



Social Enterprises
Knowledgeable Economies
and Sustainable Communities

Self-Directed Funding

An Evaluation of Self-Managed Contracts in Saskatchewan

Isobel M. Findlay and Anar Damji

**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
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SELF-DIRECTED FUNDING

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ISOBEL M. FINDLAY AND ANAR DAMJI



Centre for the Study
of Co-operatives

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EXECUTIVE SUMMARY

OVER THE LAST SEVERAL DECADES, Canada and other industrialized countries have witnessed a paradigm shift guiding service provision for people with disabilities: from the medical, deficit/protective model to a community inclusion or social model consistent with people's fundamental right to dignity, quality of life, and full citizenship affirmed in the first article of the United Nations (2006) Convention on the Rights of Persons with Disabilities. The social model focuses not on impairment in the person but on barriers imposed on the person by society. In furthering the UN Convention goals (ratified by Canada in March 2010), Individualized Funding, though insufficiently known or understood, is an important tool that has been available in some form in jurisdictions around the world for over thirty years. Individualized Funding involves an individual identifying his or her needs and presenting a plan to a funding body (typically government). With the growing popularity of such programs among people with disabilities, block-funded services — traditionally based on a rehabilitative or medical model — have been transformed in many Canadian provinces to relocate choice and control over services from service providers to people with disabilities. In this changing landscape, many organizations offering block-funded services are adopting a multi-dimensional model of support.

In Saskatchewan there have been a few special cases where individual families have negotiated individualized or self-directed funding arrangements called self-managed contracts with the Ministry of Social Services, Community Living Service Delivery (CLSD), Government of Saskatchewan, to fund a person-centred plan developed to meet individual needs and goals. In many of the existing self-managed contracts, individuals rely on their families and support network to help implement and run their self-managed contracts.

This report explores self-managed contracts specifically for individuals with intellectual disabilities. The purpose of this study is to examine the process of developing and managing the contracts, and their impact on the lives of those who choose to pursue this type of funding arrangement. It includes current contracts, exploring why some individuals and families choose to maintain their self-managed contracts while others prefer to use traditional funding structures that are in place. Its guiding purpose is to enhance understanding and to provide evidence to support decision making of individuals and families, service providers, community organizations, and government policy makers. Based on a literature review and semi-structured interviews with individuals, self-advocates, family members, the Advisory Table on Self-Directed Funding, service providers, as well as government employees involved in SDF-like arrangements, this study focuses on (a) recipients' and support group stories regarding the impact of SDF-like arrangements on their lives; (b) their understandings of how the self-managed contracts and related arrangements have helped or hindered their lives and how developing and maintaining the contract has impacted their families, caregivers, and supporters; and (c) the outcomes and impact of the SDF-like arrangements on community structures, program delivery, and policy.

The findings are organized in three sections — experiences before self-managed contracts, the process of obtaining a contract, and experience with self-directed funding arrangements — followed by discussion of key themes and issues. Interview participants confirmed the literature review findings about experience before contracts and particularly poor and minimal services, low quality of life, anxiety and insecurity, frustration, and feelings of isolation and powerlessness. The record was clear on the financial, emotional, mental, and physical distress experienced by those who felt keenly a lack of voice and choice before obtaining contracts.

The process of obtaining contracts proved daunting for all but those with the professional knowledge and skills to ease the task. Without community supports (including community living associations), most felt they would have been lost. For all respondents, the task of securing self-managed contracts took years. Families felt there was an enormous burden on them to find information that was not, but should have been, more readily available. They reported a culture of secrecy that made information and knowledge often inaccessible. Participants felt the particular injustice of compromised access and equity for those already stretched emotionally, physically, and financially. Families faced accusations and inquisitions related to their sources of information. Access to information was further impeded by the

high visibility of block-funded options and agency access to media and government. When bureaucrats explained that there was insufficient funding to support family requests, parents felt officials should have been sensitive to the reality that families remain key financial resources to support their children. Similarly, while government officials understood the process as a negotiation, families felt they had few choices and were ultimately worn down by a system marked by territorialism and insufficient transparency. Adding to the difficulties faced by families in the application process was stress caused by parents' perceptions that officials were questioning and undermining family member competencies. Appeals of decisions were also problematic when those who made the first decision adjudicated appeals. Short-term contracts added to insecurities and vulnerabilities. All in all, a process designed to enhance control and choice ended up adding to uncertainty and feelings of powerlessness and hopelessness.

Experience of self-managed contracts as transformative confirmed literature review findings. Making decisions based on predictable resources, building bonds and connections with community, enjoying access to educational and other opportunities, and having a life were repeated themes. The freedom to choose and to be one's own boss, to experience an enlarged network, take on new challenges and enjoy new commitments, were widely reported benefits. Learning to trust their own judgement and not defer to experts was important learning for one family. For at least one self-advocate, the value of the contract was in the respect and dignity of feeling just like any other human. Independence and an enlarged network were important for families who shared rather than carrying all the responsibilities for their children. Although quality of life improved and some of the financial stress was alleviated, many emphasized that the financial supports were inadequate. Families remain critical sources of financial, physical, and emotional support for their children. Time commitment, management skills, contract and program development, and staff retention remained issues too in the absence of clear contract guidelines and expectations. Nevertheless, the commitments opened doors, gave flexibility, and choice, so that the possibility of losing the self-managed contract was unimaginable for interviewed families.

Although the Ministry of Social Services partnered in and supported the study, levels of fear — compounded by non-disclosure clauses — were such that some potential participants did not participate for fear of losing support. Such fears proved a powerful silencing mechanism. But participants also recognized community-based organization and agency fears that SDF arrangements might mean reduced funding to deliver their services.

Government officials recognized changes in the environment and in informed parents and self-advocates demanding inclusion rather than sheltered workshops. Yet, despite anecdotal and research evidence on the SDF model as enabling, efficient, and even cost-efficient, as well as significant achievement and change in government supports for individuals living with intellectual disabilities, there were significant tensions and ambiguities in responses of government representatives suspicious of SDF and favouring the traditional block-funded model. Many officials insisted that self-managed contracts did not represent a program and that the exceptions were put in place for those who did not fit provided services.

If there was fear among individuals and families, there was also fear among government people who did not feel entitled to speak on policy issues or to present evidence and be part of the process of change. Fears related to family competencies, overservicing, overclaiming the benefits, budgetary constraints, costs, and accountability — and to the need for a champion within government to license thinking outside the old conceptual and program boxes. While government feared the cost of sustaining SDF, families framed costs as a mutual responsibility of family and government in a context of stringent reporting requirements. Although government investment in risk management is both understandable and appropriate, it was also clear that self-managed contracts remain sufficiently demanding for families that it is something that only a small number of families want. Further, a review of the Alberta program has warned of the high costs and dangers of excessive investments in monitoring at the expense of programming.

While all agreed that self-managed contracts are not for everybody, they felt they should be added to the menu of services available to those who feel that block-funded services are not the option for them and who are willing and able to take on the related workload. There is increasing support for a service delivery model that benefits individuals and families willing to take on the responsibilities to give their family members voice, choice, and independence in making decisions on their care and their lives. And there were those who felt the current government is open and politically inclined to let families do what families do.

INTRODUCTION

OVER THE LAST SEVERAL DECADES, Canada and other industrialized countries have witnessed a paradigm shift guiding service provision for people with disabilities. The movement from the medical, deficit/protective model to a community inclusion or social model acknowledged people’s fundamental right to dignity, quality of life, and full citizenship affirmed in the first article of the United Nations (2006) Convention on the Rights of Persons with Disabilities: “To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” The social model focuses not on impairment in the person but on barriers imposed on the person by society; it focuses on changing the system to remove barriers that “may hinder their full and effective participation in society on an equal basis with others” (United Nations 2006, article 1). A “significant tool” (Dozar et al. 2012, 8) in furthering the UN Convention goals (ratified by Canada in March 2010 with the agreement of all provinces and territories) is Individualized Funding (IF) which, though insufficiently known or understood, has been available in some form in jurisdictions around the world for over thirty years. According to Lord and Hutchison (2003), “In many ways, individualized funding is consistent with the world-wide trend toward increased democracy, self-determination and community involvement” (2).

A process and funding mechanism, IF involves an individual identifying “his or her needs” and presenting “an outline of the needs including how the needs can be met in the community (a plan) to a funding body (typically government-related)” (Lynch and Findlay 2007, 1). With the growing popularity of IF programs among people with disabilities, block-funded services — based on a rehabilitative or medical model — have been transformed in many Canadian provinces to relocate choice and control over services *from* service providers *to* people with disabilities. In this changing landscape, many organizations offering block-

funded services are adopting a multi-dimensional model of support. Instead of individuals having to fit existing services, they tailor support and services to fit their needs. Despite these advances in thinking, a persistent problem for persons living with disabilities is that eligibility rules and determinations of access to supports are still based on the medical model (Dozar et al. 2012).

In Saskatchewan, the main method of service delivery for individuals with intellectual disabilities remains traditional block funding (Appendix A), a contractual relationship between government and service providers. This funding structure provides adult residency within a government-run and funded group home, and access to day programs that include support and services provided by trained support staff. Lord and Hutchison (2003) found that “although a traditional agency controlled approach works for some people, many people are required to ‘fit’ their lives around agency procedures and programs” (2). This argument is supported by Benjamin (2001), who found that “critics of the agency model argue that service decisions are based primarily on the interests of the agency, rather than those of the consumer” (4). As a result of these perceived limitations of block funding, there have been in Saskatchewan a few special cases where individual families have negotiated with the provincial government self-directed funding (SDF) arrangements called self-managed contracts (Appendix B) where government funds a person-centred plan developed to meet individual needs and goals. Self-managed contracts are defined as agreements “where consumers receive funds from the government or from an agency which is government funded, to purchase home and community care services” (Spalding, Watkins, and Williams 2006, 5). Administered through self-managed contracts between the individual and/or their network and the Ministry of Social Services, Community Living Service Delivery (CLSD), Government of Saskatchewan, these contracts provide direct payment funding for the individuals to develop their own care plan and purchase services to meet their goals. In many of the existing self-managed contracts, individuals rely on their families and support network to help implement and run their self-managed contracts. The administration is often handled in a cooperative manner among the individual’s family members, the Ministry of Social Services, and community and advocacy groups.

In the context of a province committed to making “our province the very best place in Canada to live for those with disabilities” (Wall 2011), this report explores self-managed contracts for individuals with developmental or intellectual disabilities, the process of developing and managing them, and their impact on the lives of those who choose to pursue this

type of funding arrangement. It includes current contracts in order to understand why some individuals and families choose to maintain their self-managed contracts while others prefer to use traditional funding structures that are in place. Its guiding purpose is to enhance understanding and to provide evidence to support decision making of individuals and families, service providers, community organizations, and government policy makers. Based on a literature review and semi-structured interviews with individuals, self-advocates, family members, service providers, the Advisory Table on Self-Directed Funding, as well as government employees involved in SDF-like arrangements, this study focuses on (a) recipients' and support group stories regarding the impact of SDF-like arrangements on their lives; (b) their understandings of how the self-managed contracts and related arrangements have helped or hindered their lives and how developing and maintaining the contract has impacted their families, caregivers, and supporters; and (c) the outcomes and impact of the SDF-like arrangements on community structures, program delivery, and policy.

