

Individualised Support and Funding: building blocks for capacity building and inclusion

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ABSTRACT *The paradigm in disability supports is shifting away from institutional services and professional control towards self-determination and community involvement of people with disabilities. The assumption that the best way to provide disability supports is for government to give money to agencies or services, rather than directly to people with disabilities and their support networks, is being challenged. This article reports on findings and themes from a Canadian study that investigated individualised funding projects from different parts of the world. Ten of fifteen of the most ‘promising initiatives’ were selected for more detailed study and analysis. Projects analysed were from Canada, the US, and Australia. Themes emerging from the study included the fact that values and principles mattered, a policy framework provided coherence and equity, infrastructure supports for individuals were separate from service system, the facilitator–broker role differed from case management, allocation of individualised funds was designed to be equitable and accountable to the funder and person, and a ‘learn as you go’ philosophy maximised positive outcomes. This research project demonstrates that individualised support and funding, when embedded in the new paradigm of disability and community, builds capacity of individuals, families, and communities.*

Introduction

A worldwide paradigm shift is occurring in the disability field. Regardless of whether the focus is physical disabilities, learning difficulties, or mental health service users, the paradigm shift reflects a move away from institutional services and professional control towards an emphasis on self-determination and community involvement (Nelson *et al.*, 2001; Pedlar *et al.*, 1999; Stainton, 2000). The independent living movement, for example, has stressed the centrality of consumer control and community participation to ensure rights and citizens (DeJong, 1993; Hutchison *et al.*, 2001).

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People who are leading the movement to create community supports that provide more choice and control for people with disabilities identify several anomalies with current human service systems. Traditional paradigms assume that people with disabilities need to be congregated, away from real community, in institutional or rehabilitation settings where intensive supports are best provided. Although these interventions may help, the anomaly is that these practices often limit people's community involvement and citizenship (Carling, 1995). Another dominant assumption has been that the best way to provide disability supports is for government to give money to agencies, which in turn provide agency-directed services. The dilemma of agency-directed services is that the provision of disability supports are generally developed and implemented by agencies and their paid staff, limiting self-determination and direction by the individuals and families (Roeher Institute, 1993).

In response to these concerns, person-centered planning, individualised supports, community based options, and consumer driven initiatives are emerging in most areas of disability (Lord & Hutchison, 1998; Nelson *et al.*, 2001). These recent trends are gradually shifting control of disability supports to individuals and their networks. In some cases, especially for individuals with learning difficulties or physical disabilities, individualised funding is now considered to be an integral part of these individualised approaches (Laing, 1991; O'Brien, 2001; Stainton, 2000).

Embedded in the concepts of self-determination and community, individualised funding refers to the allocation of support dollars directly to the person, in contrast to a service agency. Although a traditional agency controlled approach works for some people, many people are required to 'fit' their lives around agency procedures and programs. Individualised funding allows people to choose where they will live, how, and who will provide support. Many individualised funding programs promote a holistic view of quality of life, looking at employment supports, community living, leisure pursuits, and relationship building (Roeher Institute, 1997). Individualised funding initiatives often have infrastructure supports that include independent planning or brokerage, that is usually independent of other direct services, enabling an individual consumer to have freedom to pick and choose from an array of available services and community opportunities (Brandon, 1991; Community Brokerage Service Society, 1996).

In many ways, individualised funding is consistent with the world-wide trend toward increased democracy, self-determination, and community involvement. Direct individualised funding of disability supports is viewed as one important element for ensuring that people have genuine options and control in their lives. While a growing number of opportunities are available for accessing individualised funding and planning, the reality is that relatively few people currently receive individualised funding (Zarb & Nadash, 1994). Some writers have pointed out that despite its potential, many people are suspect of the concept (Maglajlic *et al.*, 2000); this may be because individualised funding can be perverted due to narrow, technical implementation or undue focus on the funding aspects (O'Brien, 2001; Udisky, 1999). This article shares insights from an important Canadian study that investigated individualised funding projects from different parts of the world (Lord, Zupko & Hutchison, 2000). [1]

