# More Choice and Control

## For People with Disabilities

Review of Individualized Funding and Support

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*Ontario Federation for Cerebral Palsy*

**July, 2000**

**The Review of Individualized Funding**

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**Project Co-ordinator:** John Lord

**Researchers**: Barbara Zupko, Peggy Hutchison

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# Ontario Federation for Cerebral Palsy

1630 Lawrence Ave. West, Suite 104

Toronto, Ontario

M6L 1C5

Phone:    (416) 244-9686 or

Toll Free 1-877- 244-9686

Fax:        (416) 244-6543

Website: www.ofcp.on.ca

# Review of Individualized Funding

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# PREFACE

The goal of this Review of Individualized Funding was to develop understanding, awareness, and strategies for building the capacity of individuals, families, communities, and government to implement individualized funding for people with disabilities in Ontario.

The Ontario Federation for Cerebral Palsy (OFCP) undertook this Review as part of a growing interest in how people with disabilities can have more choice and control in their lives. OFCP has recently developed tools for understanding consumer rights, person-centered planning, and outcomes for people with disabilities. The lessons and insights from this Review will build on this broader framework.

This report is organized around both general and specific understandings. We begin by exploring how the move to individualized funding is consistent with shifts in thinking that are occurring in the disability field. Sometimes called "paradigm shifts," these changes reflect the desire of most people with disabilities to experience self-determination and community involvement. We then look at some of the lessons learned from numerous projects throughout the western world that have used individualized funding. Finally, we outline, in some detail, a few initiatives that have had some success in linking individualized support with direct funding.

The research completed for this Review was also utilized by the Ontario Round Table on Individualized Funding. The Round Table group, which met for several months in early 2000, used this research to develop principles, a policy framework, and implementation guidelines for a comprehensive approach to individualized funding in Ontario. The Round Table Report, entitled *Linking Individualized Supports and Direct Funding: Making Money Work for People*, is an excellent companion document to this Review. It is available from the Individualized Funding Coalition of Ontario.

Many people and projects were very helpful to the researchers during this Review. We extend our thanks to the numerous people connected with projects in Ontario and elsewhere who shared ideas, resources, and wisdom with us.

The research for this Review shows that individualizing disability supports and funding should be the next step in the evolution of services and supports for people with disabilities in Canada. This Review will be a helpful document for those who want to participate in this journey.

**John Lord**
Project Co-ordinator

# CHAPTER I:
# EMERGING PARADIGMS OF
# DISABILITY AND COMMUNITY

We begin our Review by exploring how the move to individualized funding is consistent with shifts in thinking that are occurring in the disability field. Sometimes these changes are called "paradigm shifts." A paradigm can be thought of as a set of basic beliefs that define the nature of the "world" and the boundaries and relationships within it.[1] Changes in views of disability reflect a growing emphasis on self-determination and community involvement. A report prepared by the Individualized Funding Coalition of Ontario entitled *Individualized Funding: A New Vision* shows that changes in thinking about disability are grounded in human rights.[2]

Thomas Kuhn, in his 1962 book *The Structure of Scientific Revolutions*, is quite instructive. Kuhn noted how paradigms become dominant and the people supporting them often become defensive when a new paradigm emerges. Kuhn noted that new approaches uncover anomalies or contradictions that are not well explained by the dominant paradigm. "Paradigm shifters" are people who draw attention to anomalies, thereby promoting wider acceptance of the new paradigm. In the course of completing this Review, we met many "paradigm shifters," people who are concerned with the limitations and anomalies of the current service system, and feel that alternative approaches are required.

*There is nothing so powerful as an idea whose time has come*. Victor Hugo

# Dilemmas and Anomalies
# with Current Service Systems

People who are leading the movement to create community supports that provide more choice and control for adults with disabilities identify several dilemmas and anomalies with the current human service system. Criticisms are directed at two features of most support systems – the focus on *compliance* and *benevolence***.** Typically, there are several ways that people describe compliance and benevolence:

- *Segregation of vulnerable citizens*. Assumptions are often made that people with disabilities or frailties need to be segregated together in settings usually away from real community. One example is the fact that there are currently several thousand Canadians with physical disabilities who live in chronic care facilities. In one study, 993 people with physical disabilities under the age of 55 were in such situations in the province of Ontario.[3] Few of these individuals were in these facilities because they needed medical intervention, but simply because they required many hours of support each day.

- *Agency-controlled services*. As community-based services have evolved over the last forty years, the assumption has been that the best way to provide services and supports to vulnerable people is for government to give money to agencies, who in turn provide services that are required by individuals. This approach to community support has led to the dominant practice of agency-controlled services. While

this approach works for some people, many more people are required to "fit" their lives around agency procedures in ways that do not work for them. Another criticism of agency-controlled services is that agencies have too many functions. Prior to the changes in Windsor, Ontario, for example, the Windsor Association for Community Living served as advocate, service provider, planner, and allocator of funds. Individualized funding initiatives have created ways to separate these functions.

- *Continuum of services*. Developed in the 1970's, a continuum of services was a concept used to visually depict how individuals would "progress" if they were to become part of community life. People would have to go through several steps along the way. In terms of community living, this meant that one might have to move from a group home to an apartment building with attendant services (called Support Service Living Unit for people with physical disabilities in Ontario), and eventually to a home on their own with or without support. Continuum of services thinking continues to control the way supports are organized for people.

- *Housing and support linked*. For decades, the type of support people received has been tied to their housing. In other words, more intensive supports were seen as being best provided in more institutional or clinical settings. This link between housing and support has meant that citizens with significant disabilities have been unable to live independently with support in the community. Direct funding

programs across Canada have allowed people to begin to choose where they want to live, and when they want their supports provided.

People with disabilities need supports of various kinds to ensure a decent quality of life. Many citizens with disabilities require support to be able to participate in community life. The reality is that people with disabilities are often limited in their capacity for citizenship because disability supports are inadequate, inappropriate, or unavailable.

Federal and provincial governments have recognized that citizenship should be central to the way we organize disability supports.[4] In Canada, disability supports are seen as separate from income supports. It is widely recognized that both disability supports and income supports are required to enhance the citizenship and quality of life of people with disabilities. In recent years, many disability groups have been demanding more individualized approaches to the provision of disability supports.[5]

Research shows that people with disabilities are less likely to be employed, more likely to be poor, and often have limited social support. These factors contribute to vulnerability and poor health.[6] In addition, the growing demands on current service systems often make it impossible for people with disabilities to receive the supports they require in addressing these significant issues. As demographics shift, more and more people with complex disabilities are living in the community. And many children with disabilities being raised by younger parents have increasingly been able to experience inclusion and participation in schools and community.

*All of these factors point to the importance of developing more options for adults with disabilities and their families to access individualized disability supports.*

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*"The commitment to inclusion is so tenuous that the moment the system experiences funding pressure, community inclusion and the services that enable community inclusion are the first things to be sacrificed. Today, more energy, time, and funds are expended managing the human service systems and managing adults with disabilities, than in facilitating community inclusion, facilitating the development of relationships, or learning the art of inclusion".*

Bruce Uditsky[7]


# The Emergence of Alternatives in Canada

The emergence of individualized disability supports has been occurring in several jurisdictions over the last twenty years. According to the Roeher Institute, individualized funding (IF) is based on the principles of self-determination, choice, equality, and the right to make decisions that affect one's life. It is also based on the premise that people who have disabilities need money for basic living expenses, plus expenses related to the disability. Examples of the latter include equipment, homemaking services, and attendant services. The Roeher Institute document emphasizes that the principles that underpin individualized funding "work together to promote the social well-being of persons with disabilities " ( p. 3). Many IF programs promote a holistic view of quality of life, looking at such things as

employment supports, community living, leisure pursuits, and relationship building.[8]

Individualized funding in Canada emerged in the early 1980's in British Columbia, with the development of brokerage as a response to the closure of the Woodlands Institution. Normally, brokerage services are independent of other direct services, enabling an individual consumer to pick and choose from an array of available services and community opportunities. The province of Alberta developed the most comprehensive approach to individualized funding, and by 1990, it had become the official way for service delivery. Financed and administered under the Social Services Act and the Persons with Developmental Disabilities Act, there are two separate programs, one for people with developmental disabilities, and the other for adults with physical disabilities.

**Current Context in Ontario**

Given the importance of Ontario to this Review, a more in-depth background to the Ontario context will be provided here, before actually getting into the details of the Review process. The concept and practice of direct funding for individualized supports has been growing in Ontario during the last fifteen years. There are currently several policies and programs that mandate, allow, or encourage individualized disability supports, including direct funding. There are also several groups within Ontario that support and advocate for individualized funding.

***Special Services at Home: Family Support Initiative***. Special Services at Home (SSAH) continues to be a very popular and important family support program. Since the mid-1980's, families with children who have physical or developmental disabilities can receive individualized funds for respite, family support, community integration, or individualized supports. The government continues to put new money into the program, and it is in high demand from families.

SSAH creates an important history of learning around direct funding in Ontario. The 1993 SSAH evaluation showed that families appreciated having more control over the supports in their lives. Since 1995, the Ontario Family Alliance has stressed that SSAH is a very effective program and has asked the Ontario government to fund "consumer-directed individualized funding." The two main limitations of the SSAH Program are: first, it is not available once the person moves away from the parents' home; and second, there are no infrastructure supports to assist families with planning and implementation.

***Ontario Direct Funding Project***. The Ontario Direct Funding Program, which is for adults with physical disabilities who can direct their own support, is now a major, permanent program funded through the Ministry of Health and Long Term Care. Started as a Pilot Project in 1993, Direct Funding is highly regarded by consumers who require attendant services. The Project is co-ordinated through the Centre for Independent Living in Toronto (CILT), which receives funds from the government to distribute to individuals.

The Direct Funding Project has some infrastructure support, in the form of Independent Living Resource Centres across Ontario, that are available to support people who are applying to the program. There are many individuals who cannot access the Direct Funding Program (because of its stipulation that the individual must be able to self-direct) who would like to utilize individualized funding. This limitation has meant that individuals who are unable to self-direct often have nowhere to go if they want individualized supports.

*Pilot Projects and MCSS Initiatives*. The Pilot Projects on individualized funding sponsored by the Ministry of Community and Social Services (MCSS) in Mississauga, Thunder Bay, and Windsor have demonstrated the effectiveness of individualized funding.  In Toronto, the Family Service Association has also completed a successful demonstration project (Individualized Quality of Life Project) and has had the program extended as a regular program by the Toronto Area Office. Although not officially a pilot project, the Durham Region of MCSS has supported more than sixty individualized funding and support arrangements.

Despite the important lessons from these pilots, many people are more aware than ever of the inequities throughout the province in terms of Area Office support for the concept and the practice of individualized supports. It is possible to obtain individualized funding in some areas of the province and not in others. Also, most funding from MCSS and Ministry of Health continues to be "block funding" and goes to agencies, such as associations for community living (for people with developmental disabilities) or support service living units (SSLU's) for people with physical disabilities.

*The Ontario Individualized Funding Coalition*. The Ontario Individualized Funding Coalition has developed a number of important ideas and resources. The Coalition's belief in the value of individualized funding sets the tone for these ideas.

> The Individualized Funding Coalition supports the self-determination of persons with disabilities. We believe that all people should have control over decisions concerning where they live, with whom they live, with whom they associate, and how they spend their lives. In order to achieve this, we recognize that Ontario must develop a system of funding whereby the person requiring assistance, supported as appropriate by family and/or significant others, has access to and control over the funds allocated to his/her supports.

In the fall of 1998, the Coalition sponsored a two-day Symposium that provided a framework for change. In the Symposium Report, entitled *Individualized Funding: A New Vision*, the Coalition identifies five "building blocks" that are necessary for successful individualized outcomes:

- person-centered planning
- personal support relationships
- individualization of funds
- management supports
- community development.[9]

Recently, the Coalition released the Report of the Round Table on Individualized Funding. This Report, entitled *Individualizing Supports and*

*Direct Funding: Making Money Work for People*, was commissioned by the Coalition and developed by fourteen people in Ontario with experience with individualized funding.[10] The Round Table Report advances our thinking on the building blocks for change, and proposes a policy framework that is based on "promising approaches" identified in this Review.

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**Summary of Current Context in Ontario**

*"Increasingly, policies and programs in Ontario are offering individualized supports and direct funding. However, most of the guidelines attached to these policies are quite narrow, and the programs tend to have very limited capacity. There are almost no opportunities, for example, for adults who cannot self-direct, to access direct funding for disability supports. Both Ontario Ministries of Health/Long Term Care and Community and Social Services offer individualized funding in some contexts for some people. These programs and policies have some redeeming qualities. The Round Table has concluded that it is now time for a policy in Ontario that creates a framework for a new, inclusive approach to direct funding for any citizens with a disability who want to chose this option".*

Ontario Round Table on Individualized Funding  (2000)

# In Conclusion

*Direct individualized funding of disability supports is viewed by many in the field as a mechanism for ensuring that the paradigm shift is grounded in genuine options and increased control for individuals and families.* In many ways, direct funding is consistent with the world-wide trend toward increased democracy, self-determination, and community involvement.

However, preliminary work during this Review has indicated that the Ontario context still leaves much to be desired in terms of disability policy and practice. It was clear that a comprehensive Review of Individualized Funding was needed to assist policy makers and communities to learn from other countries and communities.

# CHAPTER II:
# HOW THE REVIEW WAS COMPLETED

## Goal and Objectives of the Review

The goal of this Review was to develop understanding, awareness, and strategies for building the capacity of individuals, families, communities, and government to implement individualized funding for people with disabilities in Ontario. To meet this goal, the Review has several objectives:

1.  To utilize an action research process to:

    a)  identify lessons learned from several existing projects that have focused on individualized funding.

    b)  identify lessons learned from the research, literature, and government documents related to individualized funding.

2.  To develop strategies that will:

    a)  engage people in the process of learning about individualized funding and its relationship to the building blocks for change.

    b)  link the lessons from this Review with the Round Table initiative of the Individualized Funding Coalition.

    c)  move the individualized funding agenda forward in Ontario.

# Review Process and Approaches

In order to respond to the goals and objectives, the following process and approaches were utilized.

The Review team began its work by gathering research documents, evaluation reports, and program descriptions of projects, programs, and policies related to individualized disability supports. These documents included the Ontario pilot projects related to individualized funding, and other direct funding initiatives in Ontario, Alberta, British Columbia, Manitoba, Western Australia, Great Britain, and several states in the United States.

We completed a documents analysis by noting categories and themes within each document. This allowed us to complete a brief summary of each project under review.

These summaries were also used to identify what could be considered "promising approaches" in the area of individualized disability supports. For example, we discovered that the most common outcomes associated with "promising approaches" are self-determination and community involvement. We also noted that promising projects ensured that individualized planning and other infrastructure supports were separate from formal services.

We then built a template for presenting the promising approaches or initiatives in detail. This template covered areas such as history,

mandate/policy, rationale/goals, criteria for receiving dollars, program infrastructures, and evaluation research. Using the template, each promising project was written up in detail. Where there were obvious gaps in the information for the template, interviews were conducted with leaders from the project.

In most cases, the written descriptions of each promising initiative were reviewed by one or two people who had been associated with the project. A final copy was then based on this feedback. These descriptions are outlined in Chapter V.

Using the documents analysis and the project descriptions based on the template, we then completed a cross-site analysis. This involved the identification of common patterns and themes across the promising initiatives. When we saw a pattern in many sites, it became a common theme or lesson. Where there were contradictions, these were also noted. These common themes were then written up as lessons on how best to construct individualized supports and funding. When writing up the lessons, we sometimes used examples from a few projects, and in other cases, we created a chart to illustrate the patterns and themes. These lessons are outlined in Chapter IV.

# CHAPTER III:
# LESSONS LEARNED -- LANGUAGE, PRINCIPLES, POLICY, AND IMPLEMENTATION

During our Review of promising individualized funding initiatives, several themes and lessons emerged about language, principles, policy, and implementation. Taken as a whole, they provide important insights into how to construct a viable approach for developing individualized disability supports and funding. The eight lessons are summarized here.

**Lessons Learned from Promising Initiatives:**
**Direct Funding and Individualized Supports**

1. Language and practice related to disability supports is increasingly inclusive.
2. Values and principles do matter.
3. A policy framework provides coherence and equity.
4. There are pros and cons to attaching direct funding projects to service reform efforts.
5. Infrastructure supports for individuals and families must be separate from the service system.
6. The role of a facilitator/broker is a main feature of many successful projects.
7. There needs to be a direct funding mechanism separate from infrastructures and a well understood approach to accountability.
8. "Learning as you go": pay attention to process and outcomes.

# 1. Language and Practice Related to Disability Supports is Increasingly Inclusive

We have been struck by the changes that have occurred in the language and frameworks that have developed during the last decade. When direct funding was initially conceptualized more than twenty years ago, it was seen as a technical way to enhance consumer control. The early programs that utilized direct funding focused on providing money for people to hire attendants to provide personal support. Much of the early writing described direct funding as a new technology and as a market driven approach.