The current study builds on ongoing research in which the Saskatchewan Association for Community Living (SACL) and Community-University Institute for Social Research (CUISR), University of Saskatchewan, have been partners exploring key elements of IF in the services and supports for people with intellectual disabilities. The first report, entitled *A New Vision for Saskatchewan: Changing Lives and Systems through Individualized Funding for People with Disabilities* (Lynch and Findlay 2007), explored IF models across eleven jurisdictions in Canada, the US, the UK, and Australia, and identified four IF principles:

- 1) Individuals can use informal and formal support networks to develop their plans.
- 2) Funding allows individuals to purchase supports and services.
- 3) Individuals must have control over the funds.
- 4) Funding must be portable within jurisdictions. (1)

It studied how programs based on this funding model are implemented, how long those programs have been offered, the extent to which they are used, and their benefits and disadvantages. Focusing on “availability, usage of support networks, involvement of an agent, role of the support broker, funding levels, method of payment, and portability” (1), the study analyzed the value of various IF program practices in upholding the principles of self-determination and community inclusion for people with intellectual disabilities. Thus, the first report provided a baseline to understand the main concepts of IF programs across jurisdictions. Benefits include increased individual control and autonomy, higher quality of life, and fuller participation in society. The recommendations for transforming Saskatchewan's

disability support system included creating an individualized funding program for people with intellectual disabilities that is portable, flexible, and attached to the individual.

The second study, entitled *Exploring Key Informants' Experiences with Self-Directed Funding* (Chopin and Findlay 2010), was based on a literature review of SDF programs in Canada, California, the United Kingdom, and Australia and interviews with key informants who were service providers, Associations for Community Living representatives, government representatives, and consultants. The key findings of the second report related to “program design and accountability measures, labour market and staffing issues, funding sustainability, client equity, outcomes and challenges, and innovation” (Chopin and Findlay 2010, 2–3). This report focused on the variability and viability of SDF within Canada, providing comparisons on a provincial level and identifying suggestions for future examination, including separating funding decisions from planning to avoid conflicts between staff and families; balancing accountability and individual control over funding while being accountable to the public purse; reducing reporting complexity; ensuring support in planning and implementing; alleviating staffing difficulties; communicating SDF sustainability to policy and decision makers; funding people on an individualized basis to enable them to secure the services and supports they need; and assessing the extent to which self-advocates agree with the challenges and strengths identified by the literature and key informants.

The current report aims to supplement these findings and follow up on these recommendations for future examination by evaluating the impact of self-managed contracts and learning from the experiences of those persons with developmental disabilities and their families using them in the province of Saskatchewan. This report explores perceptions of quality of life before obtaining a contract, the process to establish a contract with the government, and changes experienced after implementation of the contract. In this report, the terms self-directed funding, SDF arrangements, individualized funding, and self-managed contracts will be used interchangeably.

LITERATURE REVIEW

THERE IS A GROWING BODY OF LITERATURE on self-managed contracts widely implemented in the United Kingdom, Australia, and parts of the United States. In Canada, there are a few provinces, such as British Columbia, Alberta, Manitoba, Ontario, New Brunswick, and Prince Edward Island, which offer self-

directed funding arrangements (Chopin and Findlay 2010; Dozar et al. 2012). These SDF programs differ in many factors such as funding levels and uses, frequency of budget revision, organization, support, reporting, design, and delivery (Chopin and Findlay 2010).

A common drawback identified in funding models is the level of support available to families. In their study of four group homes in the state of Victoria, Australia, Clement and Bigby (2010) agree that failure exists in the handling of government-run facilities — particularly the ways that organizational, personnel, and infrastructure limitations hinder goals — and further, that “processes that foster community presence are stronger than those leading to community participation, which helps, in part, to explain why the social exclusion of people with intellectual disability remains an enduring social problem” (159). In other words, presence in the community does not equal meaningful participation in it. Also in the Australian context, Fisher et al. (2010) studied the diversity of individual funding approaches and the related supports they require, finding that overall they do not increase cost to government and do enhance wellbeing, control, and choice, although the capacity to exercise choice is limited for those with “significant cognitive disabilities” (vi). Without the appropriate supports, meaningful choice may remain elusive. Ottmann, Laragy, and Damonze (2009) assessed the potential and limits of a participatory methodology for user engagement in decision making at the lengthy policy and program design phase. Decisive in the early success was the mediating, supportive, community-building role of a project officer; the officer’s loss ended the process.

Like Carr and Robbins (2009) and Fisher et al. (2010), Cook, Terrell, and Jonikas (2004) found that individuals with disabilities suffered “minimal self-determination given society’s failure to provide them with adequate recovery-oriented services or choices in how to use available services” (2). Carr and Robbins (2009) take an even-handed approach to individual budgets or direct payments in the UK, pointing to “emerging international evidence that self-directed care can lead to health gains and consequent efficiency gains” (1) and to shifts to prevention reducing costly interventions. They also stress further research needs in the face of small samples and short-term views and ongoing challenges in balancing organizational and individual interests, increasing equity, and providing supports that will maximize the advantages.

Responding to the need for further research, Laragy and Ottmann (2011) proposed a framework to address implementation difficulties causing stress for those adapting to new processes whether in the UK, US, Canada, or Australia. Based on a four-year study (2003–

2007) of data from individual funding programs in an Australian non-profit agency, they found the following key factors in successful implementation: meaningful engagement in decisions of people with disabilities; accessible information and relevant supports; appropriate activities; familiarity with policies and procedures; accountability mechanisms; protections for labour conditions; and supports for management and staff. In addition to increased control and satisfaction, families reported that “their self-esteem was enhanced because they did not have to continually seek approval from a case manager” and, as one parent put it, they can “set priorities and be responsive to changing circumstances” and “know how much money [they] have and what [they] can spend until the end of the year” (22).

Like the majority of anecdotal evidence, the research literature shows positive outcomes from self-managed contracts (Dawson 2000; Foster et al. 2004; Glasby and Littlechild 2002; Haggland et al. 2004; Laragy and Ottman 2011; Wigham et al. 2008). A two-year evaluation of direct payment schemes in Wales by Stainton and Boyce (2004) confirms the range of positive benefits including increased lifestyle flexibility and engagement, the right to choose staff, and increased self-confidence associated with the “sensitivity and empathy of the service provided by ILS [Independent Living Scheme] staff” compared with “negative experiences with conventional care providers” and Social Services staff (446–47). When Ohio announced its Self-Empowered Life Funding in 2011, it was freedom and control, “the power to hire and to fire,” and an end to “this culture of suppression and segregation, all with the thought that this is what’s best for people” that was welcomed by self-advocates and supporters (Price 2011). Similarly, Lord and Hutchison (2008) found that self-managed contracts “increased self-determined choices, purposeful activities, strong social networks, and community participation” (50). Mansell and Beadle-Brown (2009) also found positive outcomes in both anecdotal review and in their study. A quantitative study conducted by Wehmeyer and Bolding (2001) compared test scores from the Autonomous Functioning Checklist and the Arc’s Self-Determination Scale using a paired sample t-test comparing before and after scores and showed positive gains from increased community integration (Appendix C): “After moving from a work or living environment that was more restrictive to one which was community-based and less restrictive, research participants showed gains in self-determination and autonomous functioning, and reported that they had more choice and opportunities” (Wehmeyer and Bolding 2001, 379). Caldwell (2006) added to the literature by showing the economic, health, and social benefits for family caregivers and the particular health benefits to lower income families; in particular, he found that individuals with

self-directed contracts experienced “fewer out-of-pocket disability expenses, greater access to health care, engagement in more social activities, and greater leisure satisfaction” (405).

A longtime leader in individualized funding, Victoria, Australia, confirmed the range of “life-changing” benefits, including empowerment, dignity, and independence, while its Auditor-General recommended ways to increase equity, simplify the process, clarify policy and guidelines, enhance resources, training, and monitoring, adapt information systems, develop a “customer-focused culture,” and reduce wait times (an average of 1.45 years) in a situation where demand outpaces supply (Victoria 2011, viii). Comprehensive audits of the direct payments found no fund misuse; only one case of misuse has been identified since 2006 (Victoria 2011).

In addition to reported quality of life improvements, an evaluation of Manitoba’s “In the Company of Friends” pilot project found it to be 8.3 percent less expensive for twelve of the fifteen participants (cited in Lord, Zupko, and Hutchison 2000). Despite regional differences, similar findings were confirmed in New Brunswick and US individualized programs; still, Chopin and Findlay (2010) found ongoing concerns among government informants about sustainability, although many confirmed that in the long term individualized funding can be more cost-effective than block funding.

A study by Stainton, Boyce, and Phillips (2009) of a Welsh Independent Living Support scheme detailed actual cost and resource implications of direct payments and compared them with those for traditional services to assist decision makers in “estimating real and relative costs” associated with direct payments. The study built on earlier literature including a range of claims about cost:

- 30–40 percent cost savings (Zarb and Nadash 1994)
- “value for money” (Taylor, cited in Glasby and Littlechild 2002)
- UK direct payment schemes must be “at least as cost effective” as other service arrangements (Department of Health, cited in Glasby and Littlechild 2002).
- cheaper for learning disability, costlier for “physical and sensory disability,” and “mixed for older people” (Davey et al. 2007, 33–34)

Acknowledging the multiple variables and difficulties of identifying all costs in different implementation schemes and making comparisons across different systems, the Stainton, Boyce, and Phillips (2009) study nevertheless found that direct payments were cheaper than traditional service delivery and “relatively cost neutral” compared with “independent sector

provision” (161). User creativity and flexibility was an important source of savings as was monthly as opposed to weekly payments. Direct payments also offered both significantly improved client satisfaction and greater cost-benefit savings that could be even greater if direct payments were more thoroughly integrated into policy and procedures (Dawson 2000).

In its administrative review of the Persons with Developmental Disabilities (PDD) Program and October 2010 summary report to the Alberta Ministry of Seniors and Community Supports, the independent auditing firm KPMG found that the program supporting 9,300 adults was a “good program” associated with innovation and offering “positive outcomes,” but that it represented unusually high administrative costs compared with other jurisdictions: \$142 million of a total budget of \$592 million. While other Alberta programs spent \$24 on administration to every \$100 of support costs, the PDD program spent \$31 to every \$100; other jurisdictions spent between \$6 and \$20 on administration for every \$100 of support (KPMG 2010, 6). While the number of people involved and delivery mechanisms explained some of the high administrative cost, it was also attributable to “the duplication of efforts and the lack of efficient processes” (2), a situation in which there is not even “consistent messaging” adding to “confusion, frustration, and often mistrust” (13). Although currently only 10 percent use the option, the family-managed option (as opposed to the service provider network and [most expensive] direct operations) proved to be the most flexible and supportive and also the least expensive at \$500 per individual per year (12). What KPMG found was a system mandated “to help individuals with developmental disabilities live as independently as possible in the community,” but that focused disproportionately on “monitoring the financial management of dollars” (13), thereby aggravating mistrust, inequities, and inefficiencies. Convinced that what was needed was “a better way to reduce the financial administration, promote best practices and improve assessment of client outcomes” (13), the summary report made several recommendations on administrative changes — including “a new organization model, a new governance approach and a more efficient network of service providers” — to make savings while maintaining fundamentals such as relationships and community engagement, keeping decisions close to individuals, and promoting “equity and consistency.” The ministry accepted the following recommendations for a citizen-centred and integrated system:

- Establish an organizational model for provincial program delivery: common roles and responsibilities across regions for community engagement/ consistent application of policy and service delivery.

- Clarify and enhance contracting processes with service providers: establish new process with clearly defined performance measures and administrative costs, and where possible, one service provider (though accepted, stakeholder consultations were to follow in June on a new process).
- Improve access and support for Family Managed Services: PDD-funded payroll service providers, tools and templates to assist family-managed administration with hiring, performance appraisals, staff monitoring.
- Improve IT systems for integrated case management.

The recommendation to dissolve the six boards and establish an advisory panel to reduce duplication/inconsistency was rejected as potentially overly disruptive to individuals. Bruce Uditsky, chief executive of the Alberta Association for Community Living, supported retention of the boards: “If you don’t have any community authority to address government, you have, basically, an unfettered bureaucracy.... You could have more efficient community governance, but I wouldn’t want to see no community authority or ability to address the bureaucracy” (cited in Myers 2011).

