Self-Directed Funding for People with Intellectual Disabilities	

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Location	Saskatchewan
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Partners	Saskatchewan Association for Community Living, Government of Saskatchewan Ministry of Social Services Disability Services and Operational Policy
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Methods	Literature reviews, environmental scans, key informant interviews, national and provincial policy table engagement

Introduction

Late 2006 marked the beginning of an eight-year partnership between Saskatchewan Association for Community Living (SACL), a nonprofit organization committed, "to ensur[ing] that citizens of Saskatchewan who have intellectual disabilities are valued, supported and included members of society and have opportunities and choices in all aspects of life," and Community-University Institute for Social Research (CUISR), University of Saskatchewan, long invested in, "partnerships between the university and the larger community in order to engage in relevant social research that supports a deeper understanding of our communities and reveals opportunities for improving our quality of life." Through several reports, changes in language, methods, and strategy, our case describes a unique experience of social innovation through the "disruption of the institutional patterns" (Nilsson & Paddock, 2014) in the field of intellectual disability. Speaking to domains of excellence, community relevance, equitable participation, action and change, and research design, this case study focuses on integrating collaborative community-campus research into the development of public policy. It reflects on the challenges and opportunities of partnering, of engaging in policy development, and of contributing to social change by moving marginalized voices into the center of the policy development process.

Research purpose

The purpose of this research was to build a framework for accessible, individualized resources for persons with intellectual disabilities. It was to put people first and respect the principles of citizenship, membership, and self-determination. This approach includes respecting citizenship rights and freedoms, supporting full access to and inclusion in schools, workplaces and communities, and enabling active and decisive voices to build a rewarding, enriching, and stimulating life. This research was called upon to establish best practices of individualized funding (IF) or self-directed funding (SDF), which is a funding framework that supports a process whereby individuals identify goals and needs and present a plan on how they can be met, including support networks, to the funding body (typically government). In turn, this funding framework was used to assess participant benefits and cost-effectiveness and to develop an evidence

base to make the argument for (and recognize counter arguments against) individualized service delivery in Saskatchewan.

The project built on SACL expertise (Judy Hannah, Director of Strategic Initiatives) and its record of community consultations, workshops, and research initiatives. Furthermore, the project embraced CUISR's mission, its deep networks as a trusted entry point to the university, its multidimensional impacts on community, its diverse knowledge mobilization strategies, and its proven record of interdisciplinary, inter-sectoral, and intercultural research.

Funding was obtained from SACL and the Social Sciences and Humanities Research Council of Canada (SSHRC) for the project Linking, Learning, Leveraging: Social Enterprises, Knowledgeable Economies, and Sustainable Communities, the Northern Ontario, Manitoba, and Saskatchewan Regional Node of the Social Economy Suite (Principal Investigator Dr. Lou Hammond Ketilson; Saskatchewan Principal Investigator Isobel M. Findlay).

Background

Over the last 30 plus years, Canada and other industrialized countries have witnessed a paradigm shift guiding service provision for people with intellectual disabilities. It has shifted from the medical, deficit/protective model to a more community inclusion or social model, respecting fundamental rights to dignity, quality of life, and full citizenship. That right is affirmed in article 1 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 on barriers imposed on the person by society not on any impairment in the person. Ultimately, it focuses on changing the system rather than the person and removing barriers that "may hinder their full and effective participation in society" (United Nations, 2006, article 1). Although the social model is widely accepted among government and service agencies, most supports and services in Saskatchewan remain agency-controlled, block-funded services that are funded by government.

In the context of this paradigmatic shift, individualized-funding (IF) programs have become popular and are in demand by people with disabilities. As a result, block-funded services—based on a rehabilitative or medical model—have been transformed in many provinces to relocate choice and control over services from service providers to people with disabilities, allowing support and services that are tailored to fit their needs. While programming costs have been found to remain neutral or even decline, the benefits of IF programs include increased individual control and autonomy, higher quality of life, and fuller participation in society.

Yet, despite their 30-year availability in jurisdictions around the world, the model remains fairly unknown and relatively misunderstood amongst self-advocates and their families, as well as amongst service providers and policy makers. Lack of information exacerbates the fears of families in regards to their capacity to take on additional responsibilities; aggravates structural barriers to cooperation and fears of change among service providers anxious about losing clients and funding; and disables bureaucracies linked to electoral, budgetary, and planning cycles with insufficient incentive or support for cross-departmental cooperation.

