Columbia, individualized approaches including microboards and Choice in

Supports for Independent Living have found clients experience more **choices**, **freedom** to set and meet goals, greater **independence**, and increased **participation** in and access to their community (Gauthier 2006; Lord et al. 2000).

Positive outcomes have also been found in other countries. A national survey examining clients' and families' quality of life found statistically significant improvements in scale ratings obtained before and after participating in self-determination projects for all fourteen areas examined by the evaluation, which included the ability to run their own lives, health, family relationships, community interaction, treatment by staff, and overall quality of life (Conroy et al. 2002). In the United Kingdom, the Commission of Social Care Inspection (2004) found participants "overwhelmingly" thought the concept of direct payments was excellent; moreover, direct payments afforded participants greater flexibility, choice, and control over their care.

Improved Staff Outcomes

Interestingly, an individualized approach has also been found to have positive effects on caregivers' quality of life (Foster et al. 2003). An examination of an Arkansas Medicaid program found caregivers of self-directing care recipients provided fewer hours of assistance; were less likely to self-report physical, financial, and emotional strain; were less worried about insufficient care; were more satisfied with client care arrangements; and were in better health than a control group working under a traditional model.

Interview Results

When asked about the impact of an individualized approach, the majority of interviewees reported that SDF leads to positive outcomes related to quality of life. However, interviewees also reported some negative impacts.

Improved Client Outcomes

Several interviewees reported that SDF models are **better able to meet clients' needs** because a plan is developed that identifies clients' needs and services to meet those needs. An informant in Saskatchewan commented that, anecdotally:

> We have seen some positive outcomes where families tell us that their child is doing better in school, they are able to access services and supports that they

> have never been able to access before, they are able to get respite when they were not able to before, they are able to access supported living support when they were not able to before, they have people involved in their life — I am referring to the paid support worker that works directly with an individual — to help them even when things are not going well. Funds are not pulled once someone sees successes happening.

Informants related that evaluations of their programs found **improvements on a variety of quality-of-life indicators**. Greater satisfaction with individualized approaches arises out of the greater **flexibility** of the funding program. Clients are involved with designing their own plan and are able to change aspects of their service that they do not like. Accordingly, individuals purchase services to meet their needs rather than trying to meet their needs by hoping the system will provide the services that they need. This theme resonates strongly throughout the interviews, including one key informant from British Columbia:

"It gives people choice. It gives people power. It gives people the ability not to be captive by agencies. It lets people use money to buy quality."

> The money is more likely to go to where it is most needed, whereas in conventional models, you fit the individual to the model so you can't sort of get the model to fit the individual. With individual funding you can do that — reinvent the model. Therefore you are going to have a better change — a better fit between what is purchased and what the individual needs.

Client Empowerment

Interviewees' responses included strong themes of empowerment. Most of the key informants reported that SDF results in increased **freedom**, **autonomy**, and **sovereignty**. Rather than being directed by the system (which commonly occurs in traditional models), clients participating in SDF models are active decision makers in their own lives: "It gives people choice. It gives people power. It gives people the ability not to be captive by agencies. It lets people use money to buy quality."

"People are offered unlimited experiences and that means sometimes life is great and sometimes life is the pits and everything in between that."

One government informant commented that increased sovereignty over money means

that clients can use their funding **creatively** and **innovatively**. Another key informant from Ontario found that families have increased control over their lives, which allows clients to **participate more completely in the community**: "People are offered unlimited experiences and that means sometimes life is great and sometimes life is the pits and everything in between that." An ACL representative found that "more people were able to access their communities and do things in their communities." An informant associated with a service provider stated that clients involved with individualized approaches are "accomplishing dreams people maybe never thought were possible."

Challenges and Barriers

While the interviewees felt that SDF models significantly improve quality of life for clients, they also noted some challenges that clients may face. Several key informants related that participating in SDF programs is **"harder on clients"** and their families. Clients are more actively involved in making decisions about their lives, making choices about what services they want, and often becoming employers. One key informant said that "it's more challenging logistically to live within this kind of a funding model because each individual has to learn how to figure things out as opposed to a more traditional model where, you know, people are basically told what to do."

Moreover, becoming an employer and being responsible for paper work can be **challenging**, **time consuming**, and **complex** for clients and their families. Dealing with the high level of **bureaucracy** that tends to be associated with SDF may also be a challenge. In this sense, one government informant argued that block-funded services are an "easier approach for a family." Another informant noted that being more independent sometimes leads to clients becoming **socially isolated** as they may remain secluded in their apartments if they lack an adequate social network. In addition, sometimes individuals receiving funding are poor decision makers when it comes to **managing their money**, which can lead to funding being spent on items that are outside of their plan. Still, one interviewee discussing an Ontario study noted that "in terms of the infrastructure question, people really benefited from having **facilitation** in their life."