In the context of neoliberal political and economic thinking emphasizing individual freedoms, private property, and free markets and resulting in decreased funding supports worldwide and increased offloading onto families, Hendren (2011) reviews services for people with developmental disabilities. Hendren explores claims and counterclaims about IF, arguing that the rhetoric around IF is not matched by the empirical evidence. She concludes that “the major challenge of increasing service demand and decreasing funding has never been fully articulated or overcome” (7). Hendren concludes with a powerful plea to recognize some of the contradictions of neoliberal cautions about “a moral hazard” in helping families dealing with developmental disabilities for which they bear no responsibility “because it will prevent them from learning from their behaviours and improving themselves,” while not similarly targeting “multi-national banks and American car companies during the global financial crisis” (21). Hendren also unpacks unsupported neoliberal discourse around “personal responsibility,” “community care,” and “choice,” urging people to get beyond the jargon and navigate better both the “old” system and the “new world order” in the interests of “the dignity of people with disabilities” (22).

The Australian Government Productivity Commission (2011) responded to a call for change with a report on a system that is “underfunded, unfair, fragmented, and inefficient. It gives people with a disability little choice, no certainty of access to appropriate supports

and little scope to participate in the community.... [It is] a system marked by invisible deprivation and lost opportunities.” In its place, the commission proposed “a properly funded and managed long-term disability scheme” and concluded that such a national scheme is “feasible, that it would produce very large benefits for Australians and that a realistic and clear implementation pathway is available” (3). To that end, it made eighty-six recommendations with an increased annual investment of \$6.5 billion related to a main National Disability Insurance Scheme and a secondary National Injury Insurance Scheme “that would provide lifetime support for people acquiring a catastrophic injury from an accident” based on evidence gleaned over twenty-three days, from twelve hundred submissions, and presented in over twelve hundred pages of the two-volume report. The commission concludes that the national scheme “would only have to produce an annual gain of \$3,800 per participant to meet a cost-benefit test. Given the scope of the benefits, that test would be passed easily.... Commission estimates suggest benefits of around \$7.8 billion annually (and this already takes account of the lost consumption for those people funding the scheme). This is likely to significantly understate the benefits” (12).

In order to address ongoing concerns about cost and sustainability, Stainton, Asgarova, and Feduck (2013) completed a statistical analysis of cost and usage of programs involving five service delivery models of individualized and traditional funding options offered by Community Living British Columbia (CLBC). Their study confirmed that IF modes of delivery support almost all service delivery at a cost lower or equal to block funding. It found that the two core IF funding models (host agency funding where funding is channeled through an agency of the individual’s choice and direct funding) cost less than the block-funded contracts in all areas except community-based supports and employment. Funding by micro-board contracts proved more costly than traditional models (and other IF options) because of high cost contracts entailing a high standard deviation in data, although they may be good value if social capital, network support, and support for those with complex needs are taken into account. The study also explored demographic variables: most users were male (54.6 percent); users ranged in age from nineteen to eighty-three years; 76.8 percent were between nineteen and thirty years of age (only 0.6 percent were over sixty-one); average funding per client was \$3,633.50 (minimum of \$180.00 and maximum of \$44,842.80); Kootenay had the lowest mean cost of \$3,143.10 and Upper Fraser the highest (\$4,258.56).

Faced with family, community organizations, and public pressure in the wake of changing expectations, closure of sixty-five staffed residential living facilities or group homes, demand exceeding funding, and some mishandled situations where families felt cost trumped

a child's interests, the provincial crown agency CLBC issued on 2 November 2011, an interim report commissioned by Minister of Social Development Stephanie Cadieux to update people on immediate and long-term changes to ensure quality support for individuals with developmental disabilities, including efforts to increase inclusion and employment strategies, to develop outcome-focused metrics, and to implement a quality of life framework developed by Dr. Robert Schalock, Hastings, College, Nebraska. The report promised "thorough consultation and inclusive decision making" in its efforts to find savings through lower-cost alternatives and "a sustainable model of supports and services" promoting "good lives in welcoming communities" combined with accountability to tax payers. It also requested "cross-ministry discussions" and advice on service requests from new as well as current individuals registered with CLBC (3–4). A Client Support Team including representation from CLBC and four ministries (Social Development, Children and Family Development, Health, and Education) was established to manage concerns from individuals and families. In a 17 November 2011 press release, the BC Association for Community Living (BCACL) expressed its displeasure with Minister Cadieux's suggestion that sixty-three complaints to the Client Support Team meant that the crisis was "not maybe as large as some would like us to believe." According to BCACL, the comments reflected "the government's unwillingness to acknowledge serious systemic failures within CLBC." On 19 January 2012, Premier Christy Clark and Minister Cadieux announced a comprehensive plan and a cross-ministry team to work with CLBC on implementation: increasing families' role, enhancing planning and collaboration, adding support flexibility, and committing \$40 million additional funding to address CLBC issues and supports for British Columbians with developmental disabilities (Government of BC 2012).

METHODOLOGY

IN ADDITION TO THE LITERATURE REVIEW, the method used to collect data was semi-structured interviews, which Hodges and Videto (2011) found "especially useful with populations that have language difficulties" (83). Semi-structured interviews allow the interviewer to further explore details and clarify responses given by the participants, probing more deeply and developing "an understanding of situations, beliefs, reasons for actions and the like" (Hodges and Videto 2011, 64). Participants interviewed for this study included recipients of self-managed contracts, the parents/guardians, caregivers and supporters of the recipients, service providers, as well as government officials

involved in the creation and administration of the contracts. All participants were over nineteen years old. For those with communication barriers or needing help in processing information, their supporter attended the meeting.

The rationale for participant selection is two-fold: 1) The study reviews SDF in relation to (a) the unmet needs of the recipients and (b) new ways to meet needs that are already being met. 2) The recipients are in the best position to speak to the impacts of access to self-managed contracts. According to the literature, SDF enables community development and increases social inclusion. Adopting SDF plans may affect existing supporters of people with disabilities and government programming and policy. As such, it is prudent that those who have been impacted are interviewed to gather information on the outcomes of the collaborative approach to SDF models in Saskatchewan.

Researchers drafted an invitation letter outlining the project's purpose and method for data collection and dissemination to those who currently use or have used self-directed funding arrangements. Using the invitation letter and consent form, the Community Living Service Delivery (CLSD) of the provincial government contacted (via regular mail or electronically) current or past recipients of self-managed contracts and their family members (who forwarded or shared invitation letters with supporters and service workers). The CLSD also included a letter detailing the reason for contacting the individual. Once the invitation was received, the recipients had the opportunity to contact CUISR directly (CUISR's contact information was included on the letter of invitation) if they wished to participate in the research project. The CLSD also contacted government employees by invitation letter. This protocol allowed those who used the program but did not want to participate in the study to maintain their confidentiality and anonymity. Once the packages were reviewed, individuals were able to arrange interviews where and when suited them.

Participants were given unlimited opportunity to ask the researchers questions pertaining to the research project. The support person was able to review the letter of invitation and consent form with the participant and sign to signal that, to the best of his/her knowledge, the participant understood the proposed research and freely consented to participate. Before the individual interviews, participants were reminded of their right to discontinue the interview at any time (without any penalty), to stop the recording at any time, and/or refuse to answer any questions. They were also reminded of the potential risks and benefits as well as the efforts in place to protect their anonymity and confidentiality. Participants also had the opportunity to review the final transcript and make any changes they wished.

Most of the interviews (see Appendix D for number of participants) used the face-to-face technique, which allowed the interviewers also to observe non-verbal cues, and were conducted in participants' homes, offices, or in a neutral location, dependent upon participant choice. There were a few exceptions to the face-to-face interviews; in cases where distance and time constraints impacted participation, telephone interviews were conducted. The interviews were recorded when consent was given. The interviews were later transcribed into text and analyzed for overarching themes and experiences with block funding programs and self-managed contracts. For the conversation guides used for the semi-structured interviews, see Appendix E.

Interviewees were informed that for reporting purposes pseudonyms would be used to provide confidentiality and identifiers (names, places, etc.) would be omitted from transcriptions to ensure anonymity of responses. While maintaining confidentiality is a standard in research, it was found in the interview process that some participants expressed hesitation to participate and share their experiences fully in the study because of fear of repercussions in the form of discontinued funding. This required interviewers to reassure participants that their identities would be fully protected. Participants found solace in reassurances regarding risks and benefits provided in the consent forms.

FINDINGS AND DISCUSSION

ANALYSIS OF THE INTERVIEWS showed overarching themes within the experiences of individuals and family members that used self-managed funding. Participants were interviewed in regards to their experiences before and after their self-managed contracts and how the contracts had impacted their lives. Findings are presented here in three sections: experiences prior to self-managed contracts, process of obtaining a contract, and experience with self-directed funding arrangements followed by discussion of some key themes and issues.

Experiences before Self-Managed Contracts

All the participants reported that the level of satisfaction with services received prior to obtaining a self-managed contract was poor. Confirming research literature findings,

respondents named issues such as lack of adequate supports, limited services offered, and concerns regarding safety and long-term stability at government-run group homes: “Our child’s physical, financial, social needs were not being met” and “My son’s lifestyle was very isolated because home care was not allowed to take him outside the home into the community under their mandate; his social environment was very poor.” Another parent commented, “Actual services around here — not so much. Unless we paid, we didn’t really use or get services. What we wanted, we paid for because once they reach school age, they think the schools will cover speech and language.... His needs were being met because we put so much into it.” Others offered, “My child wouldn’t have survived” and “You feel like you are in jail because you can’t do things.”

Stress on the family unit prior to obtaining a self-managed contract was widely reported: “We felt in way over our heads ... things were quite messy financially to get resources for any kind of help” and “We’re as a family stressed on trying to keep things going with our special needs child and our other children and just keep it together.” Other parents reported, “We were running hard trying to do everything and worried about the future” and “[the family] were together 24/7 and, to be very honest, not liking one another very much as time went on.” Another reflected on the impact on their “younger son. We spent so much time meeting the one son’s needs that we may have missed something.” For another, it was “very stressful. My son’s behaviours became scary. We walked on eggshells.” Multiple participants discussed the “overwhelming” stress from managing a full-time job, a family, and their child’s full-time care where the only services available consisted of respite services, which provided funds to arrange care for a limited number of hours on a couple of days per week. One family member reported receiving respite services limited to “\$30.00/month” and then elaborated that “all the help is income based. I wonder why I work. The cost of support care is quite expensive. After the cost of care, I work for almost nothing.”

Many participants in the study that have experienced the block funding and group home structure prior to establishing their self-managed contract found that the current structures were unstable. Group home agencies, funding, and structural changes meant shuffling individuals from one residential setting to another. One participant pointed to the stresses and family breakups related to decisions the system entails when the child turns twenty-one: “If you want support for your son or daughter, you say, ‘take them.’ ... They did it not because they necessarily wanted to but because that is what the system wanted them to do.” One family’s child ended up in a group home. The family stayed together but the father “would

never visit her. He couldn't deal with it, couldn't physically deal with it." Many participants expressed concerns over safety and explained that changes in living arrangements, support care workers, and social support networks caused increases in behavioural problems: "All that change, it affects them, the behaviours go up, the problems go up," said one. Another emphasized that when the block funding structures break down, it leaves individuals with disabilities to deal with shuffling between group homes and having to adjust to new settings: "As a parent, when crap hits the fan, it doesn't matter if your child is in a group home or self-directed. Our kids all end up back on our doorstep... At least when stuff would break down with my child, [he/she] didn't lose [his/her] home. That kind of change for anybody with developmental disabilities is devastating." Another mentioned, "I know there are parents with a real sense of commitment around group homes too. But there are group homes where your child gets kicked out because of behavioural issues. So the government has one in Moose Jaw for people with complex needs. Nobody can get kicked out." Still, the prospect of certainty, stability, privacy, and dignity motivated one parent's decision to negotiate a contract: "I want to find a home where my daughter can live when she is twenty-one where, if I want to visit her; I only have to ask her. I don't have to ask a board; I don't have to ask a staff person."