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*No matter what anyone tells you, words and ideas* can *change the world.*

Teacher in movie, *Dead Poet's Society*

*Individualized funding is now seen less as a technical intervention, and more as an approach to enhance self-determination and community involvement*. Initiatives that use individualized funding describe the "money" component as only one feature of their approach. The Ontario Round Table on Individualized Funding, for example, developed a report with a policy framework that has five components, one of which is a direct funding mechanism. In interviews with leaders of individualized funding initiatives, we were struck by the fact that the ideas and language were so

inclusive. People did not revert to quick, technical solutions, but stayed focused on goals, process, principles, and outcomes for people.

*This language shift parallels the paradigm shift* explored in Chapter I. The emphasis is increasingly on the goal of citizenship, community involvement and the use of informal and formal supports. Paid supports, while vital for many people with disabilities, are no longer seen as sufficient. Almost all of the projects described in Chapter V stress concepts such as "building support networks," "person-centred planning," and "community inclusion." The way in which individualized funding is now embedded in the language of community and social support illustrates how disability supports are increasingly focused on quality of life.

> *"Individualized funding was really empowering and did away with a lot of stress and frustration. We had a resource person to support the family. She had the information we needed about services, and we had meetings to develop a plan … She then helped us negotiate individualized funding and select a service provider that would match the plan.  This became the foundation for building a life for Jordan. The IF process gave us a voice, as those who knew Jordan best.  It eliminated the conflict of interest for the service provider – they were accountable to Jordan, not to the ministry.  In the other system, Jordan was stuck with the way things were, so many of his needs were not met".*
>
> Pat Cattermole[11]

## 2. Values and Principles Do Matter

Clearly stated values and principles guide many individualized funding projects. Values in many of the projects can be seen as overriding beliefs about the direction of the project. Many of the explicit values are consistent with values inherent in democracy, self-determination, and community involvement. People receiving disability supports are viewed as citizens with the same rights as other people. In fact, it is these rights that suggest that disability supports should be an entitlement, helping to ensure that people with disabilities have an equal opportunity to participate in the society.

**Values and Principles Explicit and Useable**

Principles, while similar to values, act more as guides to action. They provide a set of boundaries and directions within which projects must operate. Most individualized funding initiatives do not distinguish between values and principles, but they do make their values and principles explicit and useable.

*The values and principles guiding projects that facilitate individualized disability supports do not focus just on money. Rather, they reflect a commitment to enhancing self-determination and community involvement. The goal is to enhance quality of life. In many cases, the values and principles are used to inspire, rather than serve as rules.*

The *Self-Determination Projects* (see Chapter V) in nineteen U.S. states, for example, are based on four guiding values and principles.

- freedom: the ability to plan a life with supports rather than purchase a program
- authority: the ability to control a certain sum of dollars to purchase supports
- support: through the use of resources, arranging formal and informal supports to live within the community
- responsibility: accepting a role within the community through competitive employment, organizational affiliations, and general caring for others within the community; and accountability for spending public dollars in life-enhancing ways.

*The Individualized Quality of Life Project* in Toronto (see Chapter V) has five principles that guide its work.

- enhance dignity, respect, and personal choice
- promote community integration and participation
- promote the development of support networks
- ensure that plans, supports, and services are comprehensive and accountable to the individual/family, reflecting capabilities, interests, and needs of the person with a developmental disability
- ensure continuity of supports and flexibility to meet the individual/family evolving needs.

The Disability Services Commission of Western Australia (see Chapter V) is one of the most effective programs we identified. Called *Local Area Co-ordination and Direct Consumer Funding*, the mission of the Commission is to advance the equality of opportunity, community participation, and quality of life of people with disabilities. Local Area Co-ordination is driven by principles that reflect these broader values. In a vein similar to the projects described above, these principles emphasize access to information and choice, network building, person-centered planning, and community participation.

*NABORS (Neighbours Allied for Better Opportunities in Residential Support)* is a Toronto project funded by the Ministry of Health and Long Term Care to support twelve individuals with disabilities in two co-operative housing projects. Each supported individual has his or her own individualized funding and budget. NABORS provides the infrastructure support, so that people can have support circles, individualized planning, and community involvement. In many ways, NABORS is a "circle of circles" [12] with each person and his/her network having a designate on the NABORS board. NABORS principles reflect the centrality of community and its relationship to individualized supports and funding. The principles include:

- NABORS has the responsibility to nurture community in the housing co-operatives.
- NABORS has the responsibility to help individuals in the ways that each of them needs.
- NABORS has a responsibility to help people to take control and keep control of their lives.

- NABORS has a responsibility to help people develop circles and keep them together.

- NABORS has the responsibility to:


  - assist individuals to manage the funds they receive.
  - assist and support the twelve individuals to secure additional funds when they do not have the funds they need.
  - assist individuals to maintain control over their funds should they decide not to live in either of the two housing co-operatives.


## Principles Focus on Formal and Informal Supports


In almost all of the projects we reviewed, the focus of the principles was on both formal and informal supports. This theme reflects two broad trends identified earlier in the section on shifting paradigms of disability and community (Ch. I). First, we know that *building strong networks of support enhances health and inclusion*. This is one of the key principles guiding individualized approaches. Second, we have learned over the last few years that there are *anomalies or limitations to formal disability supports*. Informal supports provide opportunities for relationship building and community connections. Particularly for people with more significant disabilities, these connections do not happen naturally. Disability supports need to be constructed to facilitate these community involvements. The values and principles serve as an inspiration and a set of guidelines for this new way of doing business.

Values and principles are not just static statements on paper. They are utilized as the basis for relating to, planning with, and supporting people with disabilities, their families, and their networks. Facilitators and others involved in individualized disability supports require ongoing value-based training and support that inspires them to play new roles with individuals and families.

## 3. A Policy Framework Provides Coherence and Equity

Most individualized funding projects that have moved beyond the pilot stage are based in national or provincial policy. We have found that policy frameworks provide both coherence and equity.

*Coherence refers to the consistency across levels* (provincial policy, community organizations, and individual projects). Research has shown that when there is coherence across levels, progress toward the new paradigm can occur quite quickly.[13] In Ontario at the present time, there is little coherence in terms of disability supports. Several of the pilot projects funding by the MCSS, for example, struggled because there was no policy support for their work. A policy framework provides principles and guidelines for community practice, and ensures that provincial actions and resources support that practice.

*A policy framework also supports equity* by ensuring that everyone who is eligible will be served, and that regional differences in service

delivery are minimized. *Equity is now a critical issue in Ontario*, where there is policy support for a small number of citizens with disabilities to receive individualized funding, but no policy support for most people who want an individualized approach. The dilemma is that there is overall inequity, because people with disabilities who cannot direct their support are unable to access individualized dollars. The *Ontario Direct Funding Project*, originally a pilot under Long Term Care, for example, has become a full program under that Ministry. The idea that adults with physical disabilities can direct their own support is one of the seven guiding principles of the Ontario Long Term Care legislation. The Project has been well received by consumers who have received individualized funding and there is equity across the province for this particular limited population.[14] A more detailed discussion of the Direct Funding Project experience is provided in Chapter V.

Via the Individualized Funding Pilot Project, Lesley's life changed dramatically. Needed services and recreational activities were suddenly so much easier and so much more quickly accessed. Because Lesley is very gregarious and likes to be busy, the opportunity to choose perfectly fits her personality. She found out early that cleaning her room and doing laundry are not what they are cracked up to be, but school, along with horseback riding, French classes, movies, the theatre, lunch with friends, and shopping are some of her choices. I am pretty sure she does know everyone in Surrey now!

From *Towards Empowerment: A Glimpse of the Future*[15]

## Policy Frameworks Based in Legislation

Some policy frameworks that address individualized disability supports are based on legislation. In *Great Britain*, the 1996 Community Care (Direct Payments) Act allows people with disabilities to receive direct funding so they can make their own support arrangements. The funding occurs through the Local Authorities, which are similar to the Community Care Access Centres in Ontario. Individualized planning is separate from services and from the process of adjudicating and allocating funds. Although little research has yet been conducted on this policy and legislation, most criticisms seem to be directed at the implementation practices, rather than at the legislation itself.

*Western Australia* is the first of Australia's six states to adopt individualized funding. It has one of the simplest yet highly developed approaches to individualized planning and direct funding. Based on the 1993 Disability Services Act, Local Area Co-ordination was developed to increase the self-reliance of people with disabilities. Personal planning is completely separate from services. Resources put into infrastructure supports and planning for individuals and families have led to very positive outcomes. The Western Australian program allows direct funding to be used for a range of supports. A more detailed discussion of the Western Australian experience is provided in Chapter V.

*Although policies embedded in legislation are in many ways more sustaining, it is not always necessary to create new legislation for individualized funding initiatives*. In Ontario, for example, there are already

regulations in place that provide for individualized disability supports and direct funding. Under the *1994 regulations of the Ministry of Community and Social Services Act*, grants can be provided directly to persons with disabilities for attendant services. In most instances, these regulations have been used to give grants to agencies that provide attendant services or personal supports. The principle of self-determination is central to these regulations, with the expectation that the individual with a disability will direct his/her own support. A broadened set of regulations under the 1994 legislation would create a more inclusive policy, and allow for initiatives where people who cannot self-direct could access direct funding for support workers.

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**A Policy Framework for Ontario**

A policy framework related to individualized approaches and direct funding should reflect the need for comprehensive disability supports throughout the province of Ontario. Our research and analysis indicates that there should be five major components to the Policy Framework:

- principles
- infrastructure supports for individuals and families
- a mechanism for direct funding
- a well understood, simple approach to accountability
- a mechanism for individuals to transition to this approach.

*Ontario Round Table Report on individualized Funding, 2000*

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**The Need for the Right Policy Framework and More!**

*A policy framework, of course, is no guarantee that an individualized funding project will be successful.* In *Alberta*, individualized funding has been in place since the mid-1980's. In 1990, it became the official way for service delivery. Financed and administered under the Social Services Act and the Persons with Developmental Disabilities Act, there are detailed guidelines for two separate programs, one for people with developmental disabilities, and the other for adults with physical disabilities. Direct funding is available to address a wide range of needs. Alberta is seen as an international leader in individualized funding.

However, the Alberta policy framework provides almost no infrastructure support for families and individuals, and unencumbered planning is rare. These have turned out to be significant weaknesses in policy and practice. Bruce Uditsky, executive director of the Alberta Association for Community Living, has pointed out some of the issues. As individualized funding grew to be routine in Alberta, it became a way for agencies to re-assert their control. Without adequate infrastructures for individuals and families, agencies gradually began to be the receiver of monies allocated for individuals. A strong policy framework that funded infrastructure supports separately would help re-new the Alberta system. Uditsky points out that other components, such as community development and family leadership, will also be needed to re-new and sustain individualized funding in Alberta. [16]

**Implementation Must Also be Coherent With the Principles and Policy Framework**

Here we extend the concept of coherence to implementation. It is equally critical that implementation be strategic and coherent with the principles and the policy framework. In terms of infrastructure supports, this means developing structures that work well with the functions. The *Ontario Round Table Report* will be particularly useful for Ontario communities that are trying to ensure coherence.

To become coherent, implementation requires strategic thinking and planning. For example, we have found that *implementation that involves both piloting and phasing allows maximum opportunity for evaluation, learning, and change.* Much strategic thinking went into the development of pilots. In the Ontario Pilots, comprehensive evaluations of the pilots led to further strategic thinking about changes that were needed. Phasing has meant that more complex issues are added over time, as the project has increased its learning and capacity. The Western Australia project is one example of a program that has added more complex issues over time.

We have noted *three things that helped strategic thinking* in these IF initiatives. First, having someone from the "outside" to inspire people was often vital. Second, much of the leadership from "inside" came from people who do not provide direct services. Leaders are needed who can think "outside the box" of formal service systems. Third, implementation requires involvement of major stakeholders. People who affected by the changes must have ways to be involved. The levels of involvement vary, ranging

from opportunities to sit on committees, to participating with evaluations, to being part of a steering group which guides the project.

In conclusion, we have found that *a policy framework is important for building sustaining approaches to individualized disability supports*. Few initiatives we studied have coherence among policy, principles, and practice. Exceptions would include the Ontario Direct Funding Project and Western Australia Local Co-ordination, where principles are understood and experienced in policy, implementation directions, and practice.[17] Many programs in Canada are not based on policy, but have emerged from pilot projects and local initiatives. Successful programs in Great Britain and Australia are based in policy and legislation, as is the Direct Funding Project in Ontario. *The most successful policies and programs have a blend of infrastructure supports for individuals/families, an individualized funding mechanism, and a well understood approach to accountability*.

## 4. There are Pros and Cons to Attaching Direct Funding Projects to Service Reform Efforts

When provinces, states, or communities consider creating individualized disability supports, they need to decide if they want the initiative to be part of reforming the entire service system or if the initiative would work better if it were a stand alone option. In reviewing several initiatives, we have noted pros and cons.

### Advantage of Linking with Service Reform

The main argument in favour of linking individualized funding initiatives with service reform is that the goal is to change the system for

everyone. Probably the most interesting cases have been the *Self-Determination Projects* being carried out in nineteen states in the U.S. *New Hampshire* and *Michigan* are outlined in Chapter V as examples. Using community development and the development of new alliances and partnerships, these projects have had service reform as part of their mandate from the beginning. The catalyst, however, was the fact that "outside foundation money" was available for three years. Although many of these projects have experienced resistance from the service sector, in many cases community development enabled a variety of stakeholders, including service providers, to "buy in" to the reform agenda.

**Disadvantage of Linking with Service Reform**

The main argument against linking an individualized funding initiative with service reform is that vested interests can limit the change. In reviewing several projects that were tied to service reform, we learned that it is a struggle, but not impossible to make such broad changes. In *Dane County Wisconsin*, for example, case managers attached to residential services were replaced by support brokers who were free of conflict of interest.[18] The process of change was long and challenging. Similarly, in *Windsor-Essex in Ontario*, the move to unencumbered planning took a long time to put in place and continues to be resisted by some.

In some ways, it appears that direct funding initiatives that have had the most coherence and sustainability have been new stand-alone programs. The *Ontario Direct Funding Project*, for example, was always presented as

an option for citizens with physical disabilities who could self-direct. People who want this option must move away from the old system of "buildings with support" once they receive the direct funding. This Project, like others that are separate from the service system, has been able to stay true to its mandate and purpose.

Leaders from two other independent projects, *Local Area Co-ordination* in Western Australia, and the FSA *Quality of Life Project* in Toronto, emphasized that being "less entangled" with service reform has enabled their projects to support a broader range of people without the internal barriers associated with service agencies. Being separate from services has also meant that there has been some tension with service systems who sometimes find an IF project to be threatening. With a seven-year history, however, the *Western Australian experience is that reform begins to happen when people see the potential and outcomes of an individualized funding project once it is in place.* Below, we list some of the features of direct funding when part of service reform or not.

**Features of a Direct Funding Project Being Part of Service Reform or Independent of Service Reform**

*Part of Service Reform*

(Windsor Brokerage, Thunder Bay Choices, Mississauga Association,
USA Self-Determination Projects)

- takes time to get the major players on board
- issues of power sharing can plague the initiative and must be addressed
- existing service providers must give up something e.g., resources, control
- danger that individualized approaches may remain service driven
- possibility that direct funding will be widely endorsed and part of the new way of doing business.

*Independent of Service Reform*

(Ontario Direct Funding, Toronto Quality of Life,
Western Australia Local Co-ordination)

- initiative can get underway fairly quickly
- resistance from formal service providers can be troublesome and it may take time to gain full community support
- education of individuals, families, and services is key to success
- individualized approaches tend to be central and clearly separate from service system
- unlikely that direct funding will be fully endorsed unless policy framework and priorities support new program.

## 5. Infrastructure Supports for Individuals and Families Must be Separate from the Service System

Almost all of the initiatives that we have identified as "promising" have created separate infrastructures for a variety of functions that are needed for the development of individualized disability supports. Infrastructure supports can be thought of as supports that help individuals and families to plan, access the resources they need, and provide financial management assistance for direct funding. The Ontario Round Table on Individualized Funding identified several directions outlined below.

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**Essential Infrastructure Supports:
Purpose, Functions, and Strategies**

- The purpose of local infrastructure supports is to provide individuals, families, and their networks with several different support options, all designed to enhance their individualized disability supports.

- Several functions must be part of the infrastructure supports: personal planner, facilitator, broker support; administrative and technical support; financial management assistance; human resource management assistance; and community capacity building supports.

- The development of these supports should be local and regional, guided by provincial principles and the policy framework.

- There must be criteria for any group or organization to be able to provide the infrastructure supports, including that the organization:
    - be clearly separate from the service delivery system
    - have the technical and training capacity
    - have a philosophy and value base that is consistent with the principles.

- Should individuals and families choose to self-administer their individualized support dollars, they should be able to access financial management supports to assist them with this administration.