In addition to these "management" issues, key informants also related that clients in SDF programs often remain at the mercy of **supply and demand**. Several informants noted that block funding continues to be "very well entrenched," which creates difficulties when clients attempt to purchase individualized supports. Thus, "if you give someone money and there's

nothing for me to buy with it, it isn't much use." One informant from British Columbia noted that the capacity to provide individualized supports "may be missing in many jurisdictions." Thus, it is important to ensure there is **adequate community capacity to provide individualized supports**.

Interviewees noted another particularly important problem: **programs are often underfunded**. This was a strong current underlying many of the issues discussed by the study's key informants. Because programs have limited funding, they may have long waiting lists, forcing individuals to wait for service. In addition, pay for workers continues to be low, which affects the **quality of service** provided and negatively affects quality of life for clients and their families. In addition, agencies may have difficulties with reporting in a timely fashion if they lack sufficient administrative funding. A key informant in BC drew attention to the obvious fact that underfunding **limits what clients can purchase**: "In many cases they are inadequately funded. That would be a challenge. They get some money but barely enough. People can get a place of their own to live, but they have no money. Because they lack transport, they can't go anywhere so they are sort of trapped in their own homes."

"A lot of agencies just aren't doing it. They aren't really delivering much that's individualized. They're relabeling, but in effect the individual isn't getting a new product if you want to put it that way."

Finally, two government representatives noted that the **full potential of these approaches has not yet been realized**. Several interviewees commented that the capacity for agencies to offer truly individualized services remains limited: "A lot of agencies just aren't doing it. They aren't really delivering much that's individualized. They're relabeling, but in effect the individual isn't getting a new product if you want to put it that way." One key informant expressed a desire for increased flexibility, reporting that her provincial government was still looking at how to pilot a direct funding program. Another informant noted that highly innovative and creative approaches are rare.

Other Lessons Learned

At the end of the interviews, we asked key informants if there were any other lessons that they had learned in their experiences with SDF. They discussed issues related to philosophy, funding model development, social networks, and outcomes.

Philosophy

Many of the key informants discussed the philosophy behind SDF. The primary importance of such funding models is their ability to provide choices to individuals with disabilities. Many of the interviewees discussed **person-centredness**. SDF models offer individuals with disabilities the capacity to choose the supports that they need. Thus, they are able to have control over their supports, which improves their self-determination. One government informant stated, "Person-centred IF programs do come with a resolution that you do have to make priority choices, just like we all do in life." Several key informants connected person-centredness with **outcomes**, one of them commenting, "When given the opportunity, people use these funds in really meaningful ways. It allows them to actually make decisions, and sometimes it may not be the best decision, but it's their own decision."

"When given the opportunity, people use these funds in really meaningful ways. It allows them to actually make decisions, and sometimes it may not be the best decision at times, but it's their own decision."

Unless communities have the capacity to respond to needs, it is likely that there will be no difference between block-funded services and individualized approaches. One key informant from British Columbia suggested that developers focus on the intended outcome when designing SDF models: "It's been around for twenty-five years and we're still debating whether it's a good or bad thing. We know it's a good thing, we know it's got great results. People have great value and we know that if the conditions are right and we put together certain supports that guide it, then people benefit in value."

Funding Model Development

Many of the interviewees' lessons learned related to how to design SDF models.

Implementation

Three interviewees discussed issues related to implementing SDF. One service provider felt it was important to start the implementation process slowly and ensure that all stakeholders were **informed of the expectations** required under an individualized approach. This person emphasized the importance of an overall project co-ordinator. And careful planning may help to reduce another issue: "The intent of [the program] was to get people working closer

together; however, what has happened is that it appears that systems are becoming more defensive and narrower in what they will and will not do."

One government informant reported that his province was reaching a point where officials would have to make a decision about whether to **move entirely to block funding or entirely to individualized funding**. Another government informant, however, suggested that universally implementing an SDF model was contrary to the basic philosophy of the funding model: "If you choose to impose sort of an individualized funding approach, it takes away choice because individualized funding is about allowing choice."

"As people's needs change, they need to realize they will need different supports, and those different supports will come through making decisions, prioritizing, and making decisions based on their situations — not in the past, but in present terms."

Strong Yet Flexible Policies

Several interviewees discussed the importance of maintaining a system that is strong yet flexible when meeting the needs of clients. A core difficulty for developing policy for SDF programs, however, is the need for programs that are flexible enough to respond to individualized client needs yet capable of being applied consistently. One interviewee felt that "unless you have very clear **boundaries**, people will try to move the boundaries," which is necessary to ensure funding is being spent appropriately. At a basic level, SDF should be used to meet needs. As individuals age, their **needs change** and funding models should be able to respond to those changes: "As people's needs change, they need to realize they will need different supports, and those different supports will come through making decisions, prioritizing, and making decisions based on their situations — not in the past, but in present terms."