It was against this background in 2006 that the research team came together in a mutual education process to recommend policies and practices, and to rework relationships and capacities among the players so that all contributions and capacities count. Overall, this research project worked to ensure equitable participation, community relevance, and the best outcomes for all stakeholders involved.

Project 1—Lynch and Findlay (2007): A New Vision for Saskatchewan

The first report created analyzed the costs and benefits of traditional block-funded services and IF programs in national and international jurisdictions. It also recommended best practices for a responsive IF program that enhance independence, quality of life, and social inclusion for people with disabilities in Saskatchewan.

Research design and methodology

In addition to literature reviews, methods involved a scan of internet sources within eleven jurisdictions currently hosting or in the process of adopting IF models (four in Canada, four in the US, two in Australia, and one in the United Kingdom), online searches of community-based or non-governmental organizations engaged in lobbying policymakers on IF models, and, most importantly, participation in the inaugural Individualized Funding Advisory Table led by SACL and drawing together key Saskatchewan players, including agencies, families, researchers, and policy makers. If action and change were to be achieved, it was realized that research design must involve diverse players in a collaborative community learning process to unlearn unproductive practices and define and redefine policies and practices (Kevany and MacMichael, 2014).

The research team included a community partner (Hannah), a student intern (Karen Lynch), a CUISR community research liaison (Maria Basualdo), and the Principal Investigator (Findlay). Consistent with a participatory action research (PAR) approach (Kemmis and McTaggart, 2005; Minkler and Wallerstein, 2003; Stoecker, 2005), at all stages the team debriefed together and with the Advisory Table and was guided by CUISR's emergent model of 3-Rs—research, relationships, and reflexivity—of community-based research (Findlay, Ray, and Basualdo, 2011; 2014). The 3-Rs democratize research by respecting participant knowledge and expertise, actively engaging them in research design and analysis, and rebuilding community in the process. The 3-Rs are present from the first research design meetings between community-university partners until the final approval of dissemination strategies. This approach re-distributes expertise and authority, allows all parties to understand systemic inequities, and empowers communities to discover local

expertise and capacity. Reflexivity encourages rethinking ideas, attitudes, plans, directions, strengths and limitations throughout.

Research findings

Consistent with the social model, IF "allows individuals to take an active role in determining how they can reach their short and long-term goals," whether "aided by a support network and/or an independent planner (support broker)" which are enlisted to help negotiate and secure supports and services. Diverse IF models have been developed in different jurisdictions and have been diversely instigated by, "pressure on government via grassroots movements (e.g., British Columbia, California); adoption of the social model of disability in policy (United Kingdom, Manitoba, Dane County, WI); and court cases (Wyoming, California)" (Lynch & Findlay, 2007, p. ii). This study found that a) programming costs tend to remain neutral or even decline and b) benefits include increased individual control and autonomy, higher quality of life, and fuller participation.

Recommendations for transforming Saskatchewan's disability support system included bringing together government departments (Community Resources, Health, Education) with advocates and service providers to develop principles, eligibility criteria, regulations, evaluation, setting up demonstration projects in a variety of settings, and creating an IF program for people with intellectual disabilities that is portable, flexible, and attached to the individual.

Project 2—Chopin and Findlay (2010): Exploring Key Informants' Experiences with Self-Directed Funding

When the first report failed to move policy thinking and was even resisted as "over-arguing the case," a new strategy was collaboratively designed for the next phase of the research. It would focus on points of resistance and take seriously the lived experience of government players among others. It would address the concerns of decision makers around IF complexities and challenges, while also noting the government's responsibility to protect clients, manage risk, and administer the public purse in cost-effective ways. In other words, it would begin by integrating the government perspective on these topics, while still recognizing that there are diverse concerns of self-advocates, families, and their supports. The concerns of self-advocates, families, and their supports include:

Sustainability of self-directed funding

- Accountability measures related to the allocation of funds, including the design of appropriate reporting requirements
- Quality and risk management to ensure clients' funds are managed properly
- Labour market and staffing issues related to the availability and retention of personal support worker

Equity among different user groups

It was during this phase in the research project that the term SDF was chosen as a better term to communicate the intent to increase individuals' choice and control over supports and services and the existence of a payment mechanism to help them live an inclusive life in their communities. It was also agreed upon that the best way forward was through a joint government-community initiative, rather than an initiative seeming to pit one against the other.