- Community capacity building supports enhance the community involvement of individuals with disabilities, and should be designed to build welcoming settings in communities. Ontario Round Table on Individualized Funding, 2000

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**Examples of Independent Infrastructure Supports**

Whether it is a broker, facilitator or network builder, there needs to be a person and an organization that can help individuals and families build their capacity and individualized plans. And this person and organization must be free of conflict of interest from service providers and government. Keeping infrastructure supports separate from the direct service system helps ensure that the supports will be individualized and person centered. Facilitators not attached to the service system can put all their energy into supporting the person and family as opposed to concerning themselves with program and service issues.

The idea of separating infrastructure supports from direct services was first initiated in the late 1970's, when the Woodlands Parent Group asked the British Columbia government to set up a system of "individualized funding and service brokerage" for individuals who were returning to the community from the Woodlands Institution. The government approved the proposal, and the Community Living Society was established to provide brokerage services and manage the individualized funding. This was the first experience in Canada with individualized funding. The pioneers who started the Community Living Society left an important legacy. Although we have learned much since that time, one element remains the same: *infrastructure supports for individuals and families must be separate from the service system.* In the chart on the following page, we highlight the infrastructure supports and roles of five projects that have successfully created these functions.

<table>
<tr><th colspan="3">Five Projects That Have Successfully Created Independent<br>Infrastructure Supports for Individuals and Families</th></tr>
<tr><th>Sites/Projects</th><th>Infrastructure Supports</th><th>Main Roles</th></tr>
<tr>
<td>Toronto FSA<br>**Quality of Life Project**</td>
<td>• resource facilitators<br>• financial supports</td>
<td>• network building, planning<br>• resource guidebook, payroll<br>support available</td>
</tr>
<tr>
<td>Thunder Bay<br>**Choices Project**</td>
<td>• planner/broker<br><br>• network builder<br>• community trainer</td>
<td>• planning, information, negotiating<br>for funds<br>• network building<br>• community development</td>
</tr>
<tr>
<td>Windsor Essex<br>**Brokerage for Personal<br>Supports**</td>
<td>• brokerage facilitator<br>• active family and self-<br>advocate organizations<br>• financial supports</td>
<td>• network building, planning<br>• resources for person-directed<br>planning, education, advocacy<br>• choice of agency to do payroll</td>
</tr>
<tr>
<td>British Columbia<br>**Microboards** (Vela)</td>
<td>• facilitators<br><br>• employer support</td>
<td>• assist boards to plan, build<br>networks, advocate for funds<br>• choice to have Vela act as<br>employer</td>
</tr>
<tr>
<td>Western Australia<br>**Local Area Co-ordination<br>& Direct Consumer<br>Funding**</td>
<td>• co-ordinators<br><br><br><br>• financial supports</td>
<td>• getting to know families, planning<br>network building, negotiating,<br>community development<br>• accounting support available.</td>
</tr>
</table>

The *US Self-Determination Projects* have created "fiscal intermediaries," entities that provide technical and financial supports. This infrastructure allows the individual or family to focus on planning, hiring and managing staff, while another organization handles the financial and legal issues. Some self-determination projects have 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 are separated from the financial supports.

*Brokerage for Personal Supports* is the primary and dedicated resource for unencumbered planning in Windsor-Essex. The Toronto FSA *Individualized Quality of Life Project,* the Thunder Bay *Choices Project,* and the Western Australia *Local Co-ordination and Direct Consumer Funding Project* are also clearly distinct from direct services. All of these projects provide to individuals and families information and assistance with planning. Like many other projects, the facilitator (or broker) is a key infrastructure support for individuals and their networks.

A 1997 study by the Roeher Institute found few programs that provide brokerage supports, third party planning supports, or administrative supports.[19]

## 6. The Role of a Facilitator/Broker is a Main Feature of Many Successful Projects

**Not a Case Manager**

The role of this facilitator cannot be over-emphasized. Whether the person is called a support co-ordinator, a local animator, facilitator, or broker, the role is not that of a case manager.

**Common Process and Strategies of Facilitators
Mentioned Most Often in Eight "Promising" Sites**

- Get to know people well; *build relationships* with individuals with disabilities, their families and networks, and the local community.

- *Provide information* about network building, individualized support options, community resources, direct funding.

- Help the individual to build his/her *social support network* (circle, cluster, group, network), that would be willing to meet regularly.

- Assist individuals, with their 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 & informal settings.

- Assist people to *find and purchase supports* that may be required and provide ongoing *implementation support*.

Job descriptions and experience from Toronto *Quality of Life*, Western Australia *Local Co-ordination*, Thunder Bay *Choices*, Windsor *Brokerage*

*for Personal Supports*, and the US *Self-Determination Projects* point to the importance and practical aspect of this lesson.

**The Planning Function**

*Person-directed planning is at the heart of the Windsor Brokerage for Personal Supports.* This project emphasizes that the person with a disability is the director of his/her planning. Others in the person's network are then encouraged to participate with the person, and assist the person to think about dreams, goals, and support requirements. Only after a lot of talking and planning do these networks develop a budget and some ideas about whom they might hire as support workers. Sometimes this involves going to a traditional agency, and other times it involves hiring support workers independent from an agency.

Kubiski & Associates found that programs that provide planning supports utilize a range of planning tools.[20] They found that individualized planning approaches have a different focus from traditional models of planning.  Traditional models are based on the premise of overcoming problems and deficits, while person-centred or person-directed planning has a community development focus. This kind of planning looks at a person's place in the community and at people's strengths and capacities. Another type of individualized planning, Lifestyle Planning, can assist individuals with life transitions such as moving from an institution to a home in the community. It has been widely used in Alberta.

*Ongoing planning support is central to the facilitator's role.* Many families with individualized funding have found that without such ongoing planning support, they can become worn down. This lack of facilitative support has been a common complaint about the Special Services at Home Program, highlighted in the 1993 evaluation.[21] Elizabeth Bloomfield, a parent in Guelph whose 31 year old son has individualized funding, has expressed the concern most clearly;

> Whether a vulnerable person with a disability is supported primarily by formal services or by informal social networks, someone who is articulate has to be responsible for continuing to plan, energize and co-ordinate the set of supports so they work for that individual from hour to hour and day to day.[22]

Facilitators described *how important it is to continue to provide support once a person has been funded.* When a person's support needs are significant, this ongoing co-ordination support should be able to be budgeted within the individualized funding. For example, in the NABOR's project described in the second lesson on values and principles, each of the twelve members have a support co-ordinator who is responsible for assisting the person with ongoing planning, monitoring of staff, organizing schedules, and working with the support circle.[23] This role is budgeted as part of each person's individualized funding.

## The Network Building Function

It is well documented that many citizens with disabilities have few friends and relationships. An important infrastructure support relates to the process of *intentionally* building a support network for the person. How to

facilitate social networks has been approached in a variety of ways. Some projects, such as the Thunder Bay *Choices Project*, kept network builders separate from brokers, claiming that relationship building gets neglected if it is just part of a long list of things to do. The Toronto *Quality of Life Project* originally separated the functions, but then found it made more sense to have them integrated. Most other projects have also found there is merit in an holistic approach that keeps network building at the heart of the individualized planning process. As the Manitoba Project *In the Company of Friends* found, intentionally focusing on networks and relationships leads to very positive outcomes for individuals.[24]

The second part of this role relates to consciously facilitating community connections. Several projects emphasize this community integration element, but it is difficult to access how thoroughly this outcome is being realized.

**Qualities of a Facilitator**

Several projects stressed the unique qualities of the facilitator. These qualities exemplify the importance of values, relationships, and skills. Many of the initiatives we reviewed make intentional efforts to ensure that staff act on values and principles in their work. Since traditional disability supports have often been based on values of compliance and segregation, *it has been important for projects to find the right staff, and to provide training and support for staff once they are employed*. Several project co-ordinators noted that the most effective facilitators were people with broad community experience, and that people who had worked for years within the traditional

disability sector were often not suited for this individualized work. Some projects emphasized the importance of ongoing value-based training and support. The Director of *Local Area Co-ordination* in Western Australia, for example, brings his facilitators together several times a year, and spends a large amount of that time on values and principles. In the following chart,

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**Qualities of an Effective Local Area Co-ordinator**

Local Area Co-ordination and Direct Consumer Funding

Western Australia

- A sound *value base* – positive and contemporary attitudes towards people with disabilities

- An understanding and commitment to *principles* of co-ordination

- Ability and willingness to develop and maintain positive *relationships* with people with disabilities and their families

- Highly developed *skills* in: individual needs analysis, personal advocacy, individualized funding, planning for individuals and families, and community development

- *Effectiveness* - organization of time and resources, effective administration, and understanding and compliance with procedures and processes.

**According to the Project, these qualities lead to quality support**.

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we highlight research on the qualities of an effective local area co-ordinator in the Western Australian project. These qualities were mentioned in all other projects as well.

## 7. There Needs to be a Direct Funding Mechanism Separate from Infrastructures and a Well Understood Approach to Accountability

Once an individual and his/her network have a plan, they submit the plan to a group who decides how the money will be allocated.

**Different Approaches to Allocation**

There are several different approaches to allocation. Each one has pros and cons which will be briefly discussed here.

First, the Area offices of the government have an adjudication panel to make allocation decisions for funding and then the office releases the money to individuals. *Local Area Co-ordination and Direct Consumer Funding* in Western Australia uses this approach. The Ontario Round Table on Individualized Funding recommends this as the preferred approach, to ensure that the community can focus on infrastructure supports and not be distracted by decision-making. This approach, however, does depend on the good will and strong value-base of government.

Second, the community appoints an adjudication group that makes recommendations to government. In *Windsor*, a Community Priorities Panel made up of consumers and families makes recommendations to the local Area office of government, who then releases the money to individuals. This approach seems workable, gives control to the community, but means that individuals and families have to make some tough decisions in regard to their peers. This can be disconcerting.

Third, money for individualized funding is released to one non-service organization, which then decides how to set priorities and allocate the money. The Toronto *Quality of Life Project* uses this approach. It has an Adjudication Advisory Group, but it is senior managers within the Family Service Association who approve the individual funds. This is similar to the Ontario Direct Funding Project where regional panels appointed by the funder determine who receives direct funding. The dilemma with this approach is the perception that the funding process is too close to the infrastructure supports, with the same managers adjudicating who also supervise infrastructure supports. The two processes need to be de-linked.

*The adjudication piece has clearly been a struggle for some projects. We have found that those initiatives that have resolved it most effectively are those projects that are based in provincial or national policy.*

**Accountability**

On the following page, we outline the recommendations of the Ontario Round Table on Individualized Funding in regard to a direct funding mechanism including eligibility, applications, and criteria for funding. These

**Mechanism for Direct Funding:**
**Eligibility, Applications, Criteria for Funding**

- It is preferable for government to provide the direct funding, so that community structures can focus on planning and service delivery. It is essential that allocation and funding decisions be separate from the infrastructure supports.

- Eligibility criteria for receiving direct funding should be based on physical and/or developmental disability, and the need for disability support. Individuals and their networks, in conjunction with local facilitators, will determine the amount paid.

- The application form for direct funding will be designed so that people's strengths and capacities, not just needs, are emphasized. People should also be asked what the person will accomplish as a result of the individualized disability supports.

- The application form for direct consumer funding for individuals who cannot self-direct will include the naming of a designate or representative who will have the responsibility of making decisions about the person's supports. We strongly recommend that the person's network also be involved in this process to reduce the vulnerability and dependence on one person. Also, it is expected that supported decision-making will ensure that individuals who are unable to self-direct will be full participants in the decision-making process. Facilitators will play an important role in balancing possible differences in network members' interests and concerns. We see this as a creative enterprise based on a person-centered approach.

- Criteria for funding should be based on the Round Table principles and reflect people's capacity to build networks and nurture community involvement. Direct funding is cost effective when it is utilized for a range of people, not just for people with the most obvious needs.

- To ensure continuity of support, allocations should be permanent, with monthly financial accountability and more detailed review and reporting after each year, with funding adjusted accordingly.

- Although there should be no arbitrary caps with the direct funding, parameters and "benchmarks" will need to be set, related to a reasonable quality of life. For example, the range and maximums that the direct funding will pay for things like speech therapy, physiotherapy, and tutoring will be outlined.

- Individuals and families must be accountable for all expenditures they use for disability supports. Individuals and families should have the choice of receiving payment up front or after expenditures, with receipts in both cases.

Ontario Round Table on Individualized Funding, 2000

are the "sticky" implementation issues that need clear guidelines for individuals, families, and the community. In Chapter V, we present details of how each of our "promising" initiatives have dealt with these issues.

*Equity* is a key principle related to the direct funding mechanism. Effective direct funding projects like the Western Australia *Local Area Co-ordination* serve a range of people with disabilities. Participants include people with developmental disabilities and individuals with physical disabilities, ranging in needs from mild and moderate to extensive. Equity ensures that everyone has an equal chance of being chosen. As well, the range of people being served has been shown to increase the cost effectiveness of the program. For equity to be more of a reality in Ontario, new resources will be needed for a new direct funding initiative, and a policy framework will be needed to guide regional and local practice.

Individualized funding also requires clear and widely understood procedures that ensure effectiveness for the individual and family, and accountability to the person and the state. The Ontario *Direct Funding Project* has developed a very clear set of procedures and guidelines that consumers find helpful. It is interesting that *accountability is often a key issue for governments, even though our analysis of several evaluations of IF projects have shown the accountability mechanisms to be very effective.*

## 8. "Learning as You Go": Pay Attention to Process and Outcomes

Any provincial or local initiative that plans to utilize a direct funding approach needs to learn from concerns and criticisms that have been raised about previous individualized funding projects. This finding is consistent with the methodology selected for this Review—an intense assessment of the literature on IF projects. New initiatives must also be open to addressing the lessons that come from the on-the-ground experience of developing a project. When implemented with sound principles and policies, individualized funding projects show positive outcomes and enhanced quality of life. To obtain such outcomes, projects and leaders must be willing to learn from others experience.

### Concerns About a Market Approach

There has been one main criticism directed at individualized funding. The general critique is related to the market driven nature of individualized funding. An IF approach does indeed shift the power from the supply side to the demand side. In other words, with individualized funding, individuals and families have the power to purchase services from whomever they want. *Critics charge that this leads to privatization, uncertainty, and a low wage sector.*

*Individualized funding enables a person to purchase different kinds of supports from various providers and breaks up the monopoly over service provision.*

Michael Bach, Roeher Institute, 1991

We need to reflect further on each of these concerns. It is true that an IF approach creates a "demand side" impact. Individuals and families have resources that they can spend to purchase supports in the market place. As Michael Bach has pointed out, this can have the positive effect of giving genuine options to consumers and has the possibility of breaking up service monopolies.[25] Depending on the context and policy, this may either lead to privatization, as it did in Alberta, or it can enhance the non-profit sector, as it did in Western Australia. Several factors seem to influence the impact of a demand side approach. For example, 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 IF agreements allowed people to hire brokers. Within this context, Alberta became highly privatized.

It is also true that an IF approach can possibly lead to a low wage sector. The Alberta experience is most instructive in this regard. Uditsky (1999) has argued that the Alberta government limited how funding could be applied, and required staff to be low paid, which in turn increased staff turn over. Experience suggests that governments again have a key role to play in setting employment standards and wage guidelines. There are examples where such standards have helped maintain a positive approach to labour.

The Ontario Direct Funding Project, for example, has a fair wage standard for attendants that must be adhered to across the province.

**Learning About Process from Project Evaluations**

Almost all the projects we have reviewed have had extensive evaluations completed on their initiatives. These evaluation processes have provided opportunities for projects to learn about themselves and others. Leaders we interviewed were very knowledgeable about other projects in Ontario and elsewhere. In most cases, *people were using their evaluations and feedback from consumers to make changes and adjust their strategies*.

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**Main Process Concerns Raised by Project Evaluations
in Nine Individualized Funding Initiatives**

**Concerns located outside the project:**

1. a cap on funding, determined by the government
2. lack of a policy framework from the government
3. difficulty finding the right specialists, employment and other people involvements for people being supported.

**Concerns related to implementation:**

1. the need to keep planning separate from direct service
2. the need to keep adjudication and decisions about money separate from planning supports.
3. the need for clear roles for facilitators and other support functions
4. the need to recruit and maintain effective support staff.

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There is a strong sense that projects are *"learning as you go."* Above we list the major process concerns raised by project evaluations in nine separate initiatives. Some of these are discussed as part of other lessons. For example, while this openness to learning is very exciting, the "struggles" of projects are worsened by the fact that many are operating without policy support.

**Learning About Outcomes from Project Evaluations**

The paradigm shift to individualized supports and person-centred planning has been accompanied by a shift in how we assess improvement and change. *Personal outcomes determined by the people themselves has become an important way to determine change.*[26] Most of the projects that we have identified as "promising" did evaluations that assessed outcomes for individuals, and often for other stakeholders as well.