Process of Obtaining Self-Managed Contracts

This topic brought varied results among participants. Some found the process of obtaining a self-managed contract to be strenuous but their educational and employment backgrounds eased some aspects of proposal writing, while others who had less knowledge and experience in the area of business administration and proposal writing had a more difficult time. Overall, most participants stated that the process took "years" and prolonged uncertainties to secure a contract. One parent pointed out that you have to allow years "if your child is to get a place when she is twenty-one." And in the family's case it even took a year to find out that the government wouldn't fund equipment. The family was told that "the government can't pay for everything. You don't tell a parent that. We know that already because we pay a lot on our own."

The government employees interviewed described the process as a negotiation; however, respondents disagreed. One participant stated, "We took what was there. I don't remember being given a choice; we weren't really given a choice." In the case of one family, when they

“could afford the down payment on a house for their child and a roommate, [they] were not approved for a self-managed contract. When housing prices went up, then [they] were offered a contract but could no longer find anything decent [they] could afford so the child is in the home setting.” The parent added, “I’m not sure there would even be enough for rent anymore because rentals have gone up so much and he couldn’t access subsidized housing because he is single and subsidized housing is for families or children. So you live in squalor or you don’t live at all.” Another person talked about seeing “too many families going through hell. They have an ideal and they keep having to notch down and they have to settle for a lot less than they wanted. One family chose to move closer to family [from individualized funding in another province].... The individual has nothing and still lives with the parents, who are in their late seventies now. People get worn down; they can’t fight anymore.”

Participants voiced their concern that the process elicits emotions of “anxiety,” “stress,” and “uncertainty” and that there were “a lot of unknowns” and inequities. The biggest barrier that many faced was knowledge. Several remarked that they “didn’t even know such a thing as a self-managed contract existed.” One family member talked about departments needing to talk to one another and be “flexible and work together to figure things out and not just say that [they] don’t know what another department will say.” The result is that “a lot of programs are hidden. Sometimes you learn only from parents really late. The more people ask for a program, the less chances you have to access the money they have. That’s not fair to learn by chance.” The same family member reflected on access to information being so carefully guarded that inquiries can lead to what feels like accusations and inquisitions: “If you call and ask the office, they ask you how you found out about it. They don’t tell you about it. It shouldn’t happen that way.” Another person commented, “It’s like a well-kept secret when people do get funding. Lots of territorialism and not enough transparency ... and too many people in this field seeing themselves as rescuers of victims.” Access and equity proved a special issue to those living outside Regina. Regina residents, by contrast, could “talk with families [with self-managed contracts] and watch them over the years and see what has happened. There is no other place you can do that in the province. That’s a huge barrier.” Others reflected on the barrier of small town or rural settings: “So should we move to a bigger city? Everything costs more in the city so you might need another job. So you feel stuck.”

Respondents reported ambiguity in the application process, saying that “nothing was clear cut.” All participants agreed that there was little to no support from the government in

building the proposal or contract. One government official conceded, “We don’t advertise that [SDF] at all. It’s basically people arguing very strongly before they get it.... What has happened has happened because of strong advocacy from individuals and families and perhaps community-based organizations.” According to one family, “It’s something we shouldn’t have to do; the option should be there. We as a family are already stressed and trying to keep things going.... We are stressed enough with daily needs.” The result of all the meetings, letters, and phone calls, the waiting and the worry, was that they felt as if their “whole life” was “taken up trying to get supports along with other needs.” Again confirming literature findings, participants who had gaps in knowledge found support through community living associations and other community-based organizations which provided both support and services. One family reported “without community supports, we’d be lost.”

If advocacy has been an important source of change, a number of respondents still talked about the difficulties of getting their voices heard. Two participants shared their experience: “We didn’t hear about it. We went out and sought it out.” In order to get their child a self-managed contract, they “phoned and phoned; begged and begged; and wrote and wrote. It moved up until ‘someone’ listened.” Like other families, “they were driven. This is the only thing that will work and it has to work. I think that’s why they have been really successful.”

But others can be driven but decide “in the end it [SDF] is not something they should have chosen. They would have chosen differently if they had known and the contract did collapse.... They liked the idea, but until you do it, it’s hard. This is constant; it’s every moment. And they found other people in their lives too much.” Yet another voiced the concern that too little happened until there was a crisis: “It [a contract] usually happens with some crisis situation and then they say, ‘Well, we can make this work’ instead of ... being proactive in saying, ‘We can keep the individual in the community in the family home if that is what they want.’” Whatever the situation, one person argued that “telling the story to more families will make a difference, not just in the supply side but also in the demand side with families.”

A major barrier to getting heard, according to one respondent, is that “service providers in this province have a loud voice. They are heard. If they are speaking out against this idea, they have a louder voice than families because families tend to be disconnected from one another.... When you take ninety service providers talking to their MLAs and saying this is not a good thing, that’s a louder voice than the number of families and families are very reluctant to talk to MLAs on their own.” This barrier is aggravated in the situation where

politicians have photo opportunities related to traditional services: “They are there for ribbon cutting for a new SARCAN depot and sod turning for a new group home. They get publicity for that. There is no photo op for IF.”

Other families talked about the importance of being in the right place at the right time to get their wishes heard and choices respected. One family found they “couldn’t get in the door to meet the minister.” Opportunity came at a conference where the minister spoke. In question period, the family “asked if he was willing to meet with parents who wanted to look at different options and he said, ‘yes, he would,’ and we kind of jumped the bureaucracy.” “The tipping point” for others “was a meeting ... of families with folks at the funding level and they understood at that point that it wasn’t families trying to create a group home for one person; it was families trying to create a place for their son.... Social Services understood that this was a way of helping families and not just a way of getting around something else.” The key when dealing with people who were closer to the decision making was “helping them understand that this [SDF] is not really different from a group home. We are doing essentially the same structure. They may be family members and not some of the registered things, but it’s ... not that different except that it is for one individual.” Yet others found the right people who were open and flexible:

You have to pick your battles and you have to be realistic. Some things aren’t going to change right now. So how do you work around it or work with the system? You are not going to change the bigger picture today if you are in crisis or in care. But you can edge toward that. We lucked in to have individuals within Community Living Division who really did think outside the box and they were challenged and it was exciting to see them open up that door for us and our family. But some are not going to change anything. They are doing their job and they are not going to have any kerfuffles. We were very fortunate how everything lined up and the minister was a man of his word.

Another recommended that the biggest thing for parents is “not to be confrontational” or see “government as their nemesis. You have to change that mindset. You have to sell to them that this is a good option too.... You definitely have to understand the mechanics of bureaucracy and you won’t get your foot in the door if you are confrontational.” One self-advocate by contrast stressed the struggle among parents, self-advocates, and government people and warned that the government seems to think that “IF is taking away another pro-

gram which it's not; it's just another option." Yet another respondent emphasized "personal understanding" as the means to open eyes and doors. SACL's "Adopt-an-MLA" program invites MLAs into the home so that "MLAs can see what the family is dealing with. [Then] Justice Minister Don Morgan said it let him see what shoes they are wearing if not to walk in their shoes. We see changes through personal connection. We have seen amazing stuff and seen some changes because MLAs suddenly have a personal connection."

A major area of "stress" expressed by family members was related to the concept of competencies and how individuals felt undermined in their competencies in the ways that officials handled the application process. The stated goal of government officials was to ensure that the families taking on self-managed contracts understand the responsibilities that come with the independent management of those contracts, with the stresses that accompany financial bookwork, accountability of funds and acting as an employer for their family member's support staff. One government official was concerned that families "know what they are getting into. Do they know they'll be the ones writing the policy, doing the hiring and firing, the training and cutting the cheques?" But one participant suggested that the biggest issue was "getting people to think that it could be done this way, that you didn't need an agency, that a family was capable of doing this.... Some figured that if you give these folks the money they'll just spend it on something silly, that people weren't going to be able to manage it."

Despite government officials' well-meaning efforts, many of the families were offended because they felt that their knowledge and competencies were put in question. Many, in fact, had management backgrounds and experience of accounting and annual reports and did not take kindly to assumptions about their lack of competence. Families expected more sensitivity in the handling of these relationships. One parent summed up the feeling: "One of the things that I really felt was the way they looked at us, and you know you just give your head a shake. Are we competent enough to do this? What do you call competent? Let's look at competent; let's look at what is happening in some of the group homes and you guys just put blinders on." For one family, the bookwork "was the least of our concerns. We wanted to start to create a life for our child outside the home he had grown up in." By the time the parents left the meeting with government officials, they knew their roles and responsibilities but warned about "the one thing that anyone contemplating a self-managed contract has to understand":

It isn't a walk in the park and it's not for the faint of heart. You have probably as much responsibility in some ways as when your child was at home, but it's different. It gives us the opportunity to allow our child to experience a bigger world and it allows us as parents a chance to live more normal lives and not be total caregivers of our sons and daughters.

The families who were denied on their initial application had the opportunity to appeal. That the process involved the same people who made the decision in the first place added to their sense of intimidation and fear, to the emotional dynamics, and to suspicion of government. Participants reported worrying about "what are they going to change?" Participants reported the same instability during a renewal process that entailed substantial amounts of paperwork. They reported "worry and stress about what we are going to do." In other words, a process designed to enhance people's sense of control and choice, independence and self-determination, ended up reinforcing the sense of uncertainty and hopelessness it was designed to address.

Experiences with Self-Managed Contracts

Study participants agreed that self-managed contracts allow individuals to be empowered and play a more active role in their daily care needs. Contracts provide the flexibility and choice for persons with disabilities and their families to personally select support staff, arrange appropriate accommodations, and select daily activities that best suit the interest, needs, and goals of the individual. For one self-advocate, the strength of the contract was that "you can manage your resources and have the supports you want. If you don't like them, you have the option to change them." Another said, "I like my freedom. In a group home, you don't get that. I like being my own boss." Another has learned life skills, enjoys a range of activities, and even attended university and convocated with the other students who, their professor said, "get more than they give the student with disabilities." Yet another worked out at the gym and went to university: "I do physical exercise once a week to try and strengthen myself and I get to go to university." "Campus for All is heaven-sent," added a family member. "He went for orientation in the fall and really enjoyed it and now he is taking classes this semester. He found Cosmopolitan extremely boring. Though good for some, it was not a program for him." Independence and an enlarged network were the contract strengths for one family: "We don't have total responsibility for one another. He has people in his life." Another respondent stressed:

You have to have some experience of group homes and what other options there are. [The self-advocate] has her own home. And her life is in many respects like yours or mine. There's lots she can't do but she lives with people who are there and committed to her.... Her support network has grown to ten to fifteen people — mostly young people her own age. The promise of having someone there to take care of her when parents are no longer there is becoming a reality. One of the women, her former roommate who has stuck with her all these years, will become her guardian.... People make a different commitment. They have made long-term commitments to folks not for the money but to the individual.

Although the self-managed contracts “relieve some of the financial stress,” many stressed that the level of funding is “inadequate” but crucial to quality of life. One pointed to a service that was not funded by the government, so the physiotherapist “didn't dare tell of the possibility when there is no money because it creates a need and they are stuck.” But the family would have preferred to know and pay for the service. Another family explained that you have to be comfortable with people coming and going in your home at all times and with a child's raised expectations: “Now he wants someone to entertain him. Still, the alternative wasn't always good because he'd leave and take off. Trust me, when you have to go out at eleven o'clock at night to look for him, it's not a lot of fun.” Another still contributed nineteen hours a day and augmented financially: “He's not covered for activity, just the support worker, so we have to cover the rest.” As result, the family “has accomplished lots.” Their child “is a teacher for all the people in the community” and he volunteers and “feels good.” Despite the gaps, the contract means the family quality of life is “way better”:

If it got cut off tomorrow, it would be miserable around here. I don't know what we'd do. For our child there is no other option. He wouldn't last in a structured program.... People spend years and years trying to find out what works for an individual and we have found it. We know what works for him and what will set him off and set him back. It would be awful, awful, awful if he were cut off.