One government interviewee described the need for an "escalator," which would increase funding as needs increased, thus avoiding having participants "hit the ceiling." Finally, one government informant discussed **innovation** as a form of flexibility. Because developing innovative solutions is one aspect of an individualized approach, it should be supported by the funding model: "Any IF payment mechanism needs to be accompanied by good procedures of thinking and planning; you need to have — you could use the term fiscal intermediary — you need to have conscious activities, training, education. Because people don't naturally think out of the box and think differently, they need supports to do that. So I think that's a strategic investment that needs to be made."

Two informants noted that **flexibility is needed within the broader program**. One in-

terviewee related a "need to continue with a model that is so flexible that you are constantly evolving and modifying." In addition, two key informants (one from government, one from a service provider) discussed a desire to be more flexible when deciding on hourly rates for staff. As an Ontario informant stated, "There shouldn't be any artificial limits on hours or wages, you know? They should be based on … they should be individualized as well." According to a government key informant, such flexibility may be particularly important as caseloads increase and become increasingly complex. One key informant from government felt it would be beneficial to attach funding to the individual so that it is portable to wherever the client is in the system.

Unfortunately, the high level of flexibility within SDF models has led to wide variability and **lack of standardization** within the field. One service provider suggested that agencies and governments should be in closer contact to increase opportunities for learning and the development of best practice. According to one government informant, this lack of standardization has led to confusion and a lack of common practice:

> There's not a common set of language around individualized funding models on a universal basis. You've got different systems out there, different ways of calling the same system by different names and that all just brings confusion because, you know, it's almost like there needs to be a stepping back and saying, 'OK, we are going to standardize some of these approaches.'

Strong Supports

Another theme among interviewees was the need to ensure that clients receive **sufficient support to deal with their funding**. Ensuring strong supports may be particularly important when implementing SDF programs. As one ACL representative stated, "Having IF is only one step in the process, then you need to ensure the community has the capacity to deliver the IF supports." It is also important to consider the repercussions of expanding access to funding without ensuring supports are in place first. One government representative commented, "One of the things about IF is, if not done right, it makes people's lives a job.… There has to be enough support around me, but to do so, it doesn't mean that all I do every day is control my money."

The Importance of Social Networks

Several key informants discussed the importance of social networks in improving the lives of individuals with disabilities. As one key informant from Manitoba stated, "What we learned

is how vulnerable people are when they don't have natural relationships in their life, when the only relationships in their life are paid." Programs often focus on **building connections between the client and their community**. Relationships do not just have to be with family members, although one key informant noted that family relationships seem to "work much better." However, the relationships should be **"reasonably permanent"** so that clients are provided with a sense of **continuity** and **reduced isolation**. Forming relationships is particularly important when one considers that retaining high quality disability support staff is a nation-wide problem. One interviewee also noted that it is important for staff to detect cues that signal when a social network is in danger, so they can proactively address issues when they occur.

"It has not led to wholesale abuse of funding, it hasn't led to people left in the streets, dying; it has not led to that. It has not led to any bankruptcy of government; it hasn't led to agencies going out of business. None of those anticipated fears have ever come to light."

Benefits and Outcomes

Finally, many interviewees reflected on the benefits and outcomes of SDF models. One key informant related that SDF approaches have been **extremely successful with difficult-to-serve clients**.

Two government informants reported that the **most common fears** surrounding such funding models **have not been realized**. For example, **abuse of the system** is extremely rare and governments have not been bankrupted by introducing these funding models: "It has not led to wholesale abuse of funding, it hasn't led to people left in the streets, dying; it has not led to that. It has not led to any bankruptcy of government; it hasn't led to agencies going out of business. None of those anticipated fears have ever come to light."

Indeed, throughout the interviews, several key informants discussed the benefits of trusting participants, one of which includes simplification of reporting requirements. Another government representative reported that SDF programs have led to **"more efficient use of scarce resources."** On the same note, a third government informant observed that block funding is more costly in terms of infrastructure, which diverts money away from clients and their support.

Another common fear — that service providing **agencies will all go out of service** — has also not been realized, although one interviewee related that responses to market pressures have resulted in improvements in services:

> In a well-developed and robust individualized funding mechanism, the agencies that are existing that are sometimes block funded, they're not threatened. In fact, good agencies survive.… Service providers who give you poor service don't survive, or they have to change to start to provide high-quality service because if not, then consumers won't buy their service.

"Just because you have an IF model doesn't mean you're going to get IF supports."

Finally, one ACL representative reflected on **difficulties** that some clients have had **locating individualized supports**. Because clients with individualized supports often go to agencies to purchase services, they may be required to compromise on services that the agencies choose to offer: "Just because you have an IF model doesn't mean you're going to get IF supports."

SUMMARY AND CONCLUSIONS

THIS RESEARCH CAPTURED WELL the many complexities, challenges, and strengths associated with Self-Directed Funding models. The literature review and key informant interviews revealed several key themes.