In this section, we summarize outcome data from ten sites that have utilized individualized supports and funding. All ten projects had comprehensive evaluations completed over a minimum of two years. Outcomes were studied in all the projects, although only three utilized an experimental design with a control group (Western Australia, New Hampshire, and Michigan), while others had more typical evaluations (Ontario Direct Funding, Toronto, Windsor, Thunder Bay, MicroBoards of British Columbia, Manitoba, and Alberta). Most project evaluations used interview data with individuals and the people in their networks, including staff. Interview questions usually asked people to compare their lives now

with what they were like prior to having individualized supports and funding.

---

**Outcomes of Ten**

**Individualized Funding Projects**


| **Personal Outcomes** | # of sites |
|---|---|
| (increased or improved) | |
| Control and choice | 9 |
| Community presence | 8 |
| Relationships (family, friends) | 8 |
| Independence | 6 |
| Pursuing goals | 4 |
| Social and leisure participation | 4 |
| Employment | 3 |
| Education | 3 |
| | |
| **Community Outcomes** | # of sites |
| (Enhanced or new) | |
| Personal plans developed | 8 |
| Increased planning capacity | 5 |
| System changes | 4 |
| Cost-effectiveness | 4 |
| Flexible supports | 4 |
| Partnerships | 3 |

---

In the chart on the above, we highlight findings that are similar across sites. In order for a project to be chosen for a personal outcome category, it had to have the outcome identified by at least 50% of the participants. The community outcomes were identified by leaders and evaluators. Not all of the sites studied all the outcomes.

*Relationships – A Personal Outcome.* We use relationships as an example of a personal outcome. In Thunder Bay, there was increased communication about desire for relationships, stronger relationships with family, better quality relationships with existing friends, and more new friendships with non-paid people. Relationships were identified as one of the keys to the success of Microboards in British Columbia. Relationships between individuals, families, and friends often underwent positive changes. For many, relationships became more personal, stronger, and more balanced in power. Vela facilitators stress the importance of allowing the relationship to develop before "providing service." Pedlar and her colleagues have shown through their research that Microboards are an example of how individualized funding and network building can lead to a "textured life."[27]

*Partnerships – A Community Outcome*. Pedlar and her colleagues in their national study found that in individualized funding projects, relationships between staff and the person supported did not have an *imbalance of power* found in more traditional support systems. The Self-determination Projects in the U.S. also found enhanced partnerships and changes in the way services were delivered. Although it is not well researched, one project leader suggested that IF creates more leverage for

individuals and families, which in turn begins to make the service system more accountable to individuals and families.

*Cost Effectiveness*. Economic studies in four sites showed that direct funding and individualized supports were very cost-effective. In Michigan, for example, there were significant savings (between 12 % and 15%) for participants who moved from congregate settings to community living with individualized funding, which translated to savings of approximately $10,000 per person per year (a conservative estimate). The Western Australia Local Area Co-ordination and the New Hampshire Self-Determination Projects both showed that individualized funding was not more expensive. Although costs were similar to traditional programs, the outcomes were much more positive, indicating that the cost-effectiveness of individualized funding is very high. Although only four projects completed economic studies, these initial findings point to very important insights.

# Chapter IV

## Descriptions of "Promising Approaches:"

## Individualized Supports and Funding Initiatives

During the course of our research, we identified several projects in Ontario and elsewhere that can be considered "promising" initiatives related to individualizing supports and direct funding. For several of these initiatives, we describe the history, mandate, goals, and implementation approaches that have been utilized. These descriptions allow the reader to gain a more detailed understanding of projects that have been referred to in the previous section. This Chapter is divided into Ontario Projects and Projects from other Provinces and countries

## Ontario Individualized Funding Projects

## Ontario Direct Funding Project

### Centre for independent Living Toronto, Ontario

### History

In the 1980's, the Attendant Care Action Coalition advocated for direct individualized funding as an essential option for people with a physical disability who want to self manage their own attendant services. Based on principles from the Independent Living Movement (De Jong, 1979), the Coalition developed several briefs which had the effect of

mobilizing people with disabilities and getting the attention of government. A review of support services in Ontario (Lord, Hutchison, & Farlow, 1988) presented a framework for individualized funding and identified consumer interest around the province. Previous to this, a very small number of individuals (n=13) received individual funding through Orders-in-Council directly from the government. This was the first opportunity we had to learn that it was possible for people with complex needs to live outside institutions with direct funding.

By 1991, the government had decided to support a direct funding project for people who could self direct. In 1993, Bill 101 amended the Long Term Care Act and contained legislation for direct grants to individuals. Subsequently, a two year pilot project was developed, administered by the Centre for Independent Living in Toronto ( CILT).

**Demographics**

In Ontario, citizens who required attendant services had traditionally been supported through Support Service Living Units (SSLU's), where attendants were provided on an on-call basis, in a building designated solely for people with disabilities. In the 1980's, a program called Outreach was developed, enabling people to stay in their own homes, and have up to three hours of attendant care a day. The direct funding project was seen as a way to extend consumer control and to de-link housing and support. The pilot project served 77 people. Following the evaluation of the pilot, the government announced that the direct funding project would be a permanent project in Ontario, supporting up to 600 people a year.

**Mandate/Policy**

By 1993, the direct funding projects based on the Bill 101 legislation, provided direct grants to individuals. Other Independent Living Centres (ILCs) around the province (e.g., Collingwood, Kapuskasing, Kingston, London, Niagara, Ottawa-Carleton, Thunder Bay, Toronto, Waterloo) provided support to any individual from their particular community who received individual funding from CILT (Roeher, 1997). Independent Living Resource Centres are the mechanism for implementing the independent living (IL) philosophy. The independent living paradigm emphasizes that people with disabilities can best identify their own needs and can have productive lives in the community through self-help, empowerment, advocacy, and the removal of barriers (De Jong, 1979).

**Rationale/Goals/Principles**

The main goals of the project are to provide:

• an alternative attendant care program based on IL principles.

• to provide a cost effective alternative to conventional service delivery of attendant care (SSLU's, Outreach).

• to strengthen the capacity of individual consumers to self-manage.

• to provide an attendant care mechanism which provides greater control, flexibility, and empowerment for individuals with disabilities.

**Who the Program is For**

People with a physical disability who want to self manage their own attendant services are the target for the project. The person must be 16 over over, have a condition that has been stable for one year or more, requires attendant services, is aware of the type of service required, is capable of scheduling own services and making alternate arrangements if the attendant can not come, is capable of hiring and firing an attendant, just to name a few eligibility criteria (Roeher, 1997).

**Criteria for Receiving Support Dollars**

The application process begins with a letter of intent to CILT to determine eligibility. Full applications are also sent to CILT, which are then reviewed for accuracy and completeness. Application materials are then sent to nine regional panels that review the applications (two out of three of the members are users of attendant services), interview candidates, and recommend applicants to the Steering Committee. Consumers can receive a maximum number of 180 hours per month. During the pilot project, the mean number of hours funded was 140 (Roeher, 1997).

**Who Manages the Program? How Do They Do it?**

The program is administered by CILT, a Toronto based ILRC. As a transfer payment agency, CILT manages and distributes funds allocated to the project. The staffing arrangements at CILT include a program director

and co-ordinators. Other CILT staff also devote considerable energy to the project. CILT has developed application materials and a Self-Manager's Handbook (Parker, 1995). CILT also provides resources to the 9 ILRCs who in turn hire a staff person to assist individuals with disabilities and the ILRC with the management of the direct funding in that region. CILT has also established a steering committee for the project that develops policies for the project. A appeal review sub committee was established to respond to applicants who wanted to appeal their applications that had not been selected.

## Program Strategies and Infrastructures

For consumers interested in direct funding, they can receive support in two ways: first, the Self-Manager's Handbook and other resource material is available from CILT; second, each ILRC has a staff resource person who can assist people is developing their application form. This can be a fairly lengthy process for someone who has not considered all the implications of direct funding in their lives. Consumers who receive direct funding are called self-managers and all the strategies and supports that are provided insist that people indeed self-manage. Once people receive funding, there are minimal infrastructure supports, although they may continue to use the ILRCs as needed. It is expected that people will hire their own workers and manage their own budgets. There is no infrastructure support for building support networks or connecting with community. The project assumes that people who can self-direct have the capacity for developing their own networks.

**Support/Services Utilized in the Community**

The direct funding is limited to the hiring of attendants. Attendant service involves self-managers taking full responsibility for employing and monitoring attendants that work for them. Attendants can be utilized at home for a variety of tasks, at work, on vacations, and for recreation and leisure activities (Parker, 1995).

**How the Person Manages the Money**

Each person is their own self-manager. Once a consumer is accepted into the project, he or she must sign an agreement with CILT. This agreement includes their monthly budget, a payroll schedule, and sample employment agreements with employees with whom they will hire. Self-managers are responsible for everything related to employees from hiring, to remuneration, performance and supervision, and discipline and termination. Self-managers are required to keep a personal file for each employee and copies of all time sheets, payroll information, termination, and other notices. They must also keep a separate bank account for their direct funds and all cheques and withdrawals must be recorded. CILT provides an attendant job description that self-managers can utilize or adapt. The Self-Manager's Handbook provides resource material on workplace law in Ontario, which offers important guidelines regarding the employee/employer relationship.

**Evaluation Research on the Program**

The Roeher Institute (Bach, 1997) conducted an extensive evaluation for the Direct Funding Pilot Project between October 1994 and March 1997. The evaluation described the structure and organization of the project, the application and selection process, and highlighted findings in a number of areas which are discussed below.

**Successful Features/Lessons Learned**

The Roeher Institute evaluation demonstrated that there are numerous positive outcomes of the Ontario Direct Funding Project (Bach, 1997).

1.  ***Consumer-driven partnership***. The project demonstrated that self-managed attendant services enabled greater self-determination and socio-economic for persons with disabilities. The Steering Committee was a critical part of the process, with over half the members being consumers who use attendant services. As well three self-managers (also consumers) were involved on the Committee. Strong partnerships between the Steering Committee and CILT, government, and community representatives resulted in good communication and commitment to IL principles (e.g., consumer controlled self-assessment versus traditional professional assessment).

2.  ***Participation in the pilot project***. Becoming a participant in a pilot project was an involved process. The project was attempting to develop a fair application and selection process and was trying to have

a representative mix of self-managers. Helping self-managers become fully aware of the entire pilot process was important. On all these fronts, people were generally content (e.g., criterion, interview…). Fifty-six (89%) indicated they were very satisfied with their participation.

3.  *Flexibility, choice and control over attendant services*. The evaluations indicated an impressive list of accomplishments in this regard. Most participants experienced these changes in their lives almost immediately. Being able to hire, direct, and manage their own attendants was essential. More than 2/3 hired a former attendant. Many people expressed their contentment by comparing the new service to the former approaches. Areas where there was over 50% support for improvement in their lives included: management skills, independence, personal comfort, ability to travel, social/leisure activities, and relationship with family/friends, in that order of importance.

4.  *Social and economic participation*. The evaluation indicated that people have increased opportunities in social and leisure activities, especially those outside the home (e.g., visiting informally with others, attending courses, going to facilities and events, shopping). As well, some people reported an improvement in employment opportunities (e.g., now able to go on business trips, can spend more time at work, increased wages, spouse able to enter work force).

5. ***Employer/employee relationships***. For most people, this is the first time they have had this kind of relationship, where they are the employer. Over 2/3 hired mostly a former attendant, women, from diverse ethno-cultural backgrounds, well educated, and part-time workers. They reported improvements in direct accountability to the self-manager, more mutual respect, and increased flexibility for both people, especially compared to involvement with agencies (e.g., better working relationships, less bureaucratic, more consistency, better communication, fewer conflicts, fewer people in one's home).

6. ***Utilization and effectiveness of support resources***. A wide range of resources were made available to self-managers through CILT and other ILRCs (e.g., Manuals on self management, newsletters, network of self-managers). People are also very satisfied with support provided through CILT (more so than other ILRCs) (e.g., support in addressing issues, providing information, meetings with self-managers, workshops on managing attendants, peer support).

7. ***Cost effectiveness***. The evaluation demonstrated that the Pilot respresents a cost-effective alternative to agency-managed attendant service delivery for this group. The unit cost is lower, benefits outweight any drawbacks, and there was a more efficient use of health care services.

## Less Successful Features/Lessons Learned

The Roeher Institute evaluation demonstrated that there are numerous concerns of the Ontario Direct Funding Project, albeit minor compared to the positive outcomes (Bach, 1997).

1. *Consumer-driven partnership*. A few self-managers expressed interest in being more involved in the steering committee. Similarly, some attendants felt more avenues are needed for attendants to raise their concerns (e.g., 20% of attendants who responded to a survey suggested room for improvement in their employment situation).

2. *Participation in the pilot project*. While most people considered the eligibility criteria fair, a few concerns were raised: vacating their SSLU, having to have had their disability stable for a year, and having to self-manage versus self-direct were all mentioned. A few were uncomfortable with the interview process (i.e., having to defend budget, selection based on defending proposal rather than urgency of need).

3. *Flexibility, choice and control over attendant services*. Some concerns were raised. Funding policies (e.g., travel allowances for attendants, attendant wages only the Provincial average, 180 cap on hours, onerous accountability requirements) were an issue for a few people. Transition to self-management caused some problems for a few people (e.g., locating accessible housing, obtaining insurance, recruiting attendants for particular shifts, stress of taking on

management responsibilities, not being able to hire family members, interruptions in service arrangements).

4. ***Social and economic participation***. Despite the improvements, people still face substantial barriers: inaccessible facilities or programs (63%), unmet need for assistance from others (57%), high cost (58%), need for support from families or friends (only 17%).

5. ***Employer/employee relationships***. Despite all the positives, attendants still were concerned about no health benefits, fewer hours, ceiling on income, no job security, no support network as a worker, no guidelines on safety, short shifts, and lack of advance planning. Sometimes there were conflicts over issues such as working conditions and personality differences. And there was somewhat high turn-over rate of staff (59% reported turnover).

6. ***Utilization and effectiveness of support resources***. Despite overall positive comments, several issues were identified here: some feel more support is needed to attendant workers; some ILRCs in their region were not informed enough about the pilot, so they had to rely on CILT; having a roster of recommended attendants; brokering for self-managers; provision of training for attendants.

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# Individualized Quality of Life Project

## Family Service Association
## Toronto, Ontario

## History

The Individualized Quality of Life Project (IQOL) was a pilot project running from September 1997 to September 2000. It was spearheaded by the Ministry of Community and Social Services (MCSS), who asked the Family Services Association (FSA) to implement and manage it based on this agency's 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. The pilot was extended twice by the ministry (it was originally scheduled to end April 1999). The Toronto Area Office of MCSS has announced it will implement a new, permanent individualized program in the fall 2000, building on the work of the IQOL pilot.

FSA has a long history of providing generic programs that separate planning from direct service. This is an important lesson, similar to the other projects that have been reviewed, in regard to *separating planning from service* and *where to locate the individualized planning and funding*.

## Demographics

Toronto is a large urban centre, with a population base of over 3 million. Toronto has a large multicultural population, and very distinct neighbourhoods.

FSA is not a direct service provider, but does centralized intake, and planning. This pilot project was designed to support 150 families.

## Mandate/Policy

The MCSS has been gradually shifting towards more individualized approaches. In January 1997, MCSS put $15 million across the province for

young adults with developmental disabilities who have recently left school, supports to young children, and supports to adults living with aging parents. These target populations (children, transitional youth, and adults with aging parents) were directly incorporated into IQOL. $1.38 Million was made available to FSA to support the 150 individuals. FSA was given responsibility for person- centred planning with individuals and families as well as for allocating funds to support the plans.

## Rationale/Goals/Principles

In general, the project has focused on quality of life. The project has aimed to increase choice and control for individuals and families. It has also focussed on network building and strengthening families as a primary support in individuals' lives. Finally, it has aimed to increase community participation/integration and to improve access to and effectiveness of service providers. *This focus on quality of life puts the project focus primarily on individual planning and community involvement, and only secondarily on the funding required making this happen.*

Specific goals of the project are to: (a) provide planning support to families and individuals, including developing "a vision for life in the community," (b) actively assist, where requested, with developing support networks, (c) approve budgets and distribute funds, (d) track, manage, administer and report expenditures, and (e) support the individual and family with their implementation of the plan.

## Who the Program is For

Three target populations were eligible: children 0-6 and their families, young adults in transition from school to adult roles, and adults living with aging parents. All participants had developmental disabilities, of varying types and degrees. Participants did not have to self-direct; families and/or other supports were expected to be involved, and play a role in supported decision-making, planning, and implementation.

## Criteria for Receiving Support Dollars

In order to be selected to participate in IQOL, criteria were: (a) belonging to a target group, (b) date of application (first come, first served), and (c) diversity (geographic, type of disabilities, cultural background). Once selected, participants develop a plan, usually with the support of a community resource facilitator. For funding approval, the plan needs 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 are required.