How Individualised Funding and Support was Studied

This study on individualised funding was part of a strategic direction of the Individualised Funding Coalition of Ontario, Canada. In early 2000, the Coalition, which is a broad based provincial group of individuals and organisations, initiated a Roundtable on Individualised Funding. A parallel activity, an extensive review of individualised funding programs worldwide, was funded by the Ontario Federation of Cerebral Palsy. The goal of this review was to develop understanding, awareness, and strategies for building the capacity of individuals, families, communities, and government to implement individualised funding for people with disabilities. Over the course of several months, the emerging findings of the review were utilised to inform the roundtable discussions and their final report. The review, *More Choice and Control for People with Disabilities: Individualised Support and Control* (Lord *et al.*, 2000), provided the basis for this article. The review had several objectives:

To identify themes and lessons learned from several existing individualised funding projects in Canada and around the world.

To identify themes and lessons learned from research, literature, and government documents related to individualised funding.

To move the individualised funding agenda forward for individuals with disabilities.

In order to respond to the goals and objectives, the following process and methods were utilised. The review team began its work by gathering research documents, evaluation reports, and program descriptions of projects, programs, and policies related to individualised disability supports and funding. An initial documents analysis identified the purpose of each project, program descriptions, policies, and evaluation reports, including consumer and family feedback. Based upon this analysis, ten of fifteen of the most ‘promising initiatives’ were selected for more detailed study and analysis. Projects not selected lacked adequate documentation, evidence of principles of individualisation, or external evaluation/research. The selected projects included four Ontario, Canada projects: Ontario Direct Funding Project (Toronto), Individualised Quality of Life Project (Toronto), Windsor–Essex Brokerage for Personal Supports (Windsor), and Choices Project (Thunder Bay); three direct funding initiatives in Western Canada: Individualised Funding (Alberta), Microboards (British Columbia), and In the Company of Friends (Manitoba); one project in Western Australia: Local Area Coordination and Direct Consumer Funding; and two projects in the US: New Hampshire Self-Determination Project (New Hampshire) and the Michigan Self-determination Project (Michigan).

We then built a template for analysing each promising initiative in detail. This template included demographics, mandate–policy, rationale–goals, who the program is for, criterion for receiving support dollars, who manages the program and how they do it, program strategies and infrastructures, support services utilised in the community, how the person manages the money, and evaluation research, successful features—lessons learned, and less successful features—lessons learned. Using the

template, each promising project was analysed and written up in detail based upon program descriptions, policy frameworks, and evaluation reports from each site. Where there were gaps in the information for the template, interviews were conducted with leaders from the projects.

Using the case study descriptions based on the template, a cross-site analysis was completed. This involved the identification of common categories and themes across the promising initiatives. When a category occurred in many sites, it became a common theme. Where there were contradictions, these were also noted. These common themes were then written up as lessons on how best to construct individualised supports and funding. When writing up the lessons, we used examples from projects to illustrate the patterns and themes.

Three Effective Individualised Funding Initiatives Worldwide

In this section, abbreviated case studies will be presented from three of the ten promising projects documented. For each of these initiatives, we describe the history, mandate, goals, implementation approaches, and successes.

Individualised Quality of Life Project (Options)—Family Service Association, Toronto, Ontario

Toronto is a large urban center, with a population base of over 3 million. In 1997, the Family Services Association (FSA), with support from the Ministry of Community and Social Services (MCSS), spearheaded The Individualised Quality of Life Project (IQOL), now called Options. FSA was selected because of its independent status (does not provide direct service), reputation in the community, experience in planning and case management, and capacity to administer a large program and budget. This project was designed to support 150 families during the pilot phase. FSA was given responsibility for person-centered planning with individuals and families, as well as for allocating funds to support the individual plans.

In general, the project focused on quality of life and worked to increase choice and control for consumers and families. It also focussed on network building and strengthening families as a primary support in individuals' lives. Finally, it aimed at increasing community participation—integration and improving access to and effectiveness of service providers. This focus on quality of life put the project focus primarily on individual planning and community involvement, and only secondarily on the funding required to make this happen.