Program Design and Accountability Measures

While there is significant variability in how individualized approaches are conducted, there are commonalities in the philosophies and policies behind the different programs. Individualized approaches aim to empower, build capacity, and respond to individuals' needs. This may be accomplished not only by meeting medical or living supports but also through enhancing personal networks. Challenges with developing individualized approaches and accountability measures include lack of standardization within provinces, as well as nationally and internationally, and the ability to develop policy that is flexible yet clear. In addition, one key informant noted that SDF models will not automatically produce individualized service.

Labour Market and Staffing Issues

Labour market and staffing issues were a prominent concern in the literature and the interviews, which both identified difficulties recruiting, developing, and retaining staff. Participants identified a number of key staffing issues, including low wages contributing to high turnover and leading to difficulties hiring appropriately trained staff. Limited numbers of available staff led to competition among agencies and clients both looking for workers. Staff shortages also led to clients often looking for staff through informal networks. In addition, staffing difficulties are related to inequities. First, some jurisdictions allow clients to top up staff wages, which creates inequalities in clients' abilities to locate quality staff. Second, there are differences in the availability of staff in rural and urban areas, which creates geographic inequalities in services and supports for clients. Finally, becoming an employer can be a key difficulty for clients who may become overwhelmed by the responsibility of hiring and firing staff.

Funding Sustainability

Although there is a common perception that individualized approaches are unsustainably expensive, the evaluations demonstrated that IF tends to be much more cost effective than traditional approaches, particularly when considering the improved quality of life associated with direct funding. Programs have developed means of overcoming sustainability problems, putting policies in place to ensure that budgets are developed within sustainable parameters, for example. Most key informants noted that individualized approaches are less expensive than block funding.

Client Equity

Client equity emerged as a complicated issue, particularly in the interviews. The literature review found regional differences in what supports are provided and how services and supports are approved. Key informants noted the need to balance individuality with equity issues. It is important to apply guidelines in a consistent and justifiable manner, recognizing at the same time that disabilities have different impacts on the lives of individuals. Key informants also noted social, financial, and geographic inequalities. Further, differences in funding and supports available for individuals with different disabilities may be due to differences in program longevity and government priorities.

Outcomes and Challenges

The literature review and interviewees both highlighted the fact that the individualized approach improves client quality of life. It is also important to consider quality-of-life improvements relative to cost-effectiveness data. However, several key informants related that individualized approaches can be more difficult for clients because of the increased involvement in decision making and the difficulties around reporting requirements.

Innovation

The great potential for SDF to address needs in innovative ways emerged as a major theme in both the literature review and the interviews. With its person-centred approach and opportunities for innovation, the SDF model has allowed individuals to pursue a wide range of personal goals, including expanded social networks and involvement in the community.

Suggestions for Future Examination

The current project highlighted several important considerations:

- Keep funding and planning decisions separate to avoid placing staff in conflict with families. Key informants identified independent brokerage as an important part of providing support to participants.
- Balance accountability and individuals' control over funding while still accounting for public funds. Key informants linked complicated reporting requirements with a lack of trust that funding will be spent properly.
- Address reporting complexity, which interviewees identified as a key reason individuals choose to remain with block-funded services; complex reporting can result in recipients' lives being taken over by fund management. Training for fund management tends to be provided informally.
- Ensure support with planning and carrying out plans. Interviewees identified support as a necessary service. Programs should offer varying levels of support to respond to different needs and wishes.
- Alleviate difficulties with staffing as follows:
    - develop a roster of recommended staff
    - create staffing agencies

  - provide clients with educational tools to assist with hiring, maintaining, and firing staff (several jurisdictions are already doing so)
  - review wages and benefits for workers
  - develop strong family groups
- Communicate the sustainability of individualized approaches to policy makers and decision makers.
- Fund people on an individualized basis as a powerful way to enable them to secure the services and supports they require. If service providers cannot respond to needs in an individualized manner, participants will likely opt for block-funded services.

Limitations and Areas for Future Investigation

This study provided valuable insights into common difficulties and strengths associated with Self-Directed Funding models across Canada. The open-ended nature of the interview questions allowed us to identify a broad range of common concerns. This was particularly striking because the interview questions were not designed to identify specific themes within each of the priority areas.

However, the use of open-ended interview questions also limited our ability to probe the themes that emerged from the research in detail because these areas of common concern were not identified until after the interviews were analyzed. Future research should investigate individuals' experiences with SDF models to determine if clients agree with the challenges and strengths identified in this report. In addition, consultations should be conducted with government representatives and community-based organizations providing brokerage services to obtain more detailed information about program development, rollout, and assessment procedures. Information on documentation such as assessment tools, budgeting tools, and reporting templates would also be useful to assist with the development of an SDF model for Saskatchewan.