Research design and methodology

The first phase involved a literature review of SDF programs in Canada, California, UK, and Australia that was based largely on reports and websites on SDF programs. This was supplemented by a second phase of key informant interviews on SDF impacts with eight service provider and Associations for Community Living representatives, seven government representatives, and two consultants with international expertise. Key informants were from Newfoundland (n=1), Prince Edward Island (n=1), Nova Scotia (n=1), New Brunswick (n=2), Ontario (n=3), Manitoba (n=3), Saskatchewan (n=3), and British Columbia (n=3). Again, there were regular debriefs both within the research team (only the student changed to Nicola Chopin) and within the renamed SDF Advisory Table.

Research findings

The study reviewed seventeen funding models across jurisdictions in Canada, California, the United Kingdom, and Australia finding that thirteen were based on need rather than income (one program), while three used a combination of needs and income to determine funding levels. There was variation on funding uses, management (by client, appointed person, or service provider), reporting mechanisms (monthly invoices, forms, reports, government reviews), and frequency of budgetary changes (annual or in response to changing needs or income).

Program design and accountability measures

The goal of individualized approaches may be accomplished not only by meeting medical or living supports, but by enhancing individuals' personal networks.

Accountability challenges exist because of a lack of standardization.

SDF models do not automatically produce individualized services; it is important to develop sufficient infrastructure to build capacity for individualized services.

Labour market and staffing issues

Staffing issues, including high turnover rates, low wages, and varying availability of staff in rural and urban areas add to hiring and firing responsibilities.

Inequities relate to clients in some jurisdictions being allowed to top up staff wages.

Funding sustainability

Individualized approaches tend to be more cost-effective than traditional approaches and programs have developed policies (ceilings) to overcome sustainability problems.

Client equity

Client equity emerged as a complex theme. In addition to regional differences of supports and services, SDF must balance the recognition that disabilities impact individuals' lives differently and the need to justify and apply guidelines consistently.

Outcomes and challenges

Program evaluations and anecdotal accounts showed that individualized approaches have been found to improve quality of life. However, individualized approaches are more difficult for clients due to their increased involvement in decision-making, hiring staff, and reporting on fund use. Complex reporting can result in fund management taking over recipients' lives; this was identified by interviewees as a key reason individuals choose to remain with block-funded services.

Innovation

The literature review and interviews highlighted the ability of SDF to address client needs in innovative ways, including the importance of social networks in improving the lives of individuals with disabilities.

Limitations and areas for further study

Interviewing individuals with disabilities should be explored in greater depth in order to determine if they experience the challenges and strengths identified in this study. Similarly, government representatives and community-based organizations (CBOs) should be further interviewed and analyzed in order to collect information on program development, implementation, and documentation.

Project 3—Findlay and Damji (2013), Self-Directed Funding: An Evaluation of Self-Managed Contracts in Saskatchewan

Building on the 2010 findings and working in partnership with both SACL and the Government of Saskatchewan Ministry of Social Services, the third study (including student Anar Damji) departed from the official voices that dominated the first reports to listen to and learn from all stakeholders impacted by SDF, including recipients of SDF-like arrangements (called "self-managed contracts" in Saskatchewan), their families, supporters, and government representatives. It aimed to put faces and voices to the story, to identify the champions inside and outside government, and to build a collaborative, inclusive, and respectful process in order to capitalize on the momentum. Ultimately, it aimed to answer the following central research questions:

How have self-managed contracts helped or hindered lives, and how have developing and maintaining contracts impacted individuals, families, caregivers, and supporters?

What have been the outcomes and impact of SDF-like arrangements on community structures, program delivery, and policy?