All participants had learning difficulties, of varying types and degrees, and some individuals also were mental health service users as well. For funding approval, each individual plan needed to: (a) involve the individual in planning; (b) promote choice, dignity, and respect; (c) be accountable to the individual and his/her family; (d) reflect a vision for life in the community; (e) strengthen family and other significant relationships; (f) consider all existing community resources; (g) not duplicate existing funding sources; and (h) reflect market values. No formal needs assessments were required. The individual plan was submitted to the project

manager, who approved budgets under \$20,000. Larger budgets were approved by a two-person committee of FSA senior management (maximum amount of \$45,000 per individual/family, plus \$5,000 emergency money).

Individuals/families had access to *community resource facilitators* specifically to aid in planning, network support, and building personal networks. The facilitator was seen as a ‘catalyst, focuser,’ someone who helped families clarify. Getting to know the individual and the family well was a key part of this work. The role was intended to be distinct from case management. The facilitator was a connector, knowledgeable about community and resources. Facilitators generally spent a lot of time with families in the early stages of their work together. The process was person-centered, and many families were assisted in the development of a support circle or network.

The Roehrer Institute’s evaluation report (2000) found largely positive results of the project: individualised funding was a viable and useful direction; separating planning from services provided independence from service providers for families and social networks; facilitation in formulating personal plans was seen positively by all stakeholders; widespread use of generic resources was cost-effective for the Ministry and encouraged community development; reasonable ‘caseloads’ (about 24) allowed facilitators to function effectively; support network development was fostered throughout the project, and this led to successful outcomes, especially for adults; the ability of individuals and families to make decisions about support arrangements contributed to the success of the project; and the ability of families and individuals to hire coordination support enabled greater accountability to individuals and families.

Local Area Coordination and Direct Consumer Funding—Western Australia, Perth, Australia

More than 1.2 million people live in Perth, the capital of Western Australia, while 500,000 people live in rural areas. Local Area Coordination (LAC) was first tested in 1988 in rural parts of Western Australia, the purpose of which was to increase self-sufficiency of people with intellectual disabilities. The initial program was so successful that by 1993 there were 27 coordinators located in rural areas, and 11 located in urban areas. By 1998, the program was doubled to 82 coordinators, with the expressed goal of making the program available to all people with physical disabilities or learning difficulties who requested it by the year 2000.

In 1993, the government passed the *Disability Services Act*, which established the Disability Services Commission for the state, and allowed for grants to be approved to individuals. The commission assisted people with disabilities and their families in a variety of ways including; ‘by providing people with disabilities with funding to enable them to purchase their own support services.’ The commission’s mission was to advance the equality of opportunity, community participation, and quality of life of people with disabilities throughout Western Australia.

Local Area Coordination had a clear charter; ‘to support people with disabilities and their families to identify their own needs, determine their preferred services and

control the required resources to the extent they desire, so that they can pursue their chosen lifestyle.' There were two kinds of funding, tied and untied. Untied funding was designated for 'one-off' funding needs, were modest, and often used in an emergency, at the coordinators' discretion. Tied funding was normally for larger amounts and required individuals and families to submit a detailed plan. The tied plan proposal must follow several headings, including: profile of current life experience; individual and family goals; support details and costs; and supports will be in place which were not part of the funding. It was expected that people would use informal supports before they accessed paid supports.

Planning was completely separate from services. This was accomplished through the utilisation of the local area coordinators, who worked from a sound value base and set of principles. Each coordinator or facilitator spent a lot of time with individuals and families, getting to know people's strengths and needs. Coordinators also provided information, assisted people in building their support networks, and helped people to purchase their own supports via direct consumer funding. Direct consumer funding can be utilised for several purposes, including respite support, personal support, education support, professional support, leisure support, employment support, equipment support, and accommodation support.