The family member added, “We know best. I didn't always believe it. Society tells us teachers, doctors, and professionals know. I think parents know.” Another family confirmed, “Our son is happy and content and life is much, much easier for us. He has choice. His home is his safety net. He doesn't have to stick to the time sheet activity schedule. He can choose to come home after five minutes.”

In the interviews, all the participants included the following potential barriers to the administration of self-managed contracts: time commitment, management skills, contract development, program development, and staff retention. According to one government representative, there were different models of self-managed projects with some family-run, one with responsibilities shared with a community-based organization, and one with a microboard. The majority of participants reported having the necessary competencies and educational training to be able to handle the bookwork and administration associated with running an independent contract. In one case, occupational health and safety experience helped in designing and drafting the policy manual so necessary to making family and staff accountable: "Put it in writing," said one family. "You don't want hearsay or innuendo.... You are not hiring buddies to live with your child. You are hiring paid staff." All the participants found that the time commitment involved in building and running the plan was worth the independence and choice that their family member received from the self-managed contract.

For those families looking to individualize care and options that do not have a management background, participants felt that official workshops and management training held by the government would be beneficial. According to one family member, "It would have been nice if it had been laid out for me. I had to start from scratch. No guidelines. So I made inquiries.... It would be easier if they gave you a list of things you had to do. It would be easy to do to go over the four areas you need. But I wanted it so bad that I coped." Nor would that parent have wanted a financial intermediary: "I wouldn't want the money going there; I want it all for my child's program." Participants felt that receiving training directly from the government would allow people interested in pursuing self-directed funding to obtain clear guidelines and expectations minimizing the time it takes for families to navigate through the system and maximizing efficiency at the same time. Currently, participants stated that adequate support and services were being provided by associations for community living in terms of drafting a contract proposal and building a plan to support the goals of individuals with disabilities. Many participants agreed that without the information, support and advocacy they received from the associations, their self-managed contracts would not be in place.

The participants all voiced concerns in regards to staff retention due to funding limitations and explained that staff turnover was high because of the nature of support workers' duties in relation to pay. One family reflected on how hard it is, but how much harder it will be as their child gets older and no longer "fits very well with university students. That's a

problem. You bond with people and then they are gone and you lose a good friend.... Our child is very outgoing and social and you can see that he feels what's going on." One family member felt "lucky that I have a good employer that can accommodate me" because it proves "hard to find someone to come to your place. Even if they have gone through screening, it doesn't mean that they will be good. You hear all the horror stories about mistreatment and so on. So I am really careful and go by word of mouth from people I can trust." For one family, networking produced the best staff and they "shadow and do a lot of in-house training." One respondent remarked on one student who had been a care giver for three years. Both the level of pay and the program delivery were problems: "The individual had to fit into the lifestyle and day of the care provider.... There was flexibility for the care provider. That may work in some cases, but I'm not sure that is the best option for the individual. There were behavioural issues and no supports or analysis or guidance.... In self-directed where the person is isolated one-to-one and no supervisory body, [training] may fall through the cracks."

Retaining good people was an issue: "If you find good workers they have to get paid adequately because they don't leave to work for the government. You want stability when you find a good person and you want them to have a good life too and good working conditions." The major competitor for support staff is government-run group homes that are able to offer higher pay and better ongoing staff training. Another parent talked about checks and balances that reduce concerns: "As much as I can, I choose safe people and have to trust they will support him. We have a good relationship with his support workers. It's a small world. Often people say to me, 'I saw your son downtown.' We know where he goes with the worker so we are not worried that he is being taken advantage of. Our concern about his well-being or safety is very low." Still, one parent appreciated "having a say in the self-managed contracts," but worried about "what happens when we are gone?" Despite potential barriers, respondents felt that the benefits reaped from empowerment, independence, and social networking outweighed the barriers.

Manthorpe, Moriarty, and Cornes (2011) caution that, although they often have experience managing and administering, few SDF clients have experience recruiting staff and rely on their contacts and networks. If they enjoy strong networks, they were more likely to be successful. Still, they argue that while there is "emphasis on potential for better outcomes from greater choice and control" for individuals receiving SDF, there is limited exploration of "management, and negotiations of employment relationships, particularly when family members step into paid roles" (204).

Participants reported that the activities, social events, and outings that individuals are currently engaged in would not be possible had they been in a group home. Self-advocates, SACL, and Regina and District Association for Community Living (RDACL) advisory board members and family members interviewed felt that having a self-managed contract opened doors socially. One self-advocate stressed the value of being able “just to feel you’re like any other human.” Others reported that the ability to go out allowed persons with disabilities to see and interact with new people on almost a daily basis compared to what they felt could be a socially isolating daily routine in a group home with the same people. Many participants found that even as support staff left to pursue other career opportunities, it was not uncommon that many remained a part of the families’ lives socially. One family reported arranging a Christmas get together every year where previous staff and the family celebrate the holiday season together. Another person concluded:

It’s not about employment but about relationship and network building. It’s not difficult to imagine self-managed contracts ending up looking like the rest of the stuff that we do. If you had one agency providing services and it sends a different person every day, then you have created something that’s the same as what you are trying to change. It’s not just about who controls the money, but about who controls your life and how much control you have over your life.

The government officials interviewed had a very different take on the issue. They felt self-managed contracts would be more isolating because individuals would not have the socialization and friendships normally built in a group home setting. One stressed that in group homes “they’d have access to other individuals who have disabilities, with their peers,” but also added that the benefit of a self-managed contract is that “they have a lot more contact with people their own age who don’t have disabilities,” which translates into “a lot more inclusion in the community.” Another talked about “group home flexibility to meet particular needs,” but concluded it was “a less nimble response than dealing with one individual and family at a time.” And another respondent pointed to the appeal of group homes as their “sense of lasting forever. Group homes have a board of people, sometimes you know them and they have government funding. So they have a sense of security. That’s why [IF] is not for everybody.” Mansell and Beadle-Brown (2009) compared how clustered and dispersed housing affected the quality of life, self-determination, and service provision for individuals with developmental disabilities. “Clustered” housing was defined as “village

communities, residential campuses, or clusters of houses” and “dispersed” housing referred to community living arrangements (313). The meta-analysis found that individuals with disabilities who lived in dispersed settings had better “social inclusion, interpersonal relations, material and emotional well-being” (317, table 2) compared to clustered housing accommodations (Appendix F).

Fear and Vulnerability

The participating families and self-advocates reported fear in participating and found that friends who did not participate in the study were hesitant as a result of fear and vulnerability: “People are scared that if they participate the government will take away whatever funds they have.” Another family member confirmed, “You don’t want to discuss money or funding or what you have with anybody because they might say, ‘I don’t have that.’ You’re always worried about losing it [funding].” Families reported hesitation to discuss self-managed contracts with other families due to concerns that “funding will be cut” if they are identified by government officials and at times declined to discuss specific questions because of non-disclosure clauses built into self-managed contracts that they felt prevented self-advocates, families, and community groups from sharing information and advocating for one another. Although not all contracts contain confidentiality sections and some are standard in CBO contracts (related to security of information and disclosure to support service provision), when people feel insecure and vulnerable, clauses insisting on the “obligation not to disclose information to third parties except where specifically authorized by the agreement or approved by the ministry” can have the effect of silencing even when there is an explicit option to seek permission to share information.

The fear experienced by families is not only for the security of their own funding but for others as well. One participant shared this experience: “We are afraid to discuss programs and funding with others.... If we phone to inquire, they ask ‘how did you hear about this?’ I don’t want to be responsible for someone else being cut.” Many participants felt that this was an intimidation tactic to discourage self-advocates and families from seeking out additional services. Participants also felt that the “instability” of contracts and the need to renew on a “frequent basis” kept families on edge and prevented them from voicing concerns or addressing additional needs. While participants reported contracts lasting from as little as three to six months to full-year agreements, it is possible they were referring to individual support contracts which are designed for short terms of three to six months.

One family was especially anxious about the effects of ill health and what would happen if their child moved into a home and the funding went with him: “If it didn’t work out and he wanted to come back, then we’ve lost the funding. So that’s a big concern.” Yet another feared cuts if their child was doing well. Such is the level of anxiety and stress that one participant reported fear of their child being removed from their care and placed into “protective custody.”

Others recognized fear — “fear of change” — among community-based organizations and agencies concerned that they will not receive enough funding to deliver their services if SDF were in place. One service provider stressed people’s investment in what board members and families in group home settings had achieved. Like the parents advocating for self-managed contracts, they “have strong views”:

I feel it is largely where the service has been and how it has grown that creates the fabric for how people feel. Thirty years ago this group of people struggled with their own dollars to set up the very first home for their children with disabilities. When they look at where the agency is, where the service is, the accessibility of dollars, the accessibility of infrastructure, they are just in awe at how things have changed. Sometimes they are very protective of what they have built, and they are not interested in anybody tampering with the system that they have developed.... They are definitely not interested in hearing about self-directed programs. They don’t want to try and imagine going back to where they were struggling and fighting for supports and all of that.

So no doubt agencies feel threatened, but “need to separate [their] responsibility and the fears of the parents who built the agencies.” The service provider was concerned about for-profit organizations appearing on the scene “for which there isn’t a proper monitoring system in place. I would fear that and the potential for abuse in our sector.” Recognizing some of the shared struggles, one advocate argued, “If we could just talk, we could find some common ground to begin the conversation.” According to another respondent, “The perception is a challenge. Agencies would need time to adjust to this new approach to service delivery without losing capacity and staff.”

Government

Some in government recognized that the environment has changed to the extent that they hear from people that “they don’t want the same things. When individuals

were leaving the school system, twelve years ago, the expectation was that they'd automatically move into a sheltered workshop. Now when they leave the school system, they want to be working with individuals they graduated with and living in the community." Other respondents made similar points about the changing landscape, including parents who "are more informed and technology savvy and also they can and want to be involved in the life of their child. It's no longer a stigma to have a child with a disability." So there is pressure to look for other options for individuals and think in terms of the "continuum of programs"; "families are asking for this and I think they have a right." While government had "tried to become more transparent," there was also "sectarianism in the sector itself" that remains a barrier. Another official suggested that "if it is implemented in a thoughtful way, it can increase community capacity and employment opportunities in the community." Yet another official stressed, "It's not something that a good number of people want; it's something a small number of people want."

Other officials noted increasing support for self-managed contracts within government and a record of achievement including the Saskatchewan Assured Income for Disability (SAID) program as well as such SDF-like supports as respite and the Cognitive Disability Strategy. The Day Program Funding Standard implemented on 1 April 2012 was identified as another individualized program with the potential for portability from agency to agency following the individual. Likewise, the Complex Needs Enhancements effective 1 April 2012 is based on assessed need and is individualized, although extended only into residential programs and not day programs at this point. Although not self-managed, there are also examples of residential and day programs within less restrictive community-based settings.

Others conceded a culture that continues to suspect SDF and prefer the status quo despite both anecdotal and research evidence on the SDF model as both enabling to individuals and their families and efficient and cost-effective in its use of resources. One person pointed to a "whole cultural thing" whereby "if you are receiving Saskatchewan Assistance, there is something wrong with you and you are really trying to cheat us. And we are not going to get too close to you because we know you are going to cheat us. That kind of thinking needs to change." While Community Living Service Delivery Division sees itself as "advocating for people with disabilities, those in Social Services do not see themselves as facilitating people but as keeping them off your back."

The ambiguous status of SDF was clear in reports of multiple government officials that "self-managed contracts aren't really a program. I don't know what you would call it." It is

offered as an “exception” for those who have unique circumstances and do not fit the current services [block funding]. Instead of recognizing how SDF might empower those who have been made to fit delivery models that can do them a serious disservice, one government official identified the self-advocate as the problem: “It’s [SDF] been put into place for those who don’t fit in the current services provided.”