## Who Manages the Program?

The individual and/or family and/or others invited by the individual/family form a plan. Assistance is available from Community

Resource Facilitators. The plan is submitted to the Project Manager, who approves budgets under $20,000. Larger budgets must be approved by a two-person committee of FSA Senior Management. There are two levels of appeals, the last one with the MCSS. There is a maximum amount of $45,000 per individual/family, plus $5, 000 emergency money. Part of the planning process involves a deliberate attempt to seek funds and in kind resources from the community *before* accessing IQOL funds. For the new permanent program that will begin in September, FSA is recommending that there be a Council appointed to be in charge of allocations. This *separation of planning/facilitation from allocations* enables facilitators to work as advocates with the families.

An Advisory Committee, including representatives from MCSS and various community organizations, was struck to provide feedback to IQOL staff and management. However, the Roeher (1999) interim evaluation report found that this committee has had limited impact on the project due to a perceived lack of direction.

**Program Strategies and Infrastructures**

*Planning is completely separate from services***.** Individuals/families have access to *community resource facilitators* specifically to aid in planning, and network support facilitators to aid in building personal networks. Neither is mandatory. In practice, participants often received network support from the community facilitators. Dividing the role was an important reminder that network building and community participation are critical, although *in practice the project found that it was more effective for*

*one facilitator to play both roles.*

***The facilitators appear to be one of the keys to the success of the project.*** The facilitator is seen as a  "catalyst, focusser," someone who can help families clarify. Getting to know the individual and the family well is a key part of this work. The role is intended to be distinct from case management (in fact, hiring was preferential towards those without case management experience). The facilitator is a connector, knowledgeable about community and resources. Facilitators generally spend a lot of time with families in the early stages of their work together. The process is person-centred, and many families were assisted in the development of a support circle or network.

The project and the evaluation has identified *several steps in the planning process* for individuals and their support networks, including;

- information exchange.

- network development (ongoing process).

- developing a relationship map.

- developing a community map.

- identifying strengths.

- developing a vision.

- looking at options and choices .

- defining the type of support required (formal and informal).

- developing outcome oriented goals.

- writing the plan, including costing.

These planning steps are not necessarily utilized in a linear manner, but are facilitated over a period of time with the individual and their network.

In addition to providing support with planning and budget development, facilitators also spend time helping families implement their plans. Here the facilitator may play a resource development role.

**Support/Services Utilized in the Community**

Support staff were available through several avenues: individuals and families purchased services from agencies, contracted with self-employed independent workers, and acted as employers of independent workers. Contracting with self-employed workers was far and away the most popular option.

The IQOL project actively encouraged the use of generic community resources. There is no restriction on the type of supports that can be utilized,

and the evaluation showed that funds were used for a wide range of supports. The most common supports were for community participation, community living, employment, and a number of therapies.

## How the Person Manages the Money

The funding model is indirect i.e., the MCSS transferred block funding to FSA, which then acted as "banker," distributing financial statements and money to participants. Participants submit paperwork documenting their use of services (i.e. invoices for purchased services, payroll worksheets, and time sheets for employed workers). Usually these are done bi-weekly. The FSA then issues cheques (to families or to staff). Where individuals/ families act as employers, they must report required deductions to IQOL, or request that FSA handle payroll. Monthly financial statements are provided to individuals/families. FSA provides a *Guide to Support Staff Administration* that outlines procedures for paperwork.

## Evaluation Research on the Program

The Roeher Institute's (2000) final evaluation report was released in March, 2000. Both the final report as well as the interim report dated March 1999 found largely positive results of the project. The project appears to have been implemented according to plan, with some minor deviations (for example, Community Resource Facilitators often acted to support networks; cheques were initially delayed for some workers). Total costs were $3,975,000 for 1997-1999. For 1998-99, 65% of the budget went to fund individual plans, 23.5% went to facilitator/ administrative support, 3.4%

went to overhead, and 1.5% went to evaluation. These figures are very impressive in terms of the agency's capacity to do this work in such a cost-effective manner.

In terms of *outcomes*, both positive results and challenges were found in the areas of self-determination, access to needed supports, and participation in the community. For *self-determination*, participants reported increased "clarity of vision," sense of freedom and choice, and development of personal capacities, relationships (two-thirds had new ones), and support networks. Most participants indicated they had more control in making decisions about supports. Many individuals and families indicated that the project afforded them the opportunity to make decisions that they wanted. Most people indicated that the project enabled them to have "some more," "several more," or "lots more" opportunities to pursue goals and interests.

In terms of *access to relevant supports*, almost 50% of direct support funding was used towards increased independent living and/or community participation. A wide range of generic services were used, as a direct result of the planning process, and needs were defined by individuals and families. Most individuals with disabilities required significant support. Many families used some of their resources to hire a person who was able to co-ordinate the implementation of the plan, support other staff, and co-ordinate the individual's daily schedule. This approach worked very well for families.

For *community participation*, recreational, educational, and social

activities increased overall and about 1/3 of participants increased vocational training/employment. Areas of most growth in participation were tutoring, day programs, and volunteering. The least involvement was in mainstream employment. Overall, the individualized nature of the project lent itself to more community participation

**Successful Features/Lessons Learned**

1. Generally, positive results indicated that *individualized funding is a viable* and useful direction.

2. Separating planning from services allowed for more *independence from service providers* and encouraged the establishment of genuinely new roles for families and social networks.

3. The provision of *help and facilitation in formulating personal plans* was seen very positively by all stakeholders.

4. Actively incorporating *a search for generic, non-funded, and alternately funded resources* was cost-effective for the Ministry, and encouraged community development.

5. Reasonable "caseloads" (about 24) allowed facilitators to function effectively. The *role of the facilitators* in getting to know individuals and families is a key part of the success of this project.

6. Support *network development* was fostered throughout the project,

and this led to successful outcomes, especially for adults.

7.  The *capacity of individuals and families* to make decisions about support arrangements was a factor in the success of the project.

8.  *The ability of families and individuals to hire* co-ordination support enabled greater co-ordination as well as better accountability to individuals and families. The individualized funding allowed this support to be put in place.

Overall, success lies in the *combined impact of facilitators and individualized funding*, and the focus on quality of life. Listening and planning with families created an approach to community that enabled families to expand their visions and hopes. The individualized funding enabled families to have more control over their lives. The fact that most families choose to hire their own workers attests to this theme.

**Less Successful Features/Lessons Learned**

Many of the challenges faced by the project were beyond the scope of the project (i.e., discrimination, physical barriers). Older parents were least likely to prioritize community participation, rather they tended to emphasize security and safety. Young families tended to focus on the day-to-day. Youth in transition benefited most in terms of community participation. According to the final evaluation, the project continues to face some issues:

1.  Some families saw the facilitators as working *for the funder*; one

lesson is that it may be wise to more fully separate allocation and administration from planning (as in Windsor). As the new, permanent program is developed, this will be a critical issue.

2. For *service providers*, concerns were expressed that they were not sufficiently consulted or informed about the project. The Advisory Committee, which could have meliorated this concern, was felt to be ineffective. Although some service provider resistance is natural, there is a need to prevent an "us vs. them" mentality, and to use existing expertise, when IF is implemented independently from the service system.

3. Participants appreciated that they had opportunities *to meet other people involved in the project*, and many hoped that this networking would happen more often.

4. Some families expressed concern about the *burden of the management* role. Overall, this was a small number of the total families served by the project.

5. The issues of *recruiting, developing and supporting direct support workers* was identified many times during the evaluation. The evaluators suggested that a staffing agency might be developed to deal with some of these issues.

6. Concern was expressed by many families that *cuts* to the program had

occurred when agreements were renewed in the final year. The evaluation suggested that this did not have a negative impact, although the program "feels" quite vulnerable to many parents. This vulnerability may well stem from families experience in Ontario, where individualized programs such as Special Services at Home are often "cut" or "changed" arbitrarily.

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# Windsor-Essex Brokerage for Personal Supports
## Windsor, Ontario

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## History

In 1995, the Essex-Windsor Innoventions Project, made up of families, service providers, government, and people with disabilities, began to focus on "restructuring" and how to "shift" the developmental disabilities service system from being service driven to being consumer driven and individualized. One goal was to develop "a proactive community planning capacity." By the end of the Innoventions Project, a Brokerage Pilot Project was put in place for one and a half years. During the Pilot, a government initiated restructuring process (involving all major stakeholders in the area) resulted in adoption of the brokerage/ individualized funding approach by the region.

*One of the lessons for reform is the importance of involving all stakeholders in the process*. Area Office government people were part of the process and very supportive of the changes.

## Demographics

Windsor is a medium sized city (population of 200,000) in South Western Ontario across the river from Detroit. The surrounding area of Essex County is mainly rural, with some of the best farmland in Ontario. There are two large Associations for Community Living, one in Windsor,

and one in Essex County. Christian Horizons is another residential provider in Essex. The Windsor/Essex Family Network and People First of Windsor both played important roles in the restructuring process. The President of People First was the chair of the Innoventions Project.

**Mandate/Policy**

The restructuring was centered on the existing principles of the Ministry of Community and Social Services. An agreement between the three major agencies and the MCSS Area Office was signed in 1997, insuring that block funding to the agencies would allow individual planning and self-directed and/or self-administered funding. In September, 1999, the Community Planning Committee for Adult Developmental Services approved a mission statement and principles that would insure that access to resources in the future would be based on personal choice made by families and individuals. The Brokerage Pilot has become incorporated as a new service since that time.

Brokerage *enables planning for individuals to be unencumbered and separate from the service system.* The principles are based on people's right to self-determination and community involvement, and is based on what Windsor-Essex people call an "empowerment model." This approach involves just in time planning, individual choice and control, and is highly individualized. Advocacy, planning, direct service, and allocation of funding are separate functions.

**Rationale/Goals/Principles**

The purpose of the Brokerage is "to assist people and their families/network of support who want to plan for change from the broadest possible range of options." There are several guiding principles, including;

- the broker will not make decisions for the person/support network.

- the broker will maintain an autonomous position from those elements of the system that relate to funding, policy, and service provision.

- no person will be denied the assistance of the broker because of the complexity of their personal needs.

**Who the Program is For**

Brokerage is designed for any adult citizen who has a developmental disability in Windsor-Essex. The person does not have to self-direct or self-administer, and the intention is that individuals would have their support networks involved in person-directed planning.

**Criteria for Receiving Support Dollars**

The individual, family/network of support and broker generally develop a person-directed plan, which forms the basis for receiving support. There is no formal needs assessment. Funding can be used to purchase staffing supports to assist the person in meeting their life goals. The

evaluation showed that facilitation of brokerage helps ensure that each family receives the planning help they need.

## Who Manages The Program? How Do They Do It?

Generally, the individual and their network develop a plan, usually with the assistance of unencumbered planning support like the brokerage facilitator. The request and plan goes to a Priorities Panel, which is separate from Windsor Essex Brokerage for Personal Supports, and then to the MCSS for allocation. At this point in time, it appears that the local Ministry Area Office is not comfortable with being responsible for providing direct consumer funding. The Community Planning Committee has considered a community bank that would look after the funds and allocation.

The Brokerage Management Board, made up of only consumers and families, provide guidance to the brokerage facilitators and set policies for the Project. The Area Office of MCSS participate as advisors as needed. Originally part of Family Service Windsor, Windsor Essex Brokerage has now become incorporated as a non-profit organization.

## Program Strategies and Infrastructures

Brokerage facilitators play a key role in enabling individuals and families to take the lead in planning their life. This planning will usually include strengths, dreams, and goals. Listening, network building, and supporting families to be their own planners is all part of the brokers work.

*The brokerage facilitator is an 'enabler' with individuals and families.* As people broaden their support networks, the hope is that infrastructures such as support circles will become more common place.

Prior to the implementation of the Brokerage Pilot, agencies and the Area Office of MCSS agreed on two important forms for the Project; 1) Personal support agreement, and 2) Letter of agreement between individual/family and broker. Both these forms individualize the approach and formalize agreements among the various parties.

One of the lessons from this Project is that *the role of the brokerage facilitator needs to be clear and widely understood.* Brokers do not have money to give, but they do have facilitation skills that can assist people in planning, applying for, and receiving their own funds. The commitment of the Area Office that all planning be unencumbered and separate from agencies has ensured that more and more families are using brokerage facilitation.

## Support/Services Utilized in the Community

A wide range of supports can be utilized with the individualized funding. What community resources are utilized depends on the individual plan and the goals of the person. During the Pilot with 17 individuals, there were wide variations among the people being supported. By the end of 1999, Brokerage had helped 115 people in a variety of ways, from assisting with planning, the giving of information, mediation, negotiation and network building to name a few.

**How the Person Manages the Money**

Once a person has their budget approved by the Priorities Panel and by MCSS, the money is allocated to a community transfer payment agency of the person's choice. The community agency plays the role of banker. People submit receipts to the agency and are reimbursed for approved expenditures.

**Evaluation Research on the Program**

The Roeher Institute evaluation research on Brokerage identified several achievements;

- growing sense of empowerment of families.

- development of planning capacity through multiple roles played by brokerage facilitator. These roles included:

  - helping to facilitate development of long-term person-centred plan.
  - assisting in setting up support arrangements.
  - bringing a community focus to the person
  - assisting in negotiating and obtaining resources.
  - creating a context for service system reform.

The evaluation also identified success factors and issues which are

outlined in the next two sections.

**Successful Features/Lessons Learned**

According to the evaluation and interviews conducted for this summary, there are several successful features of the Brokerage approach;

1.    an *empowering planning process* that requires the individualizing of resources and/or funding.

2.    *independence* of brokerage support.

3.    focus of *facilitating* with *various roles*, depending on the situation.

4.    a *partnership* or team approach to developing person-centred planning.

5.    facilitating shared *community responsibility*.

**Less Successful Features/Lessons Learned**

According to the evaluation and to interviews conducted for this summary, there are several issues that Brokerage struggles with;

1.    clarifying the roles of the independent brokerage function.

2.    focusing more fully on natural supports and community resources.

3.      finalizing the mechanisms for funding, accountability, and appeals.


The evaluation report indicated that no one agency should take the lead in person-centred planning and that community agencies have a role to play in this regard. Experience elsewhere (including Western Australia and the Toronto Individualized Quality of Life Project) suggests that *it is the separation of planning from service that creates the openness for new ideas, and the likelihood of families and individuals will stay focused on community, social networks, and individualized support.* In fact, the data presented in the Brokerage evaluation points to the same conclusion! This is not to say that agencies do not have a role in preparing people to move toward individualized approaches, but that resources for individualized planning should be invested in Brokerage or similar separate structure.


**Final Note**: The caution of local Ministry Area Offices in Ontario to fund individuals directly has created a dilemma for communities that are trying to reform service systems. Leaders in Windsor have stated that the ideal would be to have Windsor Essex Brokerage for Personal Supports to do the unencumbered planning with families and individuals, for the Priorities Panel to prioritize situations, and for the Ministry to allocate funds directly to individuals. For this to work well, it assumes that all parties are basing their work on similar values of empowerment and inclusion. Since the local Area Ministry offices will not likely do the direct funding, communities need to figure out how to bank and distribute the money. The concept of the Community Bank has been considered in Windsor, and it will be instructive for other communities to see how they construct this

alternative.

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# Thunder Bay – Choices Project
## Thunder Bay, Ontario

## History

Choices was a two year pilot project on systems re-design, running from September 1994 to December 1996. In 1993, during the closing of the area's largest institution, a partnership aimed at system redesign was formed by the MCSS Area Office and all six of Thunder Bay's agencies serving people with developmental disabilities. Initially, the project was an initiative

of 6 agencies providing support for people with developmental disabilities: Thunder Bay District office of the Ministry of Community and Social Services, Avenue II Community Program Services, Centre for the Developmentally Challenged, George Jeffrey Children's Treatment Centre, Lakehead Association for Community Living, Lutheran Community Care Centre, and Wesway Incorporated (Bach, 1997)

A Steering Committee including these seven players as well as representatives of People First and The Community Inclusion Group was struck. Choices emerged from this process and was funded . As of April 1997, Choices participants continued to receive funding, and strategic planning continued under a new Community Planning Group formed in March 1997 (Bach, 1997).

The lesson from this is that *individualized funding projects can emerge from system and service reform, not just new initiates*.

**Demographics**

Thunder Bay is a city in Northern Ontario. There are six agencies, of various sizes, serving people with developmental disabilities in Thunder Bay, all of which were actively involved in initiating, designing, and implementing Choices. The city has several consumer advocacy groups, including People First, which were also actively involved. The sponsoring organization, Lakehead Social Planning Council, is a community planning agency that does not provide direct services. There are an estimated 1,000 individuals in Thunder Bay with a developmental disability (Lutheran

Community Care Centre, 1999).

## Mandate/Policy

The process was welcomed by government (MCSS co-initiated it) and fits well with general provincial direction (see notes for Windsor, Toronto, etc.). Choices was not a pilot in the sense of testing *whether* to pursue individual funding – rather, it was seen as an investigation of *how* to pursue individual funding and service brokerage. Both Choices and Choices Follow-Up Supports were directed by a Governance Board made up of various stakeholders including a consumer or family member. This board's goal was to provides general guidance to Choices management, monitor expenditures, "provide accountability for the project evaluation" and make recommendations re redesign. As well, a Project Advisory Committee, consisting of an overlapping range of stakeholders (including consumers and families) assisted with ongoing evaluation as needed; identified issues and problem-solved; monitored adherence to principles of choice, control, and empowerment; and monitored accountability to consumers and facilitative approach with others. The project was sponsored by an independent agency and a separate agency acted as "banker," receiving and disbursing MCSS funds.