The literature review and the key informant interviews made it clear that individualized funding approaches are capable of having a significant impact on clients' lives. Program and policy development should be associated with careful planning and implementation, taking into account the key issues outlined above in order to develop a system that responds well to individuals' needs and to further the ability of individuals with disabilities to participate fully in the community.

Appendix A

Key Informant Conversation Guide

Introduction

I represent the Community-University Institute for Social Research, which is a research institute at the University of Saskatchewan. We are conducting a review of different funding models for individuals with disabilities for the Saskatchewan Association for Community Living. Part of the review is to consult with key informants across the country to capture different experiences with the Direct Payment and Direct Support Payment models.

Note for interviewer: the interviewees from the Associations for Community Living will all know who you are and why you are calling. Government representatives may be less aware and may need more of an explanation.

You may know Direct Payments as Individual Funding (IF), where government-funded, people-centred plans are developed to meet the individual's needs and goals. Direct Support Payments are more commonly known as Individually Funded Services (IFS), where services are planned around individual needs but are administered by a service provider.

I am recording this conversation so we don't miss anything you say. While we may quote directly from your comments, we will make every effort to ensure that you will remain anonymous and confidential. Your name will not be reported when we report the results of the consultations. Instead, we will use statements such as "A key informant from (*province*) reported…".

Interview Questions

1. I would like to start by having you describe your funding model.

   (probe: Do you use an Individualized Funding or Individually Funded Services model?

2. What are your criteria for assessing clients' funding eligibility?
   - How do clients use their funding? *(probe: What supports do clients have?)*
   - Are clients' budgets revisited regularly or as needed?
   - Who manages the funds? (e.g., family, circle of support, community-based organization, independent broker)
   - What safeguards are in place to protect clients in the management of funds? (e.g., banking controls, direct deposits)

   Note for the interviewer: it is likely that most funding will only be for individuals with intellectual disabilities or developmental delays.

3. What accountability measures does your funding model have in place?
   - What are the reporting requirements?
   - When you developed your reporting requirements, was complexity of reporting a concern? If so, please describe.
   - Are the individuals who manage the funds provided with training to ensure accurate reporting? (e.g., family, circle of support, community-based organization, independent broker)
   - Are there particular strengths to your accountability measures?
   - Have you found that there are gaps or challenges related to reporting requirements? If so, please describe.

4. Are different client groups treated equally in your funding model?

   (if clarification is required, explain that sometimes not all clients are treated the same. For example, in Saskatchewan, the families with IF are well connected, actively involved, and know where to go for help. Individuals who do not have family support or other connections are less likely to be on IF)

   - If yes, how do you ensure different client groups are treated equally?
   - If no, what are the differences in client treatment? Why do the differences occur?

5. What kind of impact has your funding model had on your client's and their family's quality of life?

(probes: positive outcomes, such as skills and knowledge? What sorts of challenges do clients face?)

6. I am going to ask you about the front-line workers who are providing services to your clients. What are the most common staffing challenges and opportunities you have experienced? What solutions have you developed? What changes in light of opportunities uncovered?

   (probes: finding qualified personal support staff?

   retaining qualified personal support staff?

   training staff?

   scheduling?

   performance management (including documentation)?

   termination?)

7. We are interested in your perceptions of the sustainability of the different funding models. How have you ensured that your funding is sustainable?
   - What common perceptions do you know of regarding the sustainability of Individualized Funding models?
   - What common perceptions do you know of regarding the sustainability of Individually Funded Services?
   - How has your experience confirmed or challenged perceptions?

8. Finally, are there any other lessons have you learned about this funding model?

   (probes: What worked or not? What could have been different or better? Were supports sufficient?)

Would you be willing to be contacted for follow-up questions? __ Yes __ No

Confirm contact information.

Thank you for taking the time to answer my questions. If you have any questions or think of any information you would like to add, please contact Nicola Chopin (email: nicola.chopin@usask.ca, phone: –306–966–2120).

APPENDIX B

Program Features Table

Table 1: Overview of Program Features across Jurisdictions

Location	Program Description	Fund Eligibility and Uses	Possible Fund Managers	Income or Needs Based	Budget Para-meters	Budget Revision Frequency	Reporting and Safeguards
Newfoundland and Labrador	• Key informant did not consider model to be true traditional individualized funding – described as direct funding. Developed to be as individualized as possible • Individuals directly manage own funds or government may purchase services from an agency directly on their behalf	• Presence of a physical disability, intellectual disability, or a mental health issue; seniors also included • Basic living income support. Clients with additional needs may purchase additional supports (including home supports, attendant care, supports for independent living) through Home Support Services Program. Other funding available: Special Needs Board and Lodging Supplement, Flat Rate Allowance, Other Special Needs Funding	Client or service providers bill Government directly	Income-based	Ceilings imposed on funding amounts	Not discussed	Quarterly or biannual reconciliations Direct deposits possible Government staff monitor expenditures Assumes individuals "can manage own money until proven otherwise"
Prince Edward Island	• Described as person-centred by key informant • Case workers help develop case plan, cost out services, identify where to purchase services; do not provide services or clients' resources	• Eligibility criteria around intellectual, physical, and neurological disabilities. Assessment determines natural supports and unmet needs • Clients use funding to address needs identified in assessment • Key informant did not discuss whether clients are provided with money to pay fund managers	Clients decide; fund managers should have a "logical connection" to client (e.g., spouse, parent, friend, sibling, public trustee)	Needs-based	Not discussed/ No information available	Budgets revisited annually	Support logs Client form to affirm funds used as outlined in case plan (not monitored) Government internal audits Case worker visits to clients Cheques used