Many of the government officials stated that they were not involved in the policy aspects of SDF and would defer to those who could “properly” speak on policy matters or would draw on what they heard anecdotally. Many of them do support SDF funding structures even if self-managed contracts are not an official program or mandated by the ministry and there is very little policy in place. One explained, “On the ministry side, the self-managed contracts are often seen as a temporary situation. It’s temporary. It’s not even clear on how to refer to self-managed contracts; it’s not really a program.” From the interviews, it became apparent that there isn’t much engagement of individuals or the community in decisions at the systems level. While officials talked about “person-centred planning,” “not putting people into programs where they don’t want to be,” and taking input from associations for community living, there was no definitive information on how that input translates into policy decisions.

When questioned about weaknesses, everyone (within the government) identified whether or not individuals or families had competencies to self-manage and whether or not government had the budgetary means of taking on and/or sustaining new contracts. There was also concern that some might be “overserved” as a result of integrating SDF. The discussion about why people chose to terminate focused on competencies and the extent to which individuals and family members found the administrative side overwhelming. In one case where a contract had been terminated, the stresses were compounded by a contract covering two individuals: “Just too many dynamics and too many things can go wrong.”

When interviewers probed the possibility of expansion, government participants stated, “It’s not something the government seems to be interested in expanding right now.” Although current legislation enables and in no way impedes the SDF option, “the biggest barrier is finding someone in government who will champion it,” according to one interviewee. It was clear, too, that there was concern that some advocates of IF made exaggerated claims for the benefits at the expense of good work done in the block-funded setting:

The argument is that IF is the only way; it respects the needs of the individual and provides support against those needs. I think that statement in and of itself

does a disservice to a lot of people that are supporting individuals with disabilities and other people with disabilities in a way that is very inclusive ... building a system that is based on individual choice, individual desires, and objectives. Comprehensive Personal Planning and Support Policy it talks about, at length, what it means to do supportive decision making. So I think that's where some advocates have to be aware of the fact that the way that they have advocated has slowed things down.

They did, however, say that there was interest to see the results of the study.

Participants within government who support the use and expansion of self-directed funding are made to feel that they cannot "create change until the legislation changes." If there is fear among self-advocates and their supports, there is also fear among government staff, who do not feel entitled to present the evidence and be part of the process of change. One person argued that "permission needs to be given for people to step outside the box." When interviewers probed with questions about what barriers existed for government in the expansion of SDF, the main issues presented were cost and accountability.

Still, there were those who felt that "politically the current government might be persuaded of this [SDF]. Their political ideology is probably more open to saying, 'Let's give it to families and let families do what families do.'" But barriers persist in the powerful agency lobby, although one participant commented, "Whether they are really afraid or not that everybody is going to run out of their group homes, that's not going to happen." The government "had moved significantly in producing a waiting list and acknowledging how many remained unsupported. That was huge," said one participant. "The government announced the separate income program for people with disabilities. They announced a four-year plan and attached dollars in the first major investment in years." Still, "opening the floodgates is a worry for government." Although one respondent thought it was an "idea that is good for everyone, not everyone has the ability to do it. If we put it in tomorrow, we wouldn't have a lot of uptake."

Cost

A repeated concern among government employees is the cost of supporting SDF programs, although family members framed costs as a mutual responsibility of family and

government. Many government officials felt that funding resources within the ministry could not sustain widespread individualized funding despite anecdotal evidence, actual cost, and cost-benefit analysis performed in other jurisdictions. Participants reported that the most common reason for a proposal being declined was “the budget wasn’t big enough to fund everyone.” But one family insisted, “We don’t expect the government to pay for everything. We never have.... It’s a co-operative thing between families and government. The funding that comes to the table is not only from government.” Families also stressed stringent reporting requirements, including quarterly and annual reports: “If you overspend, you are on the hook for that. If you underspend, government claws it back. I don’t think that is a bad thing.” Recent reviews of other jurisdictions (including British Columbia, Alberta, and the United States of America) all found self-directed funding models to be more cost-effective than traditional block funding. Reviews completed in the three jurisdictions of Alberta all found cost savings in implementing an SDF model. The October 2010 administrative review of Alberta’s Persons with Developmental Disabilities (PDD) Program found, ironically, that the largest segment of the cost wasn’t funding individuals but administrative expenses due to inefficient management on the part of the provincial government. It found that \$142 million of a \$592-million program budget was spent on administration. Hagglund et al. (2004) reviewed individualized funding models in the United States and found that “state Medicaid programs typically see cost savings when switching to a consumer-directed model” (519). Krahn et al. (2006) add that there continue to be gaps between various agencies and funding; they recommend an “increase in coordination of funding across federal, state, public, and private organizations as reflected in an integrated agenda, interagency collaborations, and shared funding of priorities” (25).

Accountability

One of the main concerns expressed by government employees interviewed who were skeptical of the viability of expanding self-managed contracts in Saskatchewan was accountability to public funds. The government employees felt it was difficult to determine if individuals who wanted to pursue this arrangement had the necessary skills to manage funds and resources. But one respondent felt that “government seems to feel more comfortable dealing with a registered non-profit,” adding, “If you look at what the government does in terms of standards and making sure the money is spent well, our response is why do you think a nursing association would want something better for a child than their parents?” In

fact, forms “are not necessarily reassuring that those in a group home are having a good life or are being treated well. The kind of monitoring in group homes could happen in self-managed contracts. It’s easier to determine outcomes for a single individual than for sixty.” A review of other jurisdictions offering SDF in the United States has found that many states “have rejected a screening approach and have chosen to offer eligible recipients the option to self-direct” (Benjamin 2001, 7). A major concern that is recognized by both government and advocates is the issue of how SDF will be managed by those with developmental and cognitive impairments. One approach that was recommended in the article is to provide support for individuals seeking SDF with a “model using supported self-determination” (Benjamin 2001, 8). Self-determination is defined by “the skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior” (Algozzine et al. 2001, 219), which would be supported by the individual’s family, support workers, social supportive networks, and associations for community living. Supported decision making is already enabled by Saskatchewan regulations on adult guardianship and co–decision making.

Limitations

Although the study provided significant insight into the impact of self-managed contracts in the lives of individuals with disabilities, their families, and support network, the data was limited by the number of respondents (Appendix F). An early low participation rate improved towards the end of the interview period; however, we had only three individuals with disabilities participate in the study and share their experiences. Although the sample was small in the study of a small population, the study drew the number of anticipated respondents among family members (with a greater response from the family member who managed and administered the contract) and more than anticipated numbers for government employees and advisory table members. We had participation from service providers but none from support care workers. Nor did we secure participation by those who had established but later abandoned self-managed contracts and this missed the opportunity to understand more fully why some maintain the contracts while others return to block-funded arrangements.

CONCLUSIONS

BASED ON A LITERATURE REVIEW and semi-structured interviews with those with experience of self-managed contracts in Saskatchewan, this study was designed to enhance understanding and to provide evidence to support decision making of individuals and families, service providers, community organizations, and government policy makers. It examined the process of developing and managing the contracts, people's understandings of how self-managed contracts have helped or hindered their lives, and the outcomes and impact of these SDF-like arrangements on individuals, families, community structures, program delivery, and policy. On the evidence, the SDF model has benefits for individuals with intellectual disabilities, improving choice, self-determination, and quality of life and furthering the goals of the United Nations Convention on the Rights of Persons with Disabilities by addressing system barriers to full participation in society and promoting respect for people's "inherent dignity."

Typical experiences before self-managed contracts were isolation, poor services, inadequate supports, insecurity, and instability. High levels of stress and anxiety, even futility, were shared widely, along with concern about the impacts not only on individuals but also on siblings and other family members. More than one family felt "like you are in jail" or "in way over our heads." Whatever the situation, they felt the burden of responsibility always coming back to the family.

Although some interviewees were professionally well prepared for the process of obtaining self-managed contracts, most agreed that the process was as long as it was mystifying, as cumbersome as it was ambiguous and uncertain. For most, it proved less a matter of negotiation and choice than of getting worn down and settling for what was offered. They reported a culture of secrecy that made information and knowledge often inaccessible. Participants felt the particular injustice of compromised access and equity for those already stretched emotionally, physically, and financially. Appeals processes handled by the same people who denied applications in the first place added to feelings of intimidation and fear. Ironically, feelings of fear and intimidation, uncertainty and powerlessness, were commonly expressed

in relation to renewal processes designed to increase people's sense of control and choice. The short terms of the contracts added to insecurities and vulnerabilities. Despite ministry support for the study, levels of fear — compounded by the intimidating non-disclosure clauses — were such that some did not participate for fear of losing support.

If interviewees felt the difficulties of getting heard once they were in negotiations, they also commented on the effect of loud voices that drowned out alternative service provision models, making it hard for people to know that they had choices and what those choices were. Compared to organized service providers with the ear of their MLAs and photo opportunities aplenty for traditional services, for example, many felt the special burden of creating opportunities by being in the right place at the right time to connect with those who were prepared to hear, think, and act outside the box. Those who did get sympathetic hearings from government warned that they did so not by being confrontational or demonizing government but by selling the case for the preferred program. And selling the case could be done by making personal connections with MLAs and other decision makers. Other families and advocates were sensitive to the fears and anxieties of agencies and families who had had their own struggles working to achieve what they thought best.

Once contracts are negotiated, both the literature and interview evidence agree on benefits to self-esteem, satisfaction, confidence, flexibility, engagement, and health — benefits related to the power to make one's own decisions and to do so based on certainties about predictable resources in the face of otherwise changing circumstances. The freedom to choose and to be one's own boss, to experience an enlarged network, take on new challenges and enjoy new commitments, were widely reported benefits. Learning to trust their own judgement and not defer to experts was important learning for one family. For another it was coming to understand that the reward for their time commitment to the plan was the independence and choice the family gained.

The SDF model provides an opportunity to set and reach individual goals while being economically viable, socially responsible, and politically feasible. Research and anecdotal evidence all show positive gains from development, implementation, and expansion of SDF programs, although they also highlight persistent issues with eligibility rules linked to the medical model as well as the need for supports to ensure meaningful choice and participation.

While all respondents agreed that self-managed contracts are not for everyone, they felt

they should be added to the menu of services officially offered to those who feel that the current block-funded services and associated care are not a suitable option for them and are willing to take on the workload involved in a self-managed contract. What the interviews made clear is the extent to which SDF-like arrangements remain hugely reliant on family resources of money, time, energy, and creativity — a reality that made it especially difficult for families to take bureaucratic explanations for delays and denials that government can't cover everything. Families pay so much to support their family members — to open the doors to expanded opportunities in a bigger world — that they feel such insensitivity keenly. Similarly, many were offended when they felt their knowledge and competency were put in question, when their actions and accountability were not deemed up to wise spending and management choices. While risk management is a proper concern of government, the KPMG (2010) review of the Alberta PDD program is a salutary reminder of the high costs and dangers of undue investments in monitoring at the expense of programming.