## Rationale/Goals/Principles

The project was intended to provide a model system that would demonstrate accessibility, responsiveness, choice, and empowerment. It aimed to help people with disabilities become aware of choices and to act on

choices that they made, and to help agencies and other people to respond appropriately. An overarching goal was to assist in more widespread system redesign. It was not an entitlement program (participants were limited to those who apply and are accepted). The goal was to ensure a choice of opportunities for all individuals with a developmental disability to have a meaningful life within the community:

- opportunity to live in decent, affordable housing of their own choice.

- opportunity to develop and maintain relationships in a social network extending beyond paid staff.

- opportunity to participate in the workforce as desired, and the freedom to pursue their own interests and lifestyles (Choices Project Steering Committee for System Redesign, 1993, p. 2.2).

The project is based upon several important principles:

- *Adequacy and fairness:* decisions about how much a person can receive are based on the fact that there is only so much money in the Community Trust Fund and since some people will need to receive higher amount, others will necessarily have to receive less.

- *Flexibility and portability:* people's needs change from year to year, so the amount one receives may also change; the money needs to be flexible to allow for increasing or decreasing funding needs; flexibility also allows individuals to re-apply mid year if a crisis arises

and the expected budget is inadequate.

- *Limits of individual funding*: money can not buy relationships, so individualized funding should only be seen as part of the overall picture (Lutheran Community Care Centre, 1999).

## Who the Program is For

The program is available to adults and children in Thunder Bay who have a developmental disability.

## Criteria for Receiving Support Dollars

Decisions are made by a Funding Approval Officer who is accountable to the Board of Directors of Lutheran Community Care Centre. An Appeal Body, made up of a member of the Board of Directors and a representative from Community and Social Services, acts as an independent arbitrator (Lutheran Community Care Centre, 1999).

Individualized funding is not an entitlement. It is negotiated according to individual disability related needs. The person should demonstrate that there is not a duplication of funding; that other sources of funding have been attempted; that the proposal includes enough, but not too much support; that the paid supports amounts are in line with those approved by the Community Trust Banker; that the combination of informal networks and paid support will maximize the person's life opportunities; that a clear system of monitoring is in place; that the person has been the centre of this planning

process; that creativity is evident in the proposal; and finally, that individualized funding will contribute to the person participating more fully in the community. Services already covered like health, training, advocacy, education, will not be approved (Lutheran Community Care Centre, 1999).

**Who Manages the Program? How Do They Do it?**

Choices was sponsored by the Lakehead Social Planning Council and funded by MCSS, with seconded staff from partner agencies. A separate agency (Wesway Inc.) Acted as "banker" for the project, holding block funds received from the ministry. Staffing for the project included: 1 resource consultant, 1 project co-ordinator, 5 brokers, all of whom were part-time.

**Program Strategies and Infrastructures**

Individualized funding through Choices is used to supplement the Ontario Disability Support Program (ODSP), which covers regular living expenses. There are five features emphasized in this program:

- individual funding is about you…"one size does not fit all.": focuses on the person's unique gifts, strengths, and dreams.

- relationships are important…"Money can't buy happiness": relationships are important to life in the community, not just paid supports.

- support circles help…"Ya gotta have friends": people applying for individualized funding are encouraged to develop a circle of support of people who will be there for the person.

- cost should be reasonable… "affordability": funding should not duplicate other funding the person is already receiving.

- how is it working?…"Value for money": individualized funding is available to assist your life in going in a better direction than is currently happening; the plan should include how this will be monitored (Lutheran Community Care Centre, 1999).

For individuals who wish, a planner/broker is available to assist with the individualized funding process. Service Brokerage is built on the belief that individuals and families need good information and good advice to make good decisions. The primary areas of responsibility include:

- *personal planning*: facilitate personal planning with individuals and their support circles; ensure the person has a voice in all aspects of the process.

- *information and resources*: gather a wide range of options for individuals in both traditional and non traditional places.

- *negotiating funding and arranging supports*: compile information to prepare budgets, write funding proposals and personal support agreements with service providers; negotiate with the Ministry of

Community and Social Services.

- *action*: put plan into action, based on direction of person and the circle.

- *monitoring*: develop a monitoring plan as part of the individualized plan in terms of what the agreed upon measures of success will be and who will be responsible to monitor.

- *liaison, support and training*: provide support to community agencies e.g., help agency provide a new service, help paid supports understand their accountability to the person.

- *organization and communication*: Keep files and regular reports on the process; use simple language; keep in touch with Choices co-ordinator (Choices Project, 1996)

**Support/Services Utilized in the Community**

- Community Support Services of Thunder Bay

- circle of support (friends, family, paid support persons)

- generic community services (schools, recreation services)

**How the Person Manages the Money**

The Community Trust acts as a banker for the Individualized Funding.

The money is held in this trust in the individual's account on their behalf. This ensures all money is spent according to the approved agreement. The banker will pay the person's bills, let the person know if he or she is under or overspending, help the person adjust their next agreement if they need more, and get the person's permission to release unused money to be used by others.

**Evaluation Research on the Program**

The Roeher Institute completed an evaluation of the Choices Project (Bach, 1997). The evaluation documented background to the project (i.e., history, structure); funding and support options and arrangements, findings (outlined in the next two sections—successful features and less successful features); and future directions.

**Successful Features/Lessons Learned**

There are several successful features that emerged from the one review of the project ((Bach, 1997).

1. ***Focus on personal networks and relationships:*** The project assisted most individuals in developing a personal network and personal relationships with the assistance of network builders, the community trainer, and support to the individual's paid staff. For example, there were increased communication about desire for relationships, stronger relationships with family, better quality relationships with existing friends, and more new friendships with non-paid people.

2.    ***Autonomous planning support organization***. The establishment of the Choices Governance Board contributed a significant achievement in the evolution of the support system in Thunder Bay. It was mandates to exclusively provide planning supports in the form of brokerage and personal network development. This enabled a vision and plan for a person to be developed, fostered relationships, led to financial and service agreement which were individually focused, provided for the co-ordination, and contributed to improved community capacity.

Choice established three roles in providing autonomous planning supports: brokers, network builders, and community trainer. The distinction between the roles was effective for the pilot. The community trainer role in particular has led to a strong community development focus. This has resulted in the availability of strong community resources for individuals, meaning less need to use individualized dollars to create appropriate services.

The fact that the project had an autonomous brokerage role separate from service providers and funders was key to the success. It enhanced accountability to individuals, provided support to individuals needing assistance with personal plans, and provided support in negotiating funding and agreements.

3.    ***Individualized funding arrangements***. Individual funding arrangements were possible for individuals of a wide age range, with a variety of support needs. These arrangements gave individuals, many

for the first time, the power to make decisions about who would support them, where, on what terms and conditions.

4. ***Management of staff and support arrangements.*** The designation of agency co-supervisors has been important. They are a solution to dealing with agency needs for liability protection acting as "administration employers" of staff, and they assist in managing support arrangements which are complex. They also approve invoices for staff of individuals.

5. ***Enabling financial accountability***. Choices, in conjunction with Wesway, have been successful in implementing an effective financial administration system. Individual contracts have been followed, financial information readily available (i.e., regular statements from service providers indicating expenditures under agreement), funding accountable to individuals, and summary information about all agreements.

## Less Successful Features/Lessons Learned

There are several issues or concerns that emerged from the one review of the project ((Bach, 1997).

1. ***Focus on personal networks and relationships:*** The distinction between the role of personal relationships and the role of an intentional personal network or support circle was not made clear.

Staff report difficulty in making community connections due to time constraints, lack of knowledge, and some family members' hesitancy about friendship development. Choices and the community trainer could do a better job of assisting service providers in developing a strategy for supporting the development of community connections and personal relationships.

2. ***Autonomous planning support organization***. Much of the community development work has focus more on the individual level i.e., working with a swimming pool to include an individual. But broader community development challenges still exist: transportation, health and dental services, school-to-work transition supports, recruitment of volunteers, support to church communities, and demand for increased funding for in-home supports (Bach, 1997).

Despite recognition of an autonomous brokerage function, there were problems. There was a perception the brokers were seconded from service agencies, hence compromising their autonomy, even though there was no evidence of this happening. Second, when brokers must relay bad news from the Ministry about their proposal, there is a perception the brokers are compromised. This information should come directly from the funder to the family (Bach, 1997).

As well, there was concern that brokers were not as accountable to individuals as they could be (more focused on direction from family and support network), that individual's support arrangement are not adequately monitored, and information sharing with other providers of

service about an individual was sometimes limited (Bach, 1997).

3.  ***Individualized funding arrangements***. Some concerns were raised about the fairness of the approval process (too much power in one person in the Ministry, reasonable proposals rejected, lack of guidelines for managing the allocation of dollars) and undercutting of wage levels of paid staff. A more comprehensive individualized funding system is needed to address these concerns about limited funding, and a more informal "appeals" process is needed to address the issue of fairness (Bach, 1997).

4.  ***Management of staff and support arrangements***. The support arrangements for some individuals are extremely complex (i.e., the need for several different workers). Particularly in complex situations, the families and support networks are feeling overwhelmed. Given the complexity of many situations, there is sometimes lack of clarity about the diverse roles of all the players.

5.  ***Enabling financial accountability***. In terms of approving invoices, Wesway receives invoices from independent contractors, but Wesway is a banker and is not in a position to monitor or really approve invoicing. Sometimes these invoices are sent in far too late, making it difficult for individuals and families to keep up-to-date on their agreements. Some find they do not have enough current information about their agreements.

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# INDIVIDUALIZED FUNDING PROJECTS IN THE REST OF CANADA

## Individualized Funding and Microboards in British Columbia

### History

In the mid 1970's, direct or individualized funding was mandated by the legislature in British Columbia, but by the 1980's and 1990's, the government's commitment lessened due to bureaucratic and provider interference (Salisbury, 2000). The Community Brokerage Services Society and Microboards have been the two made-in-British Columbia community driven models. However, despite their apparent success, they have remained small, relatively unknown, and marginal to the overall health and social services system. This is partly explained by the fact that there has not been a broad community movement to promote individualized funding in British Columbia (B.C. Coalition of People with Disabilities, 1997).

*Microboards.* In 1989, the Vela Housing Society, a non-profit organization in British Columbia initially offering subsidized housing to people with developmental challenges in Greater Vancouver, started a pilot project with 3 mircroboards (Vela, 2000) Under the provincial Society Act, a

minimum of five people may form a non-profit society or microboard. These boards consist of a small group of individuals (family and friends) who work together to address the support needs of a person with challenges. Vela facilitators also help to link up individuals who are not involved with family and friends with others who would be interested in participating in a microboard. Microboards have the option to oversee the provision of support services to the focus person (the person with a disability), thus becoming employers. Vela provides support to the mircroboard for this employer role. Microboards are able to access funding because they are registered societies similar to the Associations for Community Living (Vela, 2000). Microboards are not used consistently across the province because each government area has a different approach to service provision – there are probably only around 125 microboards now (Salisbury, 2000).

*Community Brokerage Services Society*. From 1991 until 1996, the Community Brokerage Services Society operated in British Columbia as a pilot project. The project was funded by the Ministry of Social Services. The project provided unimpeded planning supports to individuals with developmental disabilities and their families, as well as assistance in accessing individualized funding. Prior to this, people had tried to implement individualized funding, but there had only been isolated instances of government using this approach, mostly where it suited their purpose. In British Columbia, there is no policy commitment to individualized funding. A steering committee negotiated implementation for the project and service brokers helped individuals and families develop a specific plan which was negotiated with the government, the funding body to which the person was accountable (Salisbury, 2000).

***B.C. Coalition of People with Disabilities.*** In 1997, the B.C. Coalition of People with Disabilities received a grant from the Ministry of Children and Families (formerly the Ministry of Social Services) for the Individualized Funding Community Development Project. The project is a collaborative effort that recognizes that people with physical disabilities and those with developmental disabilities are facing many of the same issues with regard to support needs. The group held a conference on individualized funding in the summer of 1997 and is currently drafting a proposal on individualized funding to be submitted to the British Columbia government (Salisbury, 2000).

**Demographics**

As has been mentioned, there are now over 150 mircroboards in British Columbia. A recent study of support services across Canada affirmed the uniqueness of British Columbia compared to other provinces (Pedlar, Haworth, Hutchison, Taylor, & Dunn, 1999). A survey was sent to provincial government ministries responsible for services to adults with developmental disabilities, and provincial Associations for Community Living. The results indicated that agencies serving 10 or fewer individuals, which included microboards, were numerous in British Columbia (n=126) compared to all other provinces (e.g. Manitoba n=17; Ontario n=10; Nova Scotia n=7). When one considers the thousands of individuals with disabilities in British Columbia, however, the number of individuals served using individualized funding and brokerage is still relatively small. In other words, traditional funding continues to dominate the Canadian landscape.

## Mandate/Policy

In British Columbia, a group of five or more people may register as a non-profit society and thus gain access to funds for the support of an individual through the Society Act. The person with the disability may count as one of the five people. A person hired by the mircroboard cannot sit on the board. This is the mechanism used for the microboards (Vela, 2000). Currently there is no other legislative basis for individualized funding in British Columbia. Responsibility for microboards originally fell to the Ministry of Health, but more recently has since shifted to the Ministry of Social Services (Salisbury, 2000)

## Rationale/Goals/Principles

Microboards are grounded in a belief that empowerment is only possible when there is a shift in the power relationships between the person with a disability/family, the community, and social and political spheres (Pedlar et al., 1999). The primary focus of microboards is to provide support for an individual and a mechanism for individualized funding. The Community Brokerage Service Society, through service brokers or planners, offered unencumbered planning supports as well as assistance with negotiating individualized funding. A few examples of Vela's guiding principles include:

- Microboard members must have a personal relationship with the person.

- All people are assumed to have the capacity for self-determination.

- All services developed or contracted are based on the person's needs, not availability of services.

- Staff who work with a person through their mircroboard, are not attached to the buildings in which the person lives, works, volunteers, or recreates. They work for the person, not an agency or business (Vela, 2000).

## Who the Program is For

Microboards are for people with "challenges" and their friends and families. Due to the involvement of informal support, microboards are ideal for those who are not able to self-direct their support services (Vela, 2000). In contrast, for example, in the Ontario Direct Funding Project, individuals with physical disabilities can access attendant care using direct funding, but individuals must be capable of directing their own care (see Ontario Direct Funding Project in this document).

## Criteria for Receiving Support Dollars

A microboard, with support from Vela, develops a plan and a proposal for funding. The proposal is then need to be approved by the Ministry of Social Services (Vela, 2000) (See Mandate/Policy above). What is most important here is that funding goes directly to the person and the

microboard, not an agency like other types of funding. In addition to planning support, and other informal support, the microboard has the fiscal resources to obtain any needed formal supports and services (Pedlar et al., 1999). Not unlike any other service, the microboard must comply with government regulations around by-laws and constitution, budgeting, employment forms, bookkeeping, bank account, Workmen's Compensation, and an annual general meeting.

## Program Strategies and Infrastructures

Keeping microboard planning separate from direct services is important in British Columbia. There are several ways this happens. First, microboards have the mandate to do their own planning and support separate from Vela or anyone else. Second, Vela formed a separate Vela Microboard Association (Vela, 2000). Third, the concept of brokerage from the *Community Brokerage Services Society* (see History), ensures independence from services. In this pilot project, which is no longer running, individuals with disabilities/families had assistance from independent brokers to plan and access services

Individual microboards cannot operate with support. In British Columbia, that support primarily comes from The Vela Microboard Association. The Association has members from all over British Columbia, the majority of whom must have had the experience of being a member of an individual microboard. The association has an executive director, assistant co-ordinator, and 2 facilitators to assist with their work. Vela provides an annual microboard conference, enables members to stay connected through

the microboard webpage, and facilitators provide support and technical assistance to microboards. Facilitators come at the request of interested mircroboards and continue to provide support as long as it is requested (Vela, 2000).

## Support/Services Utilized in the Community

Microboards facilitate a wide variety of community experiences in order to ensure the person has the best quality of life possible including social, recreational, educational, and employment opportunities. Sometimes those opportunities are readily available in the community and the microboard easily accesses them; other times, the microboard may decide that the opportunities which are needed are not available and that they need to provide direct service. They then hire staff and become employers. Research has demonstrated that "The microboard approach enabled people who shared a genuine friendship and mutual liking to be paid for the formal support they provided to the individual" (Pedlar, et al., 1999, p. 112)

## How the Person Manages the Money

The person does not actually manage the money. By virtue of their status as non-profit societies, microboards have an internal structure than lends itself to the management of funds. The "official positions" of the microboard include a President, a Vice-President, a Secretary, and a Treasurer. Vela suggests the creation of a Staff Liaison position for microboards that wish to manage funds and hire staff directly (Vela, 2000).