The LAC has had several major evaluations since 1993. In 1996, a two-year study was completed, which included case studies of 15 individuals–families, survey data from 169 families, and expenditure analysis for 880 people (Lewis, 1996). In a carefully constructed experimental design that utilised a control or comparison group, several findings were identified. Successful features or lessons learned included: the effectiveness of the project stemmed from the combined impact of local coordinators and direct consumer funding; twenty discrete positive outcomes were related to individualised funding (the quality and quantity of supports improved, as well as the well being of the person and the family); direct consumer funding was a first choice option for those who wanted it. Consumers supported by individualised funding were highly positive about the project. Consistently, about 30% of consumers and families chose this option; the local area coordination was value-based and manageable. When starting up, each coordinator had 30–40 consumers. A rule of thumb was that one-third required minimum support, one-third had moderate needs, while one-third required extensive support; and coordinators were very focused on building the capacity of the individual, family, and community.

New Hampshire Self-Determination Project—New Hampshire, US

The project was funded in 1995 by the Robert Wood Johnston Foundation as part of a nationwide project to implement self-determination for people with learning difficulties. The New Hampshire Division of Mental Health and Developmental Services supported area agencies in their efforts to create new approaches to meeting the needs of people who have disabilities and their families.

Stated project goals were: to increase consumer choice and control in supports and services; to increase community capacity to provide such supports and services in non-traditional manners; to facilitate organisational change at all levels (state,

area agencies, provider agencies); and to reduce costs. Individual budgeting was focused on a minimum of 20 people in each region per year (three regions added per year).

Project leadership was the responsibility of senior administrative staff within the Division of Mental Health and Developmental Services. The project management team comprised of the project director, the project coordinator, the area agency directors of participating regions, and the University of New Hampshire's Institute on Disability. There was a 40-member advisory committee made up of family members, consumers, state and regional service system staff, the Institute on Disability, advocacy organisations, developmental service directors from other New England states, and members of the community.

The project used an action learning stakeholder approach that included ongoing leadership development for groups of stakeholders. The training focused on collaborative problem solving and communication skills, as well as training for case managers on planning and budget development. Because the project focused on systemic change, there were a number of working groups addressing different aspects of these changes, for example, education and training, community organisation, and policy development.

One of the goals of the project was to identify and utilise new forms of community support including: service brokerage; family support cooperatives; purchasing alliances; staff cooperatives; and other creative approaches to meeting needs. The project also utilised fiscal intermediaries (independent agencies that handle the money) to assist persons in managing their money.

Two evaluation tools were developed (New Hampshire Self-determination Project, n.d.). A survey developed by a statewide Quality Network Committee was designed to assess consumer satisfaction with services. The second was a survey called *Who Decides?* It was developed and administered by members of People First New Hampshire to assess consumer choice and control over services. Other evaluation data included documentation of organisational change, case studies of the participants, and cost reporting. Evaluation activities took place annually and included consumers, parents, and staff. From these evaluations, some of the lessons learned included: a responsive service system depended upon the involvement of the people who use the services in all aspects of system planning, design, and development; open communication between all levels of staff was important to the success of the project, as was the ability to engage in self-observation and critique; area agencies were looking at the possibility of creating individual budgets for all consumers and not just those who are project participants; the project showed that system change is difficult and that all stakeholders do not have equal access to information and technology.

Cross-site Analysis: lessons learned

During the review of promising individualised funding initiatives, several themes or lessons emerged about language, principles, policy, and implementation. Taken as a whole, they provided important insights into how to construct a viable approach

for developing individualised disability supports and funding for individuals who have disabilities.

Values and Principles Mattered

Clearly stated values and principles guided each of the individualised funding projects. Many of the explicit values reflected a commitment to self-determination and community participation. People receiving disability supports were viewed as citizens with the same rights as other people. In fact, often these rights promoted the idea that disability supports should be an entitlement, helping to ensure that people with disabilities have an equal opportunity to participate in society. The values of these projects were consistent with values espoused by disability consumer movements.

Principles, while similar to values, acted more as guides to action. They provided a set of boundaries and directions within which projects operated. Most individualised funding initiatives did not distinguish between values and principles, but made their values and principles explicit and usable. For example, the self-determination projects in the US were based on four guiding values and principles related to freedom, authority, support, and responsibility. The Individualised Quality of Life Project (Options) in Toronto had five principles that guided its work related to enhancing dignity, community integration, support networks, comprehensiveness, and continuity of supports. The Disability Services Commission of Western Australia Direct Funding Project was driven by principles that reflected broader values of access to information and choice, network building, person-centered planning, and community participation.