The literature and interviews revealed a number of important lessons about what makes a good program and meaningful choice:

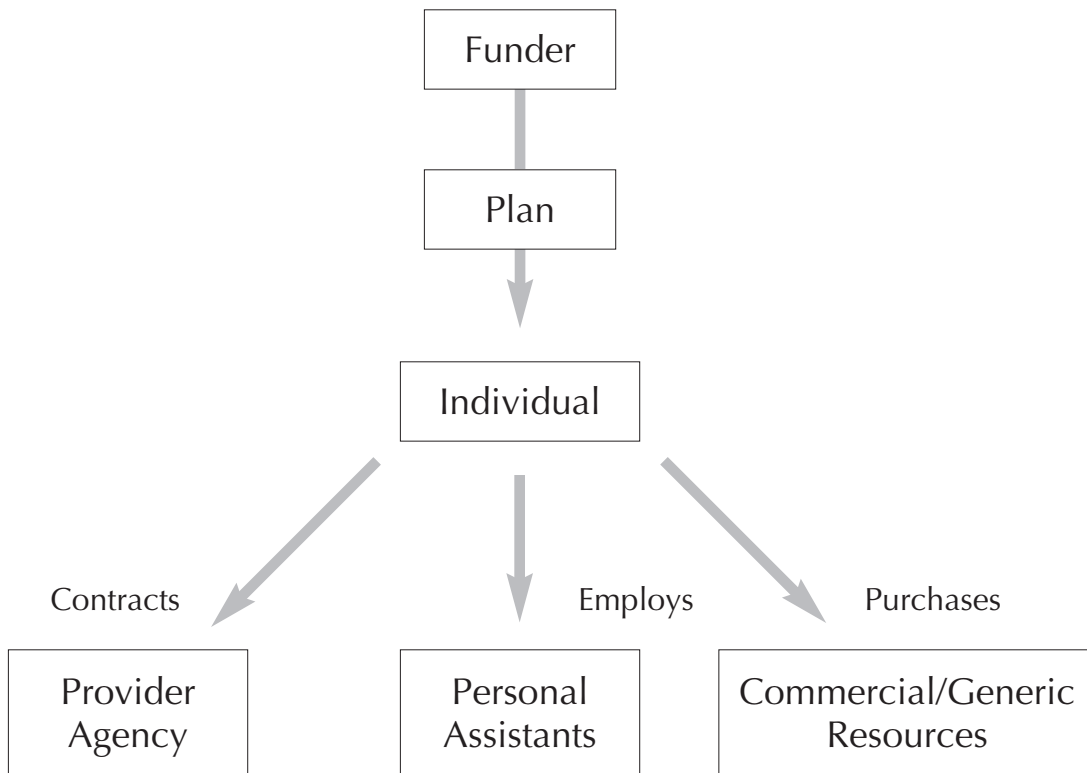
- accessible information and relevant supports
- clear policies and procedures
- longer-term, predictable funding
- consistent, coordinated application
- enhanced planning and collaboration
- inclusive decision making
- accountability mechanisms that are not disproportionately invested in monitoring financial management
- labour protections and staff supports
- a “customer-focused culture” (Victoria 2011, viii)

Saskatchewan has already recognized cultural changes in the environment and responded with programming to enhance the lives of people living with disabilities including the Saskatchewan Assured Income for Disability (SAID) program, the Day Program Funding Standard, and Complex Needs Enhancements, and SDF-like supports such as respite and the Cognitive Disability Strategy. If there remains some ambiguity about the status of SDF, there is also increasing support for a model that brings a range of benefits to individuals and families that are willing to undertake the added responsibilities to give their family members empowerment, choice, and independence in making decisions regarding their care and their lives.

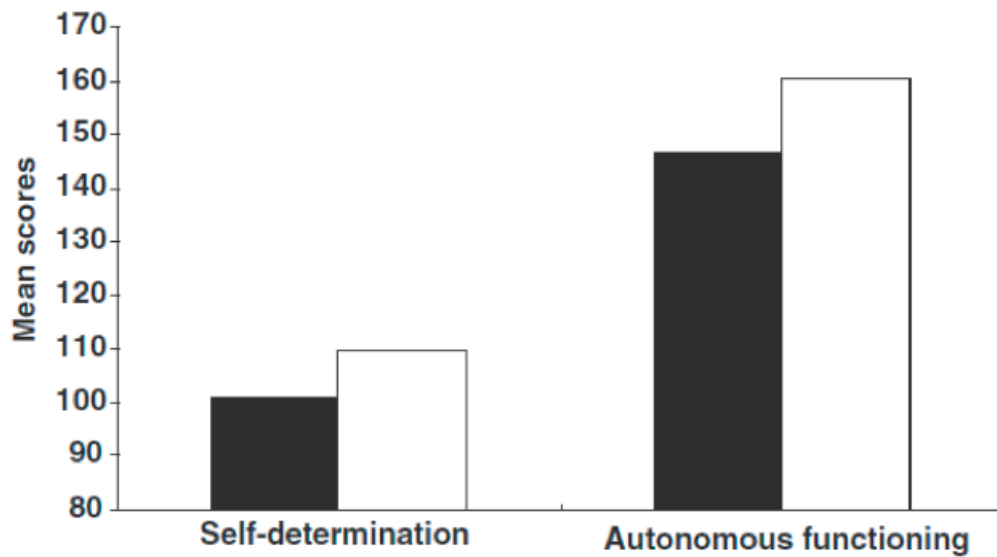
APPENDIX A
Diagram of Traditional Block Funding



APPENDIX B
Diagram of Self-Directed Funding



APPENDIX C
Results of Autonomous Functioning Checklist and
the Arc's Self-Determination Scale Paired Sample T-tests Results



The diagram shows the results of mean scores for the self-determination and autonomous functioning measures before (■) and after (□) transition from a “work or living environment that was more restrictive to one which was community based and less restrictive.” (Wehmeyer and Bolding 2001, 378–79).

APPENDIX D
Number of Participants

Target Group	Self-Advocates	Family Member(s), Guardian(s), Advocates, Supporters	Government Employees (frontline staff), Mem- bers of the SACL-SDF Advisory Table
Target Participation	8–10	10–12	6
Actual Participation	3	10	9

APPENDIX E

Conversation Guides

Researcher's Conversation Guide for Self-Advocates Who Have Been Receiving Self-Managed Contracts or Have Received Them in the Past

1. Steps to Be Covered before the Interview

a) Introduction

- Explain purpose of interview — explain that you do not have any effect on the supports they receive; the purpose of the interview is to collect information about their experience in having their own self-managed contract and the information will be used to inform policy, programming, and the process of applying for and receiving self-managed contracts.
- Go over the consent form — if the individual consents to participate, get the individual to sign the forms and give them a copy for their records.
- Go over the interview guidelines — responses are confidential, fake names will be used in a final report; the recorder can be turned off at any time, the interview does not have to be recorded; you do not have to answer a question if you don't want to; you can finish the interview at any time for whatever reason, there is no penalty for choosing to end the interview at any time.
- Explain what will happen to information from interview — i.e., all the information collected will be put together into a report about self-managed contracts and SDF-like arrangements. The report will be made public. The goal of the research is to examine the strengths and weaknesses of self-managed contracts. All participants will receive a one-page plain language summary when the report is released.
- For those who no longer have a self-managed contract, some of these questions will not be asked.

b) Getting to know the individual (DO NOT RECORD THIS PORTION OF THE INTERVIEW)

- Ask the individual for a general brief overview about themselves, e.g., age, living arrangements, day time activities, family contact, friends, likes and dislikes.

2. Interview Guide (TURN ON THE RECORDER IF PERMISSION IS GIVEN)**Section 1: Before Your Self-Managed Contract**

- 1) What types of supports and services and help did you have before your self-managed contract (also known as your plan)?
- 2) Why did you switch to a self-managed contract? (Explore: the process, i.e., any unmet needs, sources of information)
- 3) Did you have help from anyone outside your family or friends? For example, a community-based organization?
- 4) Can you tell me about your life before your plan? Was it: (Circle one response)
Really good Good Okay Not very good Really bad
- 5) Can you tell me about how your plan works? (Explore: who helps with the administration)
- 6) How long did it take you to get your plan? Did you get it the first time you tried? If not, could you tell me about what reasons you were given for being turned down?

Section 2: The Creation of Your Plan and Your Network

- 1) How did you pick your goals for your plan? (i.e., MAPS, PATHS)
- 2) Can you tell me about how you made your plan? (Explore: what worked, what didn't work, what would you have liked to do differently, did you get enough information and support; were the people you wanted involved?)
- 3) Do you have a "formal" support network that helps you? (Explore: is the support network formal or informal?) If "no," skip to #5.
- 4) How did you pick the members of your support network (the people who help you)?
- 5) How often does your support network meet?
- 6) Do you feel that your support network helps you? (Explore: relationships, having his/her voice heard, any concerns about the support network functions)

Section 3: Carrying Out Your Plan

- 1) How did you pick the things (such as services and supports) that you wanted as a part of your plan?
- 2) What skills did you need to make and keep the services in your plan? Did you have to learn these skills on the job?
- 3) What have been good things that have happened to you since you have had your plan? (Explore: if they are more satisfied with the services and supports being received and if they feel more a part of the community)

- 4) What has been hard about the plan? (Explore: what barriers they face, e.g., lack of qualified practitioners, not reaching their goals, feeling of isolation)
- 5) During your time using a Self-Managed Contract, have you felt pressured by anyone to change to another plan or program (for instance, going through an agency for day programs)? If so, can you tell me about your experience?
- 6) Does someone help you with parts of your plan, like choosing staff, or paying the bills? If “yes,” explore why; if “no,” explore why.
 - a. How did you pick this person (your service broker)?
 - b. How often do you meet with this person (your service broker)?
 - c. Do you feel that this person helps you? (Explore: relationships, having his/her voice heard, any concerns about the support network functions)

Section 4: Evaluation of Your Plan

- 1) What parts of your plan have you already done? (Explore: what has been accomplished; what needs to be done, have their expectations changed?)
- 2) How has your plan made a difference to your life? (Explore: new activities, social contact, family and other relationships, empowerment issues)
- 3) Can you tell me about your life since you have had your plan? Is it... (Circle one response)
 Really good Good Okay Not very good Really bad
- 4) If you no longer have your plan, can you tell me about why you no longer have it? Was it hard to make the change?

3. *Wrap-up*

Thank you for taking the time to talk to me/us today. Is there anything else you would like to say about your plan that you did not already tell me?

The next thing we are going to do for this study is to write down what you said during the recorded conversation (if it was recorded). Please let me know if you would like a written copy of our talk, and I can send you a copy to look at. If you want, you can make changes to your comments, or add or remove information.

Thanks, and have a good day.

Researcher's Conversation Guide for Family/Guardians of Persons Who Have/Had a Self-Managed Contract

1. *Steps to Be Covered before the Interview*

a) Introduction

- Explain purpose of interview — explain that you do not have any effect on the supports that their family member receive; the purpose of the interview is to collect information about the experience of your family member as well as yourself in having a self-managed contract and the impact on all of your lives. The information will be used to inform policy, programming, and the process of applying for and receiving self-managed contracts or Self-Directed Funding-like (SDF) arrangements for others.
- Go over the consent form — if the individual consents to participate, get the individual to sign the forms and give them a copy for their records.
- Go over the interview guidelines — responses are confidential, false names will be used in a final report; the recorder can be turned off at any time, the interview does not have to be recorded; you do not have to answer a question if you don't want to, can finish the interview at any time for whatever reason, there is no penalty for choosing to end the interview, at any time and for any reason.
- Explain what will happen to information from interview — i.e., all the information collected will be put together into a report about self-managed contracts and SDF-like arrangements. The report will be made public. The goal of the research is to examine the various elements of SDF-like plans. All participants will receive a one-page plain language summary when the report is released.
- If the family member no longer has a self-managed contract, several of these questions will be dropped from the conversation guide.

b) Getting to know the individual (DO NOT RECORD THIS PORTION OF THE INTERVIEW)

- Ask the individual for a general brief overview about their family member and themselves, e.g., age, living arrangements, day time activities, family contact, friends, likes and dislikes.

2. *Interview Guide* (TURN ON THE RECORDER)

Section 1: Before the Self-Managed Contract

- 1) What types of supports and services was your family member accessing prior to having a self-managed contract?
- 2) Do you think your family member needs were being met? (Explore: what needs were being met in a good, adequate fashion and any unmet needs prior to the project)
- 3) How did you hear about the option of obtaining a self-managed contract? (Explore: selection process, understanding of support and choice, sources of information and how gathered)
- 4) What appealed to you about a self-managed contract? Did these features appeal to your family member as well?
- 5) Why did your family member decide to apply for a self-managed contract?
- 6) How would you rate your family member's quality of life before the self-managed contract? (Circle one response)

Excellent	Good	About average	Unsatisfactory	Poor
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- 7) How long did it take you to obtain a self-managed contract? Was your family member successful in receiving the contract the first time that he or she applied? If not, what were the reasons that he or she was given for being turned down?
- 8) Can you give a brief overview of your family member's self-managed contract (Explore: who helps with administration?)
- 9) Could you tell me about how you, your family member, and your family member's supporters were able to negotiate a self-managed contract with the government? What was the process like?