Nova Scotia	• Direct Family Support (Child and Adult) provides funding to support assessed unmet disability-related needs • Independent Living Support Program (ILSP) provides funds for up to 21 hrs/wk of supports and services. Clients are semi-independent, have unmet needs • Support Services Group Co-operative program for individuals who do not fit well into other models. Co-op members pay participation fee, receive support to live in community. Co-op client coordinators assess level of funding based on support services needed, help develop plan	• Presence of mental health issue, developmental, intellectual, or physical disability. Income is also assessed • Funding is used in the way specified in the Individual Support Plan, which identifies unmet needs, goals, choices, and outcomes. Children's funding is used for respite, recreation, and other family needs. Adults use funding to live more independently, for self-support and employment supports	No government brokerage; funding goes to family or co-operative. Individuals participating in the ILSP encouraged to manage own funds	Funding based on types of support services required	Ceilings in certain categories (can be negotiated)	Quarterly after admission, then annually or as needed	Monthly invoices Cheques go to family or co-op Co-op clients have own bank account; co-signer writes cheques

New Brunswick	• Disability Support Program provides person-centred, flexible disability supports for seniors and persons with disabilities to achieve goals in personal disability support plans • Person-centred planning process looks at life, goals, and supports • Government case worker helps individual identify key needs, determine how to enhance community participation • Pilot completed 2009; will be expanded to whole province March 2011	• Presence of long-term disability, New Brunswick resident, 19-64 years of age, require disability-related supports to address unmet needs • Funding can be spent in a variety of ways, including personal care services, home worker supports, respite, skill enhancement, transportation, equipment, community participation • Clients cannot spend funding on services covered by other sources (e.g., addictions/ mental health/medical services, vehicle retrofitting, employment services	Clients self-manage, trustee can be appointed, money goes directly to agency	Income-testing conducted	Not discussed	Every two years or as needs or financial situation changes Limited flexibility for revising budgets Status not reviewed if on a fixed income (e.g., social assistance)	Monthly invoices Invoices reviewed Few safeguards for clients
Ontario — Centre for Independent Living (CILT)	• CILT provides monthly funds that enable clients to hire, train, and schedule own attendants. Participants become employers; determine how and when services are provided	• 16 years of age or older, Ontario resident, require attendant services for permanent physical disability, able to complete application on own, capacity to meet with Selection Panel to discuss needs, able to schedule attendants, capable of managing attendant workers, meet legal criteria for being an employer, able to manage and account for own funds • Clients must use funding on attendant services (on average, max 6 hours/day)	Participants must manage own funds; funding available assistance with payroll and bookkeeping	Needs-based	Not discussed	Not discussed	Participants receive funds monthly Report quarterly Participants must apply for business number from Canada Revenue Agency

Ontario — Special Services at Home (SSAH)	• SSAH provides the ability to access services outside home (e.g., personal growth, family relief)	• Client must be living with family member • Clients may use funding for variety of supports that fall under two categories: (1) personal growth and development and (2) family relief and support • One key informant stated funding used for "very extensive supports" in past	Individual or family can self-manage or may choose to have funding paid directly to agency.	Needs-based	Not discussed	Participants apply for funding annually (unless no changes desired) Budgets revised every 3 years	Monthly invoices More formal annual reporting (from fund manager) Periodic government reviews (workers and families)
Ontario — Individualized Quality of Life (IQOL)	• IQOL provided individualized planning support; assistance developing support networks; funding approvals; individualized financial tracking, banking, administration, and reporting; information sessions for clients and families	• Families with children aged 0-6 years at risk for/diagnosed with developmental disability; young adults with developmental disability transitioning to work, education, or community activities; adults with developmental disability with parents over 65 years of age • Funding used on variety of supports (e.g., equipment, housing, community participation, employment, community living supports, respite, professional services, transportation, behaviour management services)	Individual or family	Needs-based	According to Vincente (2000), funding approval was based on clear guidelines (not discussed)	Participants monitored every 3 months or as needed Budget reviewed every 6 months	Bi-weekly or monthly invoices Monthly financial statements
Ontario — New Funding Framework	• New Funding Framework will determine level of funding based on support needs • It is anticipated that Ontario's individualized projects will be absorbed into this initiative	• Modified version of Support Intensity Scale, a tool that evaluates support needs, will be used • Allocation tools have not yet been developed but they will use the needs assessment to determine the individual's funding level	Not discussed	Needs-based	Not discussed	Not discussed	Not discussed