Research design and methodology

With the support of the SSHRC funding and a CUISR student intern (Emily Hurd), the research team was now connected with and learning from the national Individualized Funding Discussion Group (Dozar, et al., 2012). The national group was tasked with leading dialogue and sharing data that would address both government and community needs and concerns, gaps in research, communications strategy to answer stakeholder questions, develop a standardized evaluation framework (including outcomes) for national implementation, and conduct pilot evaluations. The 2012 report identified six provinces already implementing SDF, which rather than letting resources define needs, built funding around individual needs. Key framework elements include:

- Eligibility: Criteria that are fair, transparent, and based on disability-related support needs.

- Funding: Based on person-directed plan developed by the individual; involves direct payment to the individual (or designated supporter); is subject to transparent ceilings and guidelines.
- Planning: Directed by the individual, and involves planning functions that are separate from eligibility, service delivery, and funding functions.
- Supports for Implementation: A support structure is necessary, which may be informal (Support Circle) or formal (Microboard); supports are distinct from funding, eligibility, and assessment processes.
- Quality and Evaluation: Standards, safeguard, and ongoing evaluation are in place.
- Accountability: Individuals are accountable, and procedures are both simple and flexible.

The study also built on focus group work that was organized by the provincial Advisory Table and facilitated by CUISR faculty, students, and staff. These focus groups worked to identify myths and stereotypes, the possibility of collaborative governance, the need to tap into voices that are not well represented, the meaning of sustainability, the necessity of leadership and of ensuring consistency and a common vision without sacrificing complexities, and the importance of recognizing SDF as a choice and an option, not an exclusive or comprehensive answer.

Semi-structured interviews proved especially useful for probing more deeply into the thoughts and feelings of participants. In this project research design, debriefing, analysis, and dissemination engaged the multi-stakeholder research team, the Advisory Table, and government representatives. This process was critical in making visible the systemic factors that had hindered productive dialogue, and the organizational cultures that had so powerfully shaped engagement of key players and silenced voices that needed to be heard inside and outside government. It was a process of disrupting old habits and changing relationships that helped to build respect and trust, to identify champions, and to begin forming allies of those who had too often been considered adversaries.

Target group	Self-advocates	Family members, guardians, advocates, supporters	Government employees, SDF advisory table members
Target participation	8-10	10-12	6
Actual participation	3	10	9

Research findings

The literature review confirmed anecdotal and research evidence on the cost-effectiveness and life changing impacts of SDF. Interview participants spoke powerfully about their experience before contracts, particularly on only having access to poor and minimal services, low quality of life, anxiety, insecurity, frustration, and isolation and powerlessness. The following questions summarize their responses: "we felt in way over our heads", "my child wouldn't have survived", "you feel like you are in jail because you can't do things." The record was clear on the financial, emotional, mental, and physical distress for those who experienced a lack of voice and choice before obtaining contracts. Families felt the burden of over-reliance on them: "all that change, it affects them, the problems go up", "our kids end up back on our doorstep."

The process of obtaining contracts proved daunting for all but those with professional knowledge and skills. Without community supports, most felt "we'd be lost." For all respondents, the task took years. Families felt there was an enormous burden on them to find information in face of a culture of secrecy: "we phoned and phoned, begged and begged, and wrote and wrote. It moved up until 'someone' listened." Participants felt the particular injustice of compromised access and equity for those already stretched emotionally, physically, and financially thin. Families faced accusations and inquisitions related to their sources of information, "how did you hear about this?" Access to information was further impeded by the high visibility of block-funded options and agency access to media and

government for photo ops. 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: "you don't tell a parent that. We know that already because we pay a lot on our own."

Similarly, while government officials understood the process as a negotiation, families felt they had few choices in a system marked by "territorialism and not enough transparency", where any option was "a well-kept secret". In fact, participants provided statements like, "I don't remember being given a choice" and, "people get worn down, they can't fight anymore." Adding to the difficulties was stress caused by parents' perceptions that officials were questioning and undermining family member competencies. All in all, a process designed to enhance control and choice ended up aggravating uncertainty and feelings of hopelessness.

Experiences of self-managed contracts as transformative funding models confirmed literature review findings. Making decisions based on predictable resources, "build[ing] bonds and connections in the community," enjoying access to educational and other opportunities, and having a life were repeated themes. The freedom to be one's own boss, "I like my freedom", to experience an enlarged network, and to take on new challenges and commitments, "I do physical exercise...and I get to go to university", were widely reported benefits. Learning to trust their own judgment, "we know best", and not defer to experts was an important learning outcome 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 of support were important for families who were able to share rather than carry all of the responsibility for their children: "We don't have total responsibility. He has people in his life."