## Evaluation Research on the Program

The Women's Research Centre (1994) conducted a review of microboards for the Vela Housing Society. The evaluation focussed on the role of the Vela Housing Society and was not an evaluation of microboards per se. Nevertheless, the review presents an important analysis of the issues related to microboards.

The book *A Textured Life* (Pedlar et al., 1999), while not an evaluation of the microboard approach, also presents some useful observations on microboards. Included in the book are the types of support that are offered through the microboard approach, how this support differs from more traditional models, and some of the outcomes for people receiving support.

## Successful Features/Lessons Learned

1. Microboards provide people with "*more choices, more opportunities, and greater independence*" (Women's Research Centre, 1994, p. 4). In particular, flexibility in funding is related to, and allows for, stronger connections with the community, in other words, opens "pathways to the community" (Pedlar, et al., 1999).

2. *Relationship*s are the key to the success of microboards. Relationships between individuals, families, and friends often undergo positive changes. For many, relationships become more personal, stronger, and more balanced in power. Vela facilitators stress the importance of

allowing the relationship to develop before "providing service."

3. A good *person-centred planning process* is essential. It is important to take the time to dream because the more individualized approach to providing supports opens up new possibilities and opportunities perhaps not thought about before. Vela uses a planning process called MAPS.

4. Individuals and especially families find the *technical supports* afforded by the microboards to be invaluable.

5. Relationships between staff and the person supported did not have an *imbalance of power* found in more traditional support systems and were more individualized and personal (Pedlar et al., 1999).

6. Staff report greater *flexibility and creativity* in their when providing more individualized support through a microboard approach work (Women's Research Centre, 1994).

7. Microboards afford the *option of hiring someone with whom the person has a good relationship.* While some individual funding models discourage or even prohibit friends and family members from being paid to provide support, members of microboards seem to value the opportunity to pay those who have a personal relationship with the individual for whom the formal supports are provided.

8. *Individual funding alone does not guarantee a textured life.* Pedlar et

al. (1999) observed that "individualized funding *along with* a microboard service model seemed most promising in terms of fostering empowerment-in-community and the realization of texture in people's lives. We doubt that either one of these approaches … would function particularly well without the other" p. 124). When people receiving individualized funding purchased services from agencies (many in the private, for-profit sector), there were limits to their participation in community life as compared to those involved with microboards.

**Less Successful Features/Lessons Learned**

Many of the lessons learned in the following section are not necessarily "less successful features" but might be more accurately termed "challenges" or "issues to be addressed."

1.  It is not always easy *to determine the wishes of the person* supported, particularly if there are difficulties with communication. Several of Vela's guiding principles address this notion: have a personal relationship with the person; assume the capacity for self-determination; the more complex a person's needs, the more customized the supports; conduct business in spirit of mutual respect; staff works for person, not an agency.

2.  The *wishes of the person may not always appear sound (*Women's Research Centre, 1994*).* This issue raises the question of whether "this right to self-determination should be considered absolute or if there

are situations when the microboard should try to prevent what they believe could be a serious mistake" (, p. 14). This means microboards are "balancing board responsibility with respect for the person's right to privacy, independence and self-determination" (p. 19). As well, the "right to make decisions includes making some choices that some or all board members disagree with or are hurt by" (p. 13).

3.   *Finding the right staff can be difficult*, particularly at the beginning. Staff are often found through the networks of other staff or board members, although some people have encountered difficulties with hiring friends and relatives when things do not work out. People who have worked in the traditional service system are not necessarily a good fit with microboards because the way in which support is provided is very different, as is the administrative structure. Also, because the pay is low, staff may be hard to keep.

4.   Due to provincial regulations, the *role of employer* for microboard members is often a challenging one. Microboards are seen as "doing well" in terms of accountability for funds (Women's Research Centre, 1994). Vela facilitators encourage boards to be reasonable in their requests, i.e., not "pad the budget." On the other hand, microboards "should be assertive about their needs and not 'play games' with the government" (p. 27).

5.   Some critics have asserted that the administrative role of family members has a *negative effect on family relationships*. While microboard members have not found this to be true, reviewers have

pointed out that simplifying the administrative requirements would address this concern.

6.  It is difficult to draft *clear policy statements* due to the individual nature of the supports with the microboard approach. "Staff in the Ministry of Health who have had the most extensive experience with microboards have found that their philosophy statement and a 'framework' for monitoring have worked better than a more detailed policy would" (Women's Research Centre, 1994, p. 28). Reviewers from the Women's Research Centre go on to say that "a more defined government policy and guidelines for monitoring could be a way to entrench the concept of microboards and help protect them against ad hoc intrusions by ill-informed bureaucrats" (p. 28). This is of particular concern since the transfer of responsibility has shifted from the Ministry of Health to the Ministry of Social Services.

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# The Alberta Experience
# With Individualized Funding
## Province of Alberta

## History

Individualized funding became available in Alberta in 1985. By Jan. 1st 1990, individualized funding had become the official way for service delivery.

In Alberta, the Provincial Government used provisions under the Social Development Act to set-up, finance, and administer individualized funding in response to a growing demand from advocacy organizations and disabled people. These groups had lobbied for individualized funding in response to the shortfalls they saw in both the institutional approach in supporting people with disabilities and the block funding to service agencies. The demand of the service providers rather than the needs of the person drove both these models with a disability.

*There are two funding mechanisms in Alberta that could be called 'individual'.* Alberta Health operates a program that is available to adults with

physical and sensory disabilities. Self-managed care for people with physical disabilities was a pilot project within Home Care from 1991 to 1993 in four cities. It became a full-fledged program in 1993. Alberta Family and Social Services operates a program for people with developmental disabilities and children. These systems operate alongside more traditional funding mechanisms, such as contract agencies and government run services (institutional services and group homes).

## Demographics

Alberta is a largely rural province with several major urban centres. The pilot project sites were in both rural and urban settings. "The Individualized Funding system was set up on the back of oil revenue in the 1980's and it remains to be seen whether it will become one of the cuts to social services of the mid 1990's" (Short, 1997, p. 7). Privatization has been a long-standing approach to social services in Alberta. Numerous for-profit companies are utilized by individuals and families for hiring attendants and other kinds of support workers.

## Mandate/Policy

Until recently, individualized funding was covered under the Social Development Act and Administered by Alberta Health and by Alberta Family and Social Services. It is now a program under the Persons with Developmental Disabilities Act and as such has been de-linked from welfare. *Community Inclusion Supports: Individual Funding Program Manual* is the Provincial policy which governs the delivery of the Individual Funding Program. Unless otherwise stated, regional delivery is to be consistent with the stated policy. Individual staff do not have the authority to contravene policy. Exceptions to this Provincial Policy can be

requested from the Executive Director of Services to Persons with Disabilities, on an individual basis. These exceptions must be noted on the individual's file. Delivery of the IF program is regionally based.

Information about the program is available to the public. The information is written in simple language describing/explaining the process and all aspects of the program; eligibility, how to apply, guidelines, supports available, etc. Assistance is available to help with the submission of an application. This information includes:

- regional application process.

- regional decision making process.

- regional contact people.

**Rationale/Goals/Principles**

"The purpose of the Individual Funding Program is *to provide direct funding* for adults with developmental disabilities to purchase supports required to live, work, and participate in the community" (Alberta Family & Social Services, Policy and Procedures Manual, 1998, p. 01-1). Within Family and Social Services there is a stated commitment to a guiding philosophy on which all services are based. The Department is committed to the development of responsive and personalized supports that enable inclusion. It is also committed to innovation and the development of flexible, enabling policies, which invite creative and dynamic supports in the community.

Principles of services to persons with disabilities program are:

- Inclusion: opportunities to become fully included in community life and personal relationships.

- Equality: equal value and worth of all people.

- Empowerment: meaning full choices and self-determination, recognizing the role of personal and informal supports.

- Equity: development and implementation of policies which promote equitable opportunities and access to generic resources.

- Support: development of responsive and personalized supports to enable inclusion, empowerment and equity.

- Innovation and quality: flexible, enabling policies which invite creative and dynamic community supports and services.

**Who the Program is For**

The Individual Funding Program under Services to Persons with Disabilities is available *only* to adults with developmental disabilities. People requesting an Individual Funding Application who do not have a developmental disability can be referred to Alberta Health and/or Alberta Advanced Education and Career Development depending on their needs. Those who self-direct and/or self-manage and those who utilize other supports such as fund administrators or service brokers

are eligible for both forms of Individualized Funding, although the Self-Managed Care option offered by Alberta Health allows a person greater control over who provides the personal supports. The fact that a person is allowed a 12% administration fee in addition to their personal support money enables them to contract with provider agencies to handle the recruitment and employment aspects of their personal support, which they as individuals may not wish to or be able to manage.

**Criteria for Receiving Support Dollars**

Under Alberta Family & Social Services, there are certain eligibility criteria that must be met. To qualify a person must:

- be 18 years of age or greater.

- be living in Alberta.

- have an Alberta personal health number.

- have a disability, which is assessed as a "developmental disability."

There are also income criteria that must be met. A person must also:

- be eligible for Supports for Independence (SFI), Assured Income for the Severely Handicapped (AISH) and/or the Guaranteed Income Supplement (GIS) at the time of application, *or*,

- have monthly income not greater than the supports required under individual funding, plus $810 monthly income at time of application (this requires Director's approval). Persons leaving active treatment hospitals, nursing homes, auxiliary hospitals or institutions/direct government operations are eligible.

The assessment process usually takes the form of the parent, guardian, or individual completing a *Lifestyle Planning* package which evaluates 10 different aspects of lifestyle and disability including a profile of the individual, their strengths and needs. *Advocacy groups and service providers may assist parents through this process.* They assist in identifying needs and supports available and can act as service brokers for the person with a disability. The extent to which the individuals themselves are involved in the process of determining their needs will depend on the philosophy of the people involved in preparing the plan. *Staff from the Social Services Department review costs and assess whether the service plan is reasonable.*

The individual/guardian is welcome to use any informal networks such as family, friends, neighbours, and professionals whom they feel would assist them in developing a good plan. The individual/guardian may request departmental assistance in fulfilling this role. In practice much of the planning supports are provided by service provider agencies and PDD staff. *Unencumbered planning support is rare.*

In order to receive Individualized Funding, three forms must be submitted to the program:

- An approved Individualized Funding Application.

- A signed Individual Service Agreement.

- A signed approved Service Provider Agreement.

The application specifies the type and volume of services, the staffing model and costs of services, and information about how funds will be administered. There can be no duplication of services, services may not be purchased from family members (even those hired through an agency), family members may receive reimbursement expenses related to administration of funds,

## Who Manages the Program? How Do They Do It?

The Program is managed by the Services to Persons with Disabilities Community Boards, which are regional bodies. The same organizational structure exists in each of the six regions. The funding guideline for Individual Funding is:

- up to an average of $3,000 per month, not to exceed $36,000 per year.

- up to 12% of the monthly approved plan for administration.

For exceptional circumstances, where the proposed support requirements exceed $36,000 per year, the region will have a separate approval process. In these circumstances, the limit may be raised to as much as $6000 per month. These funds are in addition to the disability benefit payment received by the individual.

Costs are generally based upon congregated settings for receiving supports.

Individualized funding was recently de-linked from the welfare system. It is now a program within the Persons with Developmental Disabilities Act, rather than a legislated program. This puts individualized funding at some risk, however, there have been some benefits in terms of funding restrictions being lifted. Staff from the two government bodies review costs and service plans. Service provider agencies may also become involved in managing aspects of planning, budgeting, and service provision (and often do). The system is monitored by Services to Persons with Disabilities (SPD), a branch of the Social Services Department.

## Program Strategies and Infrastructures

Two sets of principles are guiding the Individualized Funding Program. Program Principles (see Rationale/Goals/Principles), and Funding Principles. The ladder include:

- Individualization: people will have access to services and supports that meet their individual needs.

- Choice: people will be able to choose and change service providers throughout the province.

- Equity/portability - people will be to move from one location to another within the province and continue to receive comparable funding, services and supports.

- Flexibility: services, supports and funding can be readily adapted to meet changing needs.

- Effectiveness: the services and supports purchased will meet the identified needs and focus on outcomes within available resources.

- Efficiency: people are able to access funding, services, and supports in a timely and responsive manner.

- Accountability: individuals and service providers will be held accountable for the expenditure of public funds attained through services to persons with disabilities.

A lifestyle, or 24-hour service plan is required. Client service coordinators (government employees) are available to assist with planning or administrative funds may also be used for purchasing the services of an independent planner or broker. *The lack of a good, unencumbered planning infrastructures to support IF in Alberta has been identified as a major issue* (Uditsky, 2000). There was never an infrastructure created to support individualized funding and where unencumbered supports exist they do so only sporadically. *Planning is mainly done by service provider agencies or PDD staff.*

**Support/Services Utilized in the Community**

The eligible services under Individual Funding are:

- **Community Living Supports**

- Overnight - Staffed Residences

- Support Homes – In Home Support

- Supported Independent Living – Out-of-Home Support

• **Community Access Supports**

- Employment Supports

- Employment Preparation

- Employment Placement

• **Specialized Community Supports**

- Start-up Community Living Allowance

- Transportation

- Assessment/Case Co-ordination Fee

- Emergency Supports

- Professional Supports

- Behavioural Supports

- Other Specialized Supports

• **Administration Funding**

**How the Person Manages the Money**

People may self-manage or pay a broker or fiscal intermediary to manage funds. There is assistance available for planning or the person may use a part of the 12% administration fee to pay for the services of a planner. The method of payment will be determined at the time of application based

on information in the Individual Funding Application. Where a Funds Administrator has been identified on the Individual Funding Application, funding will be provided directly to that individual. Where no Funds Administrator is identified, payment by Services to Persons with Disabilities will be made directly to the Service Provider(s) identified on the approved plan. In some cases, there is a need to conduct an assessment of an individual's skills, needs and potential or to provide assistance with the developing a support plan required for the Individual Funding Application. Payment for such assessments cannot exceed $500 annually.

**Evaluation Research on the Program**

There was an evaluation of the Home Care pilot project (under Alberta Health) completed in March 1993. There was an evaluation of individualized funding for persons with developmental disabilities completed for the government in 1995, but never made public. Some of the themes from these evaluations will be incorporated into the lessons below.

**Successful Features/Lessons Learned**

1. The evaluation of the Alberta Home Care project indicated *several positive outcomes*. Most participants had an increased sense of control over their lives. Others reported reduced stress and increased feelings of relaxation. Providers also reported feeling more relaxed and more comfortable with their employment situations. Case coordinators reported a greater awareness of their clients' needs.

2.      The Alberta program links resources directly to an individual's requirements across a wide range of needs. *The Individualized Funding mechanism includes a person's living situation, their personal care supports, day or employment programs, and leisure supports.* This enables all of these supports to be established on a distinctly personal basis and therefore avoid the problems associated with people fitting into centralized, service systems.

3.      There is a clear encouragement for the *role of parents and advocates*. The Lifestyle Planning process is built around a self-assessment of need by the person with their appropriate supports. In this approach, the individual, with an advocate, parent or service provider, will draw up his or her own lifestyle plan and seek funding for it.

4.      There is a clear commitment to *flexibility*. Funding levels are varied according to need, and supports can be more flexible and better able to respond to an individual's needs.

5.      Funding is relatively easy to access and thus *waiting lists have been reduced*. When individualized funding is available, individuals and families are much more likely to be able to secure the supports they require as opposed to sitting on a waiting list for an inordinate amount of time.

6.      *Funding is portable*, which has allowed many individuals to move from group homes into smaller living arrangements or into their own homes.

7.      The *de-linking of IF from welfare* means that income is no longer a criteria for disability supports. In terms of policy and practice, disability supports

should be separate from income supports.

8.  There is an *appeal process* for disagreements over funding and/or the plan.

Overall, the success of the Alberta experience lies in its *comprehensiveness*. Individualized funding in Alberta is akin to a universal program, whereby anyone who meets the criteria can receive funding. The lack of waiting lists for adults with developmental disabilities has been a major achievement when compared with the rest of Canada. Initially, individualized funding in Alberta produced some very positive outcomes, with individualized supports and small living arrangements often commonplace.

**Less Successful Features/Lessons Learned**

In recent years, criticisms of the individualized funding program in Alberta have increased, and we summarize these concerns in this section.

1.  The Alberta Health Homecare Pilot Project Evaluation noted two difficulties for clients; *problems with bookkeeping and with finding appropriate staff*. Other less successful features were inconsistent training supports across sites for clients who were becoming employers and the lack of policies and procedures for reviewing books. There was a lack of clarity about whether the client or the health unit held the responsibility for the funds.

2.  The *"cap"* on funding ($3000/month) has limited creative individual arrangements, and has contributed to families pooling money within agencies. Most people are contracting with agencies.