Section 2: The Creation of Your Family Member's Plan

- 1) How did your family member pick their goals for their plan? (Explore: if the process was hard, overwhelming for the family member, MAPS, PATHS)
- 2) How did your family member pick the members of his or her support network?
- 3) Did you help with picking your family members goals for their plan? Are you involved in their support network? If so, what is your role in the network?
- 4) How often does the support network meet? (Explore: is it too often, too infrequent or needs to be mandated?)
- 5) Do you feel that their support network helps your family member? (Explore: relationships, having their voice heard, any concerns about the support network functions)
- 6) Do you have any concerns about the role that the support network plays?
- 7) Does your family member use the services of a fiscal intermediary? If "yes," explore why; if "no," explore why. (Explore: What supports they have for administering plan, financial aspect...)

Section 3: Carrying Out Your Plan

- 1) How did your family member select the services and supports for their plan? (Explore: is there sufficient community capacity for the support services required by their family member?)
- 2) Can you tell me about the process of developing your family member's plan? (Explore: what worked, what didn't work, what would you have liked to have done differently, did you get enough information and support; were the people you wanted involved?)
- 3) Are the type of services and supports that your family member needs available in the community? (Explore: if the services and supports are not available, how does the family meet the unmet needs e.g., through unpaid labour, reliance on informal networks?)
- 4) What have been good things that have happened to your family since he or she has had the plan? (Explore: if they are more satisfied with the services and supports being received and if they feel more a part of the community)
- 5) What has been challenging about having the plan? (Explore: what barriers their family members face, e.g., lack of qualified practitioners, not reaching their goals, feeling of isolation)
- 6) During your family member's time using a self-managed contract, have you felt pressured by anyone to change to another plan or program (for instance, going through an agency for day programs)? If so, can you tell me about that experience?
- 7) What do you and your family contribute to the plan?
- 8) Did your family member choose the service broker?
 - a) If yes, how did they go about it?
 - b) Do you feel that the support broker helps you? (Explore: relationships, having his/her voice heard, any concerns about the support network functions)

Section 4: Evaluation of the Self-Managed Contract

- 1) What components of your family member's plan have been carried out? (Explore what has been accomplished, what needs to be done, have their expectations changed?)
- 2) How has participating in the self-managed contract made a difference to your family member's life? To yours? (Explore: is the family member involved in new activities, forming social contacts, developing family and other relationships, find that the family member has more empowerment?)
- 3) Has participating in the self-managed contract given your family more flexibility? Is life more manageable?
- 4) How would you rate your family member's quality of life with the self-managed contract? Yours? (Circle one response)

Excellent

Good

About average

Unsatisfactory

Poor

- 5) Do you think that your life, and the life of your family member, would be different without the self-managed contract?
- 6) If your family member no longer has a self-managed contract, can you talk a little but about why the change was made? Was it an easy transition? A difficult transition?

3. Wrap-up

Thank you for your time and your interest in this project. Is there anything else you would like to add to the conversation today that we did not talk about that is important for me to understand about your family member's self-managed contract?

The next step in this research will be to write down what you said during the recorded conversation (if applicable). Please let me know if you would like a written copy of the interview, and I can send you a copy to look at. If you want, you can make changes to your comments, or add or remove information

Thanks, and have a good day.

**Researcher’s Conversation Guide for Government Employees,
Support Workers, Service Providers, and Members of the
SACL Self-Directed Funding Advisory Table**

1. Steps to Be Covered before the Interview

a) Introduction

- Explain purpose of interview — the purpose of the interview is to collect information about their experiences and the impact of self-managed contracts on their client (the self-advocate). The information will be used to inform policy, programming, and the process of applying for and receiving self-managed contracts and Self-Directed Funding-like (SDF) arrangements in the future.
- Go over the consent form — if they consent, get the individual to sign the forms and give them a copy for their records.
- Go over the interview guidelines — responses are confidential, pseudonyms will be used in a final report; the interview does not have to be recorded, the recorder can be turned off at any time; you do not have to answer a question if don’t want to, and the individual can choose to end the interview at any time, for any reason, without penalty. Explain what will happen to information from interview — i.e., all the information collected will be put together into a report about self-managed contracts and SDF-like arrangements. The report will be made public. The goal of the research is to examine the strengths and weaknesses of the self-managed contract. All participants will receive a one-page plain language summary when the report is released.

b) Getting to know the individual (DO NOT RECORD THIS PORTION OF THE INTERVIEW)

- Ask the individual for a general brief overview of their interests, their employment, and their family.

2. Interview Guide (TURN ON THE RECORDER)

Section 1: Supporter/Service Provider Background

- 1) What types of supports and services do you or your organization provide?
- 2) How many clients do you provide services to? (Explore: the range of needs, and the service area)
- 3) How do people access your services? (Explore: referral, walk-in, other)

4) Were you aware that there was a self-managed contract being used by one of your clients?

Section 2: Services/Supports Provided to an Individual with Intellectual Disabilities with a Self-Managed Contract

- 1) How did you and/or your organization accommodate the request for individually-tailored services/supports for the individual with intellectual disabilities?
- 2) Why did you decide to participate in the life of the individual receiving a self-managed contract?
- 3) What challenges did you and/or your organization face in developing programs suited to the individual's needs?
- 4) Do you and/or your organization have any concerns about payment for services/supports?
- 5) Ask only if their client uses a service broker: Can you tell me about your experience working with a service broker?

Section 3: Working with Government Officials

- 1) What information did your local government contact provide to you in regards to the self-managed contract?
- 2) Has your relationship with government officials changed during the self-managed contract?
- 3) What kinds of support do you need from government? What kinds of support do you receive?
- 4) Do you feel you receive enough support from the appropriate government departments?

Section 4: Assessment of the Self-Managed Contract

- 1) What are the lessons that you learned over the course of your work with the individual?
- 2) How have you found working with the individual, their family, and other support workers and what do you think could be different — what are the challenges and the strengths?

3. *Wrap-up*

Thank you for your time and your interest in this project. Is there anything else you would like to add to the conversation today that we did not talk about that is important for me to understand about the self-managed contracts you have been involved with?

The next step in this research will be to write down what you said during the recorded conversation (if applicable). Please let me know if you would like a written copy of the interview, and I can send you a copy to look at. If you want, you can make changes to your comments, or add or remove information.

Thanks, and have a good day.

Researcher's Conversation Guide for Government Officials

1. Steps to Be Covered before the Interview

a) Introduction

- Explain purpose of interview is to collect information about self-managed contracts funded by the provincial government.
- Go over the consent form — if the individual consents to participate, get the individual to sign the forms and give them a copy for their records.
- Go over the interview guidelines — responses are confidential, pseudonyms will be used in a final report; the recorder can be turned off at any time, the interview does not have to be recorded; you do not have to answer a question if you don't want to, can finish the interview at any time for whatever reason.
- Explain what will happen to information from interview — i.e., all the information collected will be put together into a report about self-managed contracts for individuals with intellectual disabilities. The report will be made public. The goal of the research is to examine the strengths and weaknesses of self-managed contracts. All participants will receive a one-page plain language summary when the report is released.

b) Getting to know the individual (DO NOT RECORD THIS PORTION OF THE INTERVIEW)

- Ask the individual for a general brief overview of the ministry they work for and their job.

2. Interview Guide (TURN ON THE RECORDER)

Section 1: Current Policies/Programming

- 1) What do you feel are the strengths and weaknesses of current disability-related programming?
- 2) From your perspective, what do customers or clients consider to be the strengths and weaknesses of current disability-related programming?
- 3) What is your involvement with self-managed contracts?
- 4) What are the ministry's policies and procedures around self-managed contracts?
- 5) Have ministerial priorities changed to put more focus on achieving the goals of the individual? If so, what has influenced this change?

- 6) Is there active involvement of individuals with disabilities and their families in policy decisions at the system level (respecting the design, implementation, and evaluation of a program), including:
- consideration of input from consumers?
 - participation on governing boards and councils?
 - joint sign-off on policies by governing board/council?

Section 2: Self-Managed Contracts

- 1) What can you tell me about the general principles of self-managed contract programming?
- 2) Could you tell me about the criteria on which an application for a self-managed contract is judged?
- 3) On what basis do employees and/or the consumers decide that products or services are needed?
- 4) What are the strengths and weaknesses of self-managed contracts? (Explore: geographic restrictions, conflict between departments, service providers, lack of resources)
- 5) In terms of case management, has the ministry developed policies and procedures for service coordination to ensure that individuals with intellectual disabilities receive the services they need, particularly where services are provided by multiple agencies?
- 6) What typical concerns are heard from government employees and/or the individuals and their families about self-managed contracts?
- 7) What recommendations to improve self-managed contracts have been suggested by government employees and/or individuals and their families?
- 8) What do you see families and networks of support contributing to an individual's self-managed contract?
- 9) Could you tell me about some typical reasons why individuals/families choose to terminate their self-managed contract and the process of doing so?

Section 3: The Future of Self-Managed Contracts in Saskatchewan

- 1) How do you see self-managed contracts fitting into the existing range of programming offered in Saskatchewan?
- 2) If your ministry (branch) were to adopt self-managed contracts on a broad scale, what policy changes would have to happen?
- 3) What would be required, in terms of system change, in order to deliver self-managed contracts to a broader population?
- 4) Based on the current self-managed contracts, do you see self-directed funding being added as an option to the menu of services in the future? Why or why not?

3. Wrap-up

Thank you for your time and your interest in this project. Is there anything else you would like to add to the conversation today that we did not talk about that is important for me to understand about self-managed contracts?

The next step in this research will be to transcribe this interview. Once the interview is transcribed, I will get in touch with you so that we can set up a time to go over your transcript.

Thanks, and have a good day.

APPENDIX F: Clustered vs. Dispersed Housing Results

Table 2: Social Inclusion, Interpersonal Relations, Material and Emotional Well-Being

Quality of life domain/indicator	Dispersed housing better	No difference	Campus/cluster housing better
Social Inclusion	5		
Access to local community/neighbourhood	2		
Use of community facilities		2, 19	
Number of community amenities visited	19		
Community activities and opportunities	15, 16, 17	7	
Residential well-being	17		
Interpersonal Relations	16, 18	3, 17	
Sexual activity		5	
Relationships with family, carers, others	5 ^f	5 ^g	
Number of people in network	6 ^b , 7, 11	6 ^a	
Composition of network		7	
Contact with family/family members in network		6, 7, 15, 19	13
People with ID in network	6 ^b	6 ^a , 15	
Local people in network	6		
Contact with friends	19 ^b	15	19 ^e
Contact with neighbours		19	
Observed contact from others		7	
Stayed away / guest to stay		19	
Visitors to home	19 ^b		19 ^e
Material Well-Being	5 ^f	5 ^g , 17	
Emotional Well-Being		6 ^a	
Challenging behaviour/stereotypy	7	3, 19	
Satisfaction in all areas except friendship/relationships		12	
Satisfaction with friendships relationships			12
Chaos and confusion	18		

Source: Mansell and Beadle-Brown 2009.

^a Comparison between dispersed housing and village communities; ^b Comparison between dispersed housing and campus settings; ^c Comparison between ordinary dispersed housing and campus/clustered settings; ^d Comparison between specialized dispersed housing and campus/clustered settings; ^e Comparison between clustered supported living and other settings; ^f Rated by staff; ^g Rated by users or families; ^h Comparison between supported living and campus/clustered settings; ⁱ Comparison between group homes and campus/clustered settings.

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