In almost all of the projects reviewed, the focus of the principles was on both formal and informal supports. This theme reflected two broad trends: the idea that building strong networks of support enhanced health and inclusion; and that there were anomalies or limitations to formal disability supports. In all projects, informal supports provided opportunities for relationship building and community connections. In the Company of Friends (Manitoba), for example, relationship building principles guided the work of staff and families.

These individualised funding projects intentionally wove together principles related to individualised planning, support, and funding. Individualised funding was seen as a mechanism to enhance these concepts and quality of life. Typically, each individual developed an individualised plan that formed the basis for individualised supports and funding. In most projects, individualised funding was embedded in the language of community and social support. Projects stressed concepts such as building support networks, person-centered planning, and community inclusion.

A Policy Framework Provided Coherence and Equity

Half of the individualised funding projects were based in national or provincial policy. We found that policy frameworks provided both coherence and equity.

Coherence referred to the consistency across levels (provincial policy, community organisations, and individual projects). In a minority of sites, a policy framework provided principles and guidelines for community practice, and ensured that resources supported that practice. In these same sites, a policy framework also supported equity by ensuring that everyone who was eligible was served, and that regional differences in service delivery were minimised.

Some policy frameworks that addressed individualised disability supports were based on legislation. Western Australia was the first of Australia's six states to adopt individualised funding. Based on the *1993 Disability Services Act*, Local Area Coordination was developed to increase the self-reliance of people with disabilities. Although policies embedded in legislation were, in many ways more sustaining, some sites found it was not always necessary to create new legislation for individualised funding initiatives. In Ontario, for example, there were already regulations in place that provided for individualised disability supports and direct funding. In most instances, these regulations had been used to give grants to agencies that provided attendant services or personal supports. The principle of self-determination was central to these regulations, with the expectation that the individual with a disability would have to direct his/her own support. In the Canadian context, this regulation has proven to be discriminatory and inconsistent with the disability consumer movement's principles of equity and inclusion.

A policy framework was no guarantee that an individualised funding project would be successful. In Alberta, where individualised funding had been in place since the mid-1980s, the Alberta policy framework provided almost no infrastructure support for families and individuals, and unencumbered planning was rare. In terms of implementation, these were serious limitations.

The most coherent implementation of policy utilised both piloting and phasing, which allowed maximum opportunity for evaluation, learning, and change. Most projects initially had pilot projects that allowed them to test out concepts and evaluate processes and outcomes. Because individualised funding arrangements created major changes in disability systems, most projects carefully phased their work, either starting with a small number of individuals, or beginning in a small geographic area. As part of project phasing, several projects that lacked provincial or national policy worked hard to develop local policy frameworks. Choices in Thunder Bay, Ontario, for example, utilised a community-wide process to develop policies that would shift resources from agencies to individuals and families.

In conclusion, we found that a policy framework was important for building sustaining approaches to individualised disability supports. Only a third of the initiatives we studied had coherence among policy, principles, and practice. Well understood principles, a blend of infrastructure supports for individuals/families, a direct funding mechanism, and a broad approach to accountability were evident. The lack of policy coherence and equity in many projects points to a serious gap that must be addressed in order for individualised funding projects to become more sustaining. In addition, governments and projects could rely more heavily on national and provincial consumer groups for direction on policy development.

Infrastructure Supports for Individuals were Separate from Service System

Nine out of the ten initiatives created separate, independent infrastructures. Infrastructure supports for individualised funding were supports that helped individuals and families to plan, to access resources they needed, and to provide financial management assistance for direct funding. Infrastructure supports in these sites included a broker, facilitator, or network builder. This person was vital to the individualised process and was free of conflict of interest from service providers and government. Projects emphasised that not having facilitators attached to the service system enabled them to put all their energy into supporting the person and family as opposed to being concerned with program and service issues. Consumers and families in several projects expressed satisfaction with having an independent facilitator assist them with planning and network development.