Manitoba	• Funded by Manitoba Family Services and Housing, In the Company of Friends (ICOF)'s philosophy is built on creating social networks • Living In Friendship Everyday (LIFE), a non-profit organization, is contracted by Family Services and Housing to support ICOF • LIFE provides resources, training, information, and case management; oversees and monitors budgets; ensures quality service. • Individuals purchase services directly • Person-centred plan developed to identify supports and services to meet individuals' needs and help them live as independently as possible	• Mental disability (as defined by Manitoba's Vulnerable Person's Act) manifesting prior to age 18; Canadian citizen (or legally entitled to remain permanently in Canada); Manitoba resident, 18 years of age or over. Clinical assessment required to confirm individual has full scale IQ of 70 to 75 or below • ICOF participants must be willing to accept input about their life from other people; must have an active viable support network (or be willing to build one) • Funding used to purchase supports individual requires to be most successful as outlined in the individual's plan and budget (e.g., basic living expenses, supports)	Self-manage-ment with assistance of social network	Needs-based	Not discussed	Annual (to ensure budgets match needs)	Monthly reports (submitted quarterly) LIFE conducts in-depth progress review every six months Agencies submit annual audited financial statements Safeguards include financial transaction records (retained for seven years), account tracking documents Periodic reviews of staff's personal fund management

Saskatchewan — Community Living Division (CLD)	• CLD's primary objective is "to ensure physical, emotional, and social needs are met and that people with intellectual disabilities live and function as independently as possible within their own communities" • Described as "individually funded services"	• Must be eligible to receive service from CLD; majority of participants have diagnosis of mental retardation • Daily Living Skills Assessment (DLSA) conducted to assess strengths and challenges to determine necessary supports • Funding used for variety of purposes including residence, quality of life needs, emotional needs, one-on-one support for difficult needs • If CLD does not provide support directly, may help individual access particular support	Families sometimes self-manage but often prefer CBO to manage funds	Income- and needs-based	Contract lays out funding provided over contract period Funding must be spent on approved items	Budget revisions conducted at least every 2 years (many reviewed annually or as needs change)	Clients submit invoices to funder, who then provides payments (as long as amount invoiced is within terms of contract) Regular audits conducted Relies on self-report and trust; does not use direct deposits, has no banking controls in place
Saskatchewan — Cognitive Disabilities Strategy (CDS)	• CDS's objectives include improving availability of assessment and diagnostic services, providing services to address unmet needs of people with cognitive disabilities and their families, providing training opportunities for individuals with cognitive disabilities, and enhancing provincial Fetal Alcohol Spectrum Disorder prevention and intervention initiatives • Use integrated planning model to fund unmet service or support needs that cannot be met by existing services/supports	• Criteria for cognitive disability are significant limitations in learning and processing information; behavioural challenges that limit interpersonal, social, and emotional functioning; developmental challenges that limit daily living; unmet needs; persistent and long-term limitations and impairments • Benefits based on support plan identifying individual's goals and strategy for accomplishing those goals; preferred that a team be involved in development of the plan to ensure individual has effective supports	Team member is identified as fund manager Options are receive funds directly and act as payee; have service provider invoice government directly; contract third party fund manager funds	Needs-based	Not discussed	Annually (although changes may as needed)	Clients report annually Service providers also required to report

Alberta	• Persons with Developmental Disabilities (PDD) program operates under the founding principle that "individuals, with the assistance of their families and friends, are the primary source for identifying what is best for themselves and what kinds of support they require" • PDD provides direct funding for individuals with developmental disabilities to purchase supports required to live, work, participate in community • PDD began modifying its program as of March 31, 2009; detailed information about changes unavailable	• Onset of disability prior to adulthood; intellectual capacity significantly below average; limitations in two or more adaptive skill areas • Funding is portable; may be used for community living supports (e.g., up to 24-hour support, respite, and supported independent living); preparation for and placement with employment supports, community access supports, and specialized community supports (e.g., behavioural support, professional services, start-up community living supports, and transportation)	Clients may choose either to self-manage or pay a fiscal intermediary to manage funds on their behalf	Income- and needs-based	Not discussed	Plans and budgets may be revised to adapt to changing needs	Monthly invoices (submitted after services provided)