Although quality of life improved and some of the financial stress was alleviated, many emphasized that the financial supports were still inadequate. Families remained critical sources of financial, physical, and emotional support for their children. Time commitment, management skills, contract and program development, and staff retention remained issues in the absence of clear contract guidelines and expectations. Nevertheless, the commitments opened doors, and gave flexibility and

choice, so that the possibility of losing the self-managed contract was unimaginable for interviewed families: "it would be miserable around here. I don't know what we'd do."

Although the Ministry of Social Services partnered in and supported the study, some potential participants did not participate for fear of losing support. Such fears proved a powerful silencing mechanism. Participants also recognized CBO and agency fears that SDF might mean reduced funding to deliver their services. Government officials recognized changes in the environment and in informed parents and self-advocates who were demanding inclusive rather than sheltered workshops. Yet, despite anecdotal and research evidence on the SDF model as enabling, efficient, and even cost-effective, as well as significant achievement and change in government supports for individuals living with disabilities, there were significant tensions and ambiguities in the responses of government representatives.

If there was fear among individuals and families, there was also fear among government personnel who did not feel entitled to speak on policy issues or to present evidence and be part of the process of change. Self-censorship was related to fears about family competencies, over-servicing, over-claiming of benefits, budgetary constraints, costs, accountability, and to the need for a champion within government to license thinking outside the old conceptual and program boxes.

Champions did emerge within the Ministry, as a minister open to listening and learning from families and policy people was involved in the Advisory Table and in reviewing draft findings. In addition, the premier made a public commitment to make Saskatchewan, "the very best place in Canada to live for those with disabilities." Whereas the study found government officials representing self-advocates as themselves, the problem was that, "it's been put into place for those who don't fit in the current services provided." However, there emerged a new respect for different perspectives and understanding of the particular barriers within a system and culture overly invested in the status quo.

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, which 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 on the menu of services available to those who are willing and able to take on the responsibility and workload. With this option, individuals give their family members voice, choice, and independence in making decisions on their care and their lives.

Although it took an enormous investment of time, people, and resources, the commitment of this socially innovative process to build trust and share knowledge, to unlearn and relearn, and to navigate different organizational cultures and politics over several years, has had an impact on individuals and families and on each of the partner organizations and individuals. In 2014 the Ministry of Social Services has continued to be open to allowing families do what families do by engaging in an ongoing process of co-construction and co-production of policy, bringing previously underrepresented voices to the forefront (Vaillancourt, 2009).

Currently, the Ministry is working on the development of the SDF option and hosting a pilot project with participants selected on criteria developed collaboratively with the Ministry and the SDF Advisory Table. Evaluation and information gathered during the pilot project will be used to review and refine the proposed SDF option. Our collaborative research practice proved an important site of learning, relationship and capacity building, and community renewal. By mobilizing and sharing knowledge across communities, we were able to develop new models for policy and practice without the luxury of new resources.

Domains of research excellence

Although reflexivity is often resisted in academia and the community as indulgence, inaction, delaying research results, or adding to report writing challenges, for us it was part of a conscious commitment to go beyond lip service to ensure community engagement and equitable participation. It is an important investment in trust building, and over time can create an enhanced sense of people and place and our responsibilities to them. To the extent that we deepened relationships in the research protocols, the

research is as rigorous as it is relevant. The CUISR 3Rs is an investment in extended timelines and an iterative process of listening, linking, learning, and leveraging together to promote community relevance, transformative ends, and collective benefits.

In the effective engagement of diverse communities, and respectful and ethical collaboration, relationships themselves become a vital resource in enabling innovative practice. By pooling expertise and experience, building trust through the redistribution of intellectual authority and modest resources, mutual and collective transformation can revitalize our sense of community, understanding, and capacities for innovation.

Links

http://usaskstudies.coop/socialeconomy/files/LLL_Final_Reports/Report_CL1_15_SK.pdf

http://www.usask.ca/cuisr/sites/default/files/SACL%20Final%20Report.pdf

http://www.usask.ca/cuisr/sites/default/files/Self-Directed%20Funding_Final.pdf