The US self-determination projects created 'fiscal intermediaries' that provided technical and financial supports. This infrastructure allowed the individual or family to focus on planning, hiring, and managing staff, while another organisation handled the financial and legal issues. Some self-determination projects also established 'support brokers' to work with individuals and families in developing their networks, goals, and plans. In some projects, the planning and network functions were separated from the financial supports.

Five of the ten projects were started as independent projects, whereas the other five were part of service reform initiatives. The five independent projects, including the Western Australia local area coordination and the Ontario Direct Funding Project, were able to get their initiatives and their independent planning functions underway fairly quickly. The assumption was that these projects would create choice and options for individuals. The five projects that were part of service reform, including Windsor–Essex Brokerage for Personal Supports, Choices in Thunder Bay, and the US self-determination projects, spent extensive amounts of time trying to reform the system and developing an independent planning function within the system. In one self-determination project, case managers previously attached to residential services, were replaced by independent support brokers that were free of conflict of interest. In the move to unencumbered planning, system reform projects found this to be a challenging process of change that was resisted by some stakeholders in the system, namely service providers. While service reform is important, our analysis suggests that independent projects that offer genuine choice and control to consumers may be the strategy to promote in the future.

Facilitator–Broker Role Differed from Case Management

The role of the independent facilitator was very similar across sites. Whether the person was called a support coordinator, animator, facilitator, or broker, several sites noted that the role was quite different from that of a case manager. Job descriptions and experience from nine sites pointed to the importance and practical aspect of this lesson. Case managers' roles tended to be much more limited, case loads larger, often affiliated with one agency, and more professionalised. Functions of facilitators mentioned most often in nine sites included:

- Build relationships with individuals with disabilities, their families' networks, and the local community.
- Provide information about network building, individualised support options, community resources, and direct funding.
- Help the individual build a social support network (circle, cluster, group, network), that would be willing to meet regularly.
- Assist individuals, families, and support networks to plan what the person wants, using a strengths-based approach (dreams, vision, outcomes, likes, dislikes, priorities, etc.), often facilitating network planning meetings.
- Help individuals and their networks to develop detailed support plans and budgets for submission to the funder.
- Facilitate community connections in both formal and informal settings.
- Assist people to find, purchase, or create supports that may be required and provide ongoing implementation support.

We found that each of the functions described above has a richness and texture. For example, assisting individuals to plan was reflected in a variety of creative ways. Person-centered planning was at the heart of the Windsor–Essex Brokerage for Personal Supports Project. This project emphasised that the person with a disability was the director of his/her planning. Others in the person's network were encouraged to participate and assist the person to think about dreams, goals, and support requirements. Project evaluations showed that many consumers and families appreciated person-directed planning because it enabled them to identify and utilise a variety of informal community supports that had not been identified prior to the planning. Several projects, such as *In the Company of Friends* (Manitoba), found that network building involved identifying a support group that would meet regularly to assist the person in expanding connections to community life.

Several projects stressed the unique qualities of the facilitator. These qualities exemplified the importance of values, relationships, and skills. Several project coordinators noted that the most effective facilitators were people with broad community experience, so that people's choices with their individualised funding were respected. Some projects noted that people who had worked for years within the traditional disability sector were often not suited for this individualised work because they were not sensitive to consumer dissatisfaction with existing services. Microboards in British Columbia learned that facilitation combined with individualised funding was critical to enhancing a textured life for people with disabilities. As facilitation grows in importance, it will be critical to develop appropriate value based training and support. Only a few of the projects have thought systematically about this issue.