British Columbia — Community Living British Columbia	• CLBC is guided by five policy foundation statements, which emphasize citizenship in community; individuals, children and youth, and families come first; working together to build capacity; a culture of change and learning; and accountability	• Clients must be 19 years or older and have an IQ of 70 or under • Allocations are based on individualized support plan • Individuals may purchase supports for home living, transition, community inclusion, education and employment, professionals, behavioural interventions, health care planning and medical, family, and crisis situations	Participants (or family) may self-administer their funds or may choose to have money flow through a host agency who works on their behalf Because of IQ requirement, families are often fund managers	Needs-based	Not discussed	Budgets reviewed annually or on crisis/as needed basis	Clients (or legal agent) provide Compliance Reports every 6 months Direct deposits Online financial reporting Cheques to purchase services
British Columbia — Microboards	• Microboards are small non-profit societies (typically comprised of the individual's social network) established solely to support one person and are a way to manage individualized funding. • Microboards are "a very popular way of bridging between IF and more traditional contracted services." At least five people sit on a microboard (a president, vice-president, secretary, treasurer)	• Same as CLBC (above)	Microboard is appointed fund manager; individual and family manage funds together	Needs-based	Not discussed	Budgets reviewed annually or on crisis/as needed basis	Microboards have same reporting requirements as a non-profit agency (including reporting to Canada Revenue Agency) Host agencies that work with microboards report on a quarterly basis to government and individual

California	• Self-Directed Services program participants have enhanced control over the decisions and resources necessary to implement their Individual Program Plan • Plans developed with assistance of Supports Broker in person-centred planning process that creates individualized budget to purchase required services and supports • Participants actively involved in choosing their preferred service providers, supports broker, and financial management service	• Individual's disability must be developmental (present before 18 years of age; includes mental retardation, cerebral palsy, epilepsy, autism); expected to last indefinitely; over 3 years of age; be willing to undergo an in-depth program orientation; agree to use only the program's services and supports; accept and manage their individualized budget; hire or designate Financial Management Services of their choice for disbursement of funds; and hire or designate a Supports Broker in implementing their Individual Program Plan • Funding used to purchase community-based services and supports as specified in their Individual Program Plan; services provided in "congregate" settings (e.g., day programs, sheltered workshops, and residential facilities), cannot be purchased with Self-Directed Services funding	Individuals self-manage their funds; able to have support from Support Broker	Needs-based	Not discussed	Progress is monitored; adjustments made to plan	Clients report expenditures and budget balance monthly

United Kingdom	• The purpose of Direct Payments is "to give recipients control over their own life by providing an alternative to social care services" • Individuals receive funding from local social services departments and use funding to purchase required services and supports • The Department of Health reasoned that individualized budgets should increase the quality of services by giving individuals the opportunity to stop receiving low-quality services and supports • Direct payments are flexible; individuals may adjust amount of money used from week to week as long as objectives of care plan are carried out; spare money may be banked and used when needed	• Participants must be "older people" (under 60) assessed as requiring community care services; person with disability aged 16 and over; person with parental responsibility for a child with a disability; an individual with a disability who is responsible for a child; caregivers 16 years of age or over • Individuals able to choose services and supports that they feel best meet needs • Funding may be used to purchase a broad range of supports, services, and equipment (e.g., personal care, community access, mental health, food preparation) as outlined in the individual's care plan • Direct payments may not be used to pay for residential care or to employ relatives	Individuals may self-manage or may ask others to assist them (families make payments on behalf of children under 16 years of age)	Needs-based	Not discussed	Monitoring frequency determined by how long individuals have self-directed and their situation	Individuals must be able to account for funding separately from other funding used for similar purposes A dedicated bank account for funding may be recommended

Western Australia	• Intensive Family Support Funding provides flexible assistance to support individuals with disabilities and their families • The program is intended to support, develop and enhance existing and new relationships, community connections and support networks; promote the individual, family and/or carer's capacity to maintain a positive home environment; facilitate, maintain and enhance the individual's independence; engage individuals, families and/or carers in community activities; increase access to and inclusion in the community • Western Australia's Disability Services Commission provides Local Area Coordination, a form of service brokerage that provides personalized, flexible, responsible support; helps individuals and their families plan, select, and receive necessary supports and services	• Families eligible if member of household has a disability that impacts the functioning of the household; is under 60 years of age; has an intellectual, psychiatric, cognitive, neurological, sensory, or physical impairment (or combination of impairments) which is permanent or likely to be permanent; disability may be episodic or chronic, must result in need for continued support services, and must result in significantly reduced capacity for communicating, social interaction, learning or mobility • Funding may be used for assistance developing and maintaining new relationships, community connections and support networks; assistance strengthening family or carer capacity to promote positive home environment; assistance enhancing the well-being of the individual with a disability; support engaging and building positive relationships between all household members; assistance with personal care; and sibling support	Individuals or family member may manage the funding with support from a brokerage organization	Needs-based household and that meets the Commission's eligibility criteria (Disability Services Commission 2009).	Not discussed	If clients wish to modify their application, they may speak with their service provider or Local Area Co-ordinator, who submits a new funding plan on their behalf	Not discussed

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