Allocation of Individualised Funds was Designed to be Equitable and Accountable to the Funder and Person

Developing a fair and equitable approach to the allocation of individualised funds had been a challenge for several of the projects. There were different approaches to allocation. Each one had pros and cons which are briefly discussed here. First, the

Area offices of the government had an adjudication panel that made allocation decisions for funding and then released the money to individuals. Both Alberta, Canada and Western Australia used this approach, which depended on the good will and strong value-base of government. Second, the community appointed an adjudication group that made recommendations to government. In Windsor–Essex, a community priorities panel made up of consumers and families made recommendations to the local area office of government, which then released the money to individuals. This approach seemed workable, gave control to the community, but meant that individuals and families had to make tough decisions in regard to their peers. Third, money for individualised funding was released to one non-service organisation, which then decided how to set priorities and allocate the money. The Toronto Quality of Life Project and the Ontario Direct Funding Project both used this approach. These projects had adjudication advisory groups, but it was senior managers who approved the individual funds. The dilemma with this approach was the perception that the funding process was too close to the infrastructure supports, with the same managers adjudicating who also supervised infrastructure supports. Although many projects believed that government should have the primary responsibility for allocation, most governments appeared resistant to playing this role. When communities took responsibility for allocation, they had to develop approaches based on principles of equity and effective accountability.

The principle of equity was served when a range of people with disabilities had equal access to individualised funding. Both Alberta and Western Australia served people with learning difficulties and physical disabilities, ranging in needs from mild and moderate to extensive. However, mental health service user issues were not included in either mandate. More typically, projects tended to serve only one disability group. While equity may have been served in a particular project, government policies and system priorities were seldom equitable. This creates a dilemma for individualised funding projects that attempt to create innovation within a broader policy framework.

Most of the ten sites emphasised the importance of accountability to the person and the state. Some sites stressed that being accountable to the person and their plan was a very different way of working. Projects had developed very clear sets of procedures and guidelines for tracking and utilising funds for disability supports. Our analysis of the evaluations of these individualised funding projects showed the accountability mechanisms to be very effective. This finding might be important for governments whose preoccupation with accountability sometimes limits their interest and capacity to support individualised funding.

'Learn as You Go' Philosophy Maximised Positive Outcomes

When implemented with sound planning process, principles, and policies, individualised funding projects showed positive outcomes and enhanced quality of life. To obtain such outcomes, projects and leaders noted how important it was to learn from their own and others' experience. Leaders we interviewed were very knowl-

edgeable about individualised funding projects in different countries. All the projects had extensive evaluations completed on their initiatives. These evaluation processes provided opportunities for projects to learn about themselves in detail. In most cases, such as In the Company of Friends (Manitoba), people were using their evaluations and feedback from consumers to make changes and adjust their strategies. This spirit of openness to addressing the lessons that came from on-the-ground experience of developing a project was particularly crucial for innovative approaches such as individualised support and funding. Several projects, such as Microboards in British Columbia, learned that money was only one of the elements of individualisation. Putting too much energy into the funding mechanism, without attending to related elements such as network building and person-centered planning, could create a false impression that having money alone would solve serious disability issues.

The paradigm shift to individualised supports and person-centered planning has been accompanied by a shift in how we assess improvement and change. Examining positive outcomes which individuals with disabilities experience when receiving individualised support and funding has become an important way to determine change. Personal outcomes that were identified most often in project evaluations by consumers and families were: increased control and choice; expanded community presence and participation; and expanded relationships with family and friends. There were also personal outcomes related to social and leisure participation, employment, and education. Engaging and asking consumers and families for their ideas and feedback is a key strategy for individualised funding projects.

Most projects we studied also assessed community outcomes. These included increased capacity of families, networks, and the broader community to plan effectively, enhanced partnerships in the delivery of flexible supports, and individualised supports that were cost effective. Three projects utilised experimental designs with a control group, which showed that costs were similar to traditional programs, but with outcomes that were much more positive. This indicated that the cost effectiveness of individualised funding was very high. Several projects, such as Microboards in British Columbia, found that relationships were a critical factor in their success.

Projects stressed that responding to concerns and criticisms about individualised funding projects was an important part of their work. One concern related to the market-driven nature of individualised funding. An individualised funding approach does indeed shift the power from the supply side to the demand side. In other words, with individualised funding, consumers and families had the power to purchase services from whomever they wanted. Critics charged that this leads to privatisation, uncertainty, and a low wage sector. We found this can also have a positive effect of giving genuine options to consumers and breaking up service monopolies. Depending on the context and policy, this may either lead to privatisation, as it did in Alberta, or it could enhance the non-profit sector, as it did in Western Australia. In Western Australia, the government was willing to fund infrastructure supports and technical supports, which enabled the non-profit sector to remain strong. In Alberta, the government did not fund infrastructure supports

directly, but individualised funding agreements allowed people to hire brokers. Within this context, Alberta became highly privatised, and limited in its capacity to facilitate personal and family networks. It is also true that an individualised funding approach could possibly lead to a low wage sector. Our research suggested that governments had a key role to play in setting employment standards and wage guidelines. The Ontario Direct Funding Project provided a reasonable wage standard for attendants. Other concerns that projects had to address included: a cap on funding; lack of a policy framework; and challenges in recruiting and maintaining effective support staff. Projects we reviewed were paying various degrees of attention to these important criticisms.

Conclusion: Individualised Support and Funding as Building Blocks for Capacity-Building and Inclusion

This research project demonstrates that individualised support and funding, when embedded in the new paradigm of disability and community, build capacity of individuals, families, and communities. There are several important themes from this study that people with disabilities, families, human services, and communities need to be aware of in order to increase consumer access to this important, but underutilised innovation.

The information gathered from ten projects in three countries affirms the need for a well thought out framework for consumer-driven, individualised disability supports and funding. Our research suggests that this framework must be fundamentally different from the direct service models utilised by most community agencies. Frameworks based on self-determination, community, and individualised approaches must stress capacity building as the goal, rather than service reform. In the projects we studied, this has meant strengthening choice and control of consumers, developing social networks with individuals and families, and expanding community connections. A framework must also provide a direct funding mechanism and infrastructure support for individuals, such as facilitators and brokers (Dowson & Salisbury, 2000; Pedlar *et al.*, 1999; Ontario Round Table on Individualised Funding, 2000).

Individualised funding within this context serves to clarify and extend our definitions and understanding of key concepts within the emerging disability and community paradigm. As we build a framework for consumer directed support, the new paradigm provides a starting point. Its focus on empowerment, self-determination, consumer control, community integration, and access to valued resources are all elements of capacity building (Carling, 1995; Nelson *et al.*, 2001). The language of the new paradigm has stressed or emphasised consumer-driven approaches and individualised support. Our research suggests that many current frameworks for implementing the new paradigm in communities are often limited. How can consumers control and direct their own lives when something as fundamental as their disability support funding is outside their control? How can a

consumer have genuine choice when people facilitating their planning for support services are often employees of the very agencies that provide the support?

Furthermore, disability policies, to a large extent, tend not to be an integral part of the broader community. Citizenship, public good, and civic society dominate our collective consciousness when thinking about community (Saul, 1995; Schwartz, 1997). Some policy makers and other important players in the disability field are recognising this limitation of disability policy and are attempting to develop broader policy frameworks that include components based in real community. Individualised support and funding, when implemented thoughtfully and with compassion, recognises individual needs for ongoing support, while also utilising the wider community as a rich context for participation and contribution.

People with disabilities no longer want or need to be protected from community, but require mechanisms for embedding their lives in community life. Innovation will be required by governments, the non-profit sector, and wider civil society for these mechanisms to truly reflect the emerging values expressed in this paper (Light, 1998; Pedlar & Hutchison, 2000). We have learned that individualised support and funding, in and of themselves, provide no guarantee that people's lives will be better. Their potential lies in their individual nature, combined with a focus on building community capacity, network building, and unencumbered planning. When these elements are based in policy that is broad based in its conception, individualised support and funding can be seen as critical elements of the new paradigm of disability and community.

NOTE

- [1] Copies of the report on which this paper is based (*More Choice and Control for People with Disabilities: individualized support and funding*—Lord, Zupko & Hutchison) may be obtained from Ontario Federation for Cerebral Palsy, 1630 Lawrence Avenue, West Toronto, Ontario, Canada M6L 1C5. Tel: +1 416 244 9686.

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