3.  The contribution of individualized funding to empowerment, inclusion, and community development has been very limited in recent years. There are several reasons for this. First, the cap on funding discussed above. Second, *the lack of an unencumbered planning process* has meant that most families have "drifted" to service providers for their planning and support, which has taken away the "edge" and innovation of individualized funding. Third, *more and more families are agreeing to "convert" their individualized funding into agency contract funding*, thus increasing service provider control, while removing the control and influence families have with the regional funding boards.

4.  There are *inequities* in terms of regional differences and in terms of the nature of information that parents receive. Again, the lack of infrastructures that provide in-depth information and unencumbered planning contributes to these inequities. Advocacy organizations have expressed concerns that there are still too many people who are not aware of the options open to them, or the support available, and who therefore opt for more restrictive services than would otherwise be possible.

5.  Staff in Services to Persons with Disabilities are concerned with the quality of some services, and that the existing *monitoring systems* are not adequate to ensure that poorer quality services are weeded out.

6.  There are general problems with *high staff turnover* and low pay. Individualized funding has contributed to these staffing problems to some degree.

**Renewing Individualized Funding in Alberta**

The Alberta Association for Community Living has raised several concerns about the current state of IF in Alberta. They recognize that IF is one critical component of the empowerment of individuals and families. Bruce Uditsky (1999), executive director of the association, has argued that there need to be at least six other components in place in order to maximize the potential of individualized funding:

- commitment to inclusion.

- community development.

- family and self-advocate leadership development.

- knowledgeable, consistent, and values-based service providers and human service practitioners.

- person/family centred focus.

- infrastructure funding and development.

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# In The Company of Friends:
# Direct Funding in Manitoba

## History

*In The Company of Friends* began in 1993 as a pilot project through Manitoba Family Services. The mandate of the pilot project emanated from the *Working Group on Community Living* that was established by the Minister of Family Services in 1990. One of the recommendations of the *Working Group* was the creation of a pilot project that would test innovative approaches to community living in Manitoba. The idea was to improve the adequacy and flexibility of services used to support citizens with disabilities (Hofsted, 1996).

The project was funded by the Province of Manitoba and Human Resources Development Canada and had a budget of $1.7 million over three years. In 1997 *In The Company of Friends* became a regular program option available throughout Manitoba. At the time of the pilot, the province of Manitoba had enacted new legislation that supported community living and self-determination for people with developmental disabilities.

Individualized funding has also been available since 1991 through Manitoba Health for people with physical disabilities. In 1999 a family-managed care program opened up individualized funding to those who

cannot, or choose not, to self-direct. Program staff believe this option will be popular in rural areas of Manitoba (Marcoux, 1999).

## Demographics

Manitoba is a prairie province, with Winnipeg as the main urban area. Participants in the program live in both large, urban settings and in smaller, rural communities. Some participants came from institutional settings and others had lived with family prior to involvement with the project. Initially, 15 people participated in the pilot project. There are now 30 participants. Participants represent a "wide variety of situations and varying levels of need" (Hofsted, p. ii).

## Mandate/Policy

The project was consistent with the 1996 provincial legislation, *The Vulnerable Persons Living With a Mental Disability Act*, which supports the program by emphasizing community living and decision-making opportunities for people who have disabilities.

## Rationale/Goals/Principles

The goal of the project was *to enhance the quality of life of people with mental disabilities through individualized funding and the development of support networks.* Unlike individualized funding in other provinces, the program provides "one-line" funding. In other words, the individual is taken off welfare and provided with funds to cover all living expenses, including

those expenses related directly to disability supports. The major emphasis of the program, however, is on social interaction and the development of support networks.

## Who the Program is For

The program focus is on relationships and supported decision-making and therefore available to anyone who wishes this option, not only those who can self-direct or those with a support network already in place. Since moving from a pilot project to a regular program, *In The Company of Friends* is available as a program option for anyone in the province of Manitoba who has a developmental disability.

## Criteria for Receiving Support Dollars

Applications to participate in the program are made to the agency that administers it (see below). The technical resource staff help the person with a disability to establish a support network. It is this support network, with assistance from staff, that develops the individualized plan and budget with the individual.

The amount of funding received by each participant varies widely, depending upon need. The average amount for the pilot project was $47,000 and the range was between $14,000 and $78,000 per year (Hofsted, 1996, p. v).

**Who Manages the Program? How Do They Do it?**

The program is administered through an agency, *Living and Friendship Everyday* (LIFE). Technical resource staff provide ongoing assistance to support networks, assist with the development of personal plans and budgets, and provide day-to-day coordination. A program consultant reviews applications, individual plans and budget proposals, and is responsible for overall reporting on the program. The program consultant reports to a management committee. The management committee reviews applications for potential participants and provides final approval. *This separation of the adjudication function from the planning/network building function is an important feature of the program.*

**Program Strategies and Infrastructures**

The support networks and project staff provide the planning and administrative supports through an approach that emphasizes supported decision making and person directed planning. The major emphasis of the program is on social interaction and the development of support networks. *Facilitators assist families and individuals with network development and provide ongoing support for these networks.*

**Support/Services Utilized in the Community**

Because the program uses one source funding, all living costs are covered, including those related to disability supports.

**How the Person Manages the Money**

The support networks assist the individual with the management of funds and maintenance of records. Technical support is provided from staff as needed.

**Evaluation Research on the Program**

Evaluation data was collected from a number of sources including participants, family and friends, paid supports, project staff, and observations by the evaluator. The evaluation took place over a three-year period. Evaluation measures consisted of desired quality of life outcomes based on the principles of:

• increased community presence and participation.

• increased opportunities to learn new skills and competencies.

• community roles based on dignity, respect and authority.

• increased opportunities to make choices.

**Successful Features/Lessons Learned**

1. The evaluation of the project demonstrated an improved quality of life for 14 of the 15 participants. The evaluators noted that the well-being and quality of life remained unchanged for the one participant who

did not show gains in this area.  Positive outcomes for participants included:

-        improved material well-being.

-        greater life satisfaction.

-        improved self-determination.

-        improving and broadening friendship and social interaction.

-        increased participation in their communities.

-        growth in personal development.

-        improved health, safety, and security.

In addition to improved quality of life for participants, the project was found to be cost effective.  In 12 of 15 situations, costs were lower than other community living options by 8.3%, although the evaluators note that staffing costs were considerably higher in the project model than in traditional models.  Due to differences in staffing costs, roles of staff, and size of "caseload" it was difficult to make cost comparisons.  The evaluators concluded that given "more optimally scaled caseloads… the project would have been cost-neutral" (Hofsted, p. vii).

**Less Successful features/Lessons Learned**

Although the project was considered successful, there were several challenges that provided opportunities for learning. Some of these challenges were located outside the project, for example:

- low wages paid to service providers created staffing difficulties.

- lack of housing for people with physical disabilities.

- lack of physical accessibility in the community limited participants' opportunities.

- some participants encountered unfriendly or negative attitudes.

- almost all participants had difficulty finding paid employment

Other challenges were related to the implementation of the project. Evaluators identified the following needs:

- a clearer orientation for paid and volunteer supports.

- a clearer definition of roles and expectations of support workers, network members, and project staff.

- a need to strengthen the development of support networks.

- a need for initial and ongoing training of paid and volunteer supports.

- a need for all stakeholders to be aware of the personal plans and to revisit them  on a regular basis.

- the development of a resource package to guide support networks.

- the importance of emphasizing the role of the support network in providing personal connections and commitment to the individual, positive social interactions and friendship in addition to other roles network members may fill.(Hofsted, p. vii-ix)

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# The Saskatchewan Blueprint:
# Individualized Funding and Brokerage Project

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In 1991, a proposal was submitted for a pilot project that would allow direct funding for 10 people in Saskatchewan who had severe physical disabilities. The project was entitled *A New Beginning* and although it received approval in the May 1992 Budget speech, later that same year the approval was withdrawn. In an effort to continue the work of the *New Beginning* project and provide an option to Home Care services in Saskatchewan, a coalition was formed between seniors and disability groups in 1994.

The coalition developed the *Saskatchewan Blueprint* for direct funding in 1996. The *Blueprint* was designed to serve all people who needed supports or services in order to live their lives in the community and provide more choice and control over how and where services were being provided. The Saskatchewan Blueprint became an 18-month project funded by Health Canada and was unique in that it encompassed all ages and disabilities. It was a province-wide approach to providing more flexible and responsive services to people with intensive support requirements.

Unfortunately, the *Saskatchewan Blueprint* for direct funding was never put into practice. Working with the Department of Health, the coalition set out to develop policies and procedures. The work proceeded

slowly and the unions lobbied against the individualized funding option. Then in 1998, the Minister of Health directed the coalition to work with the unions to create an option that would be suitable to both the coalition and the unions. As of this writing, that work is continuing. Despite the many delays, detours, and frustrations, the coalition has some support from CUPE and plans to meet with the Minister in the spring of 2000 in order to develop strategies for implementation.

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## INDIVIDUALIZED FUNDING PROJECTS OUTSIDE CANADA

**Local Area Co-ordination and Direct Consumer Funding
in Western Australia**

**Perth, Australia**

### History

Local Area Co-ordination was first tested in 1988 in rural parts of Western Australia. The initial purpose was to increase self-sufficiency of people with intellectual disabilities. This new program was shaped by gaps in rural services and by shifting disability philosophy. The initial program was so successful that by 1993 there were 27 co-ordinators located in rural areas and 11 located in urban areas. A pilot project that same year led to the involvement of people with physical disabilities in the program. By 1998, the program was doubled to 82 co-ordinators, with the expressed goal of making the program available to all who requested it by the year 2000. There are now a large number of supports that can be funded under the direct consumer funding.

The important historical lesson for implementation is that the development of this program involved both *piloting* (testing out concepts in a small area) and *phasing* (expanding over time as principles were better

understood and capacity increased).

## Demographics

More than 1.2 million people live in Perth, the capital of Western Australia, while 500,000 people live in the rural areas. As of 1997, Local Area Co-ordination supported 3926 people with disabilities. The total state expenditure for consumer directed funding in 1997 was $11 million. The total spent on all disability services was $149 million. The average amount spent per individual from LAC was $2798.

## Mandate/ Policy

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 assists 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.*" A detailed process for complaints is also established in law and policy.

The Commission's mission is to advance the equality of opportunity, community participation, and quality of life of people with disabilities throughout Western Australia. Local Area Co-ordination is the fastest growing program of the Commission. An important lesson is that *both politicians and civil servants provided strong leadership* in the implementation of the policy and the Commission.

**Rationale/ Goals/ Principles**

Local Area Co-ordination (LAC) has 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." The LAC is driven by principles, many of which are in the Disability Services Act. The general principles include:

- people with disabilities and their families should have access to accurate and timely information so that they can make informed choices.

- communities need to be mobilized and resourced to better meet the needs of people with disabilities and their families.

The LAC program is designed to build the capacity of individuals, families, and communities.

**Who the Program is For**

The funds are for any consumer with an intellectual or physical disability who requires support, and who wishes consumer directed funding.

## Criteria for Receiving Support Dollars

There are two kinds of funding; tied and untied. *Untied funding* is designated for "one-off" funding needs. The amounts are modest, and often used in an emergency. The co-ordinators have discretion to spend this money as needed. Applications are simple and approved quickly.

*Tied funding* is normally for larger amounts and requires individuals and families to submit a detailed plan. The plan and the application form for the consumer directed funding is an integral part of the relationship and process with the co-ordinator. Local Area Co-ordination has developed detailed guidelines for the preparation of plans, including; "plan should show evidence of thorough exploration of informal supports." The tied plan proposal is expected to follow several headings, including;

• profile of current life experience.

• individual and family goals.

• support details and costs.

• supports will be in place which are not part of the funding.

## Program Strategies and Infrastructures

*Planning is completely separate from services*. This is accomplished through the utilization of local area co-ordinators, who work from a sound

value base and set of principles. Each co-ordinator spends a lot of time with individuals and families, getting to know people's strengths and needs. Co-ordinators also provide information, assist people to build their support networks, and help people to purchase their own supports via direct consumer funding.

*Co-ordinators appear to be the key* to the success of the LAC, and according to evaluations on the program, they have well developed skills in the areas of needs analysis, person-centred planning, personal advocacy, individualized funding, and community development.

According the project director, "money is the last thing we do." The LAC has no brokers, but a separate adjudication process that enables money to go directly to the consumer and their family. LAC has established direct consumer funding principles, which guide the distribution of money. These principles include;

- The intent of financial support to people with a disability is to off-set the additional costs of the impact of the disability.

- Financial support should be provided directly to the consumer(individual/family/carer).

- Consumers should be expected to contribute a proportion of their available allowances and/or other benefits towards related costs.

**Support/Services Utilized in the Community**

Under the legislation, direct consumer funding can be utilized for several purposes, including;

- respite support
- personal support

- education support
- professional support

- leisure support
- employment support

- equipment support
- accommodation support

- domestic support.

**How the Person Manages the Money**

A simple and effective system of accounting has been put in place. Families have the choice of receiving money directly, in advance or as a rebate. With both approaches, families must submit monthly claim forms, that include the signature of any individuals who provided paid support. Families also have the choice of having their funds paid directly to a service provider, and many families have it this way. Co-ordinators are available to assist families in figuring out the approach that works best for them.

**Evaluation Research on the Program**

The LAC has contracted for several major evaluations since 1993. In 1997, the Disability Services Commission conducted a consumer satisfaction survey, which found a satisfaction rate of more than 90%, which is a very high rate when compared with other human service research. In 1996, Lewis completed a two-year study, which included case studies of 15 individuals/families, survey data from 169 families, and expenditure analysis for 880 people. In a carefully constructed experimental design that utilized a control or comparison group, several findings were identified.

- When individualized funding was looked at separately, two main impacts were found (with 20 discrete positive outcomes within these two areas);
  - IF increased the quality and quantity of services available to families, and
  - IF contributed to the functioning and well being of the family and the person.

- Local area co-ordinators exceeded the expectations of families. What consumers liked most about their co-ordinator was their back-up support, their availability, their personal approach, their access to funding when needed, the quality of services that were arranged on their behalf, their ability to meet their needs, and the resultant positive impacts on both the person with a disability and the family as a whole.

- While LAC could help families with many of their issues, there were

some issues that could not be resolved by the local area co-ordinators.

- In terms of utilization of individualized funding, there were some significant differences between rural and urban consumers. 64% of rural families directed their IF to a third party service provider or group, while only 32% of urban families did not self-manage. This finding suggests that urban consumers and families feel more confident in accessing supports without going through one agency.

- The most common IF expenditure was for accommodation. For people with physical disabilities, the second most common expenditure was to purchase equipment and aids. For people with intellectual disabilities, on the other hand, their second largest portion was for leisure supports.

- The budget for Local Area Co-ordination breaks down in the following ways;
    - 54% was for local co-ordination activities
    - 39% was dispersed to consumers in direct funding
    - 8% was consumed for administration and overhead.

- 30% of consumers sought and received direct funding, while most consumers utilized a wide array of other more traditional services. There is no ceiling on the amount of money available to a consumer.

## Successful Features/Lessons Learned

1.  The effectiveness of the Local Area Co-ordination stems from the *combined impact of local co-ordinators and direct consumer funding*. The coordinators provide support and infrastructures for families. Getting to know the person with the disability, their family, and their community is key to the co-ordinators work. This involves listening and helping the family to plan and develop strong support networks. The direct consumer funding then enables the consumer to build on their family and community strengths. Evaluations have shown that *when co-ordination support and infrastructures are available to families, the total costs of individualized funding are less.*

2.  Direct consumer funding is a *first choice option* for those who want it. Consistently, about 30% of consumers and families chose this option. This approach is not seen as the replacement for agency services, but as an option for those who want it.

3.  The local area co-ordination is *value based and manageable*. When starting up, each co-ordinator would have 30-40 consumers, and up to a maximum of 50. A rule of thumb is that one-third of these consumers require minimum support at any time, one-third would have some issues in progress, while one-third would require quite a bit of support. This rule does not just apply to degree of disability, but also refers to the fact that families who are in the planning phase are likely to require more support than families who are already implementing their plan.

4.      There is a *grievance mechanism* in place to minimize the possibility of a consumer being adversely affected by their local area co-ordinator.

5.      Co-ordinators have an amount of *untied money*, which allows them to quickly fund families and consumers around small support issues.

6.      Co-ordinators are very focused on *building the capacity of the individual, family and community*. Some of their work is community development oriented, which enables them to connect with community groups that can enhance the inclusion of people with disabilities.

**Less Successful Features/Lessons Learned**

1.      Families have noted *that local co-ordination does not resolve all their issues*, including their relationship with other professionals, how to access specialists, and how to find employment for their relative with a disability.

2.      The effectiveness of the Local Area Co-ordination is, to an extent, *constrained by the services and supports co-ordinators can find* in response to a families need.

        **Final Note:** This Australian program is effective in its simplicity. Consumers and families are highly satisfied with the process and the

outcomes. In dialogue with the leadership of this project of this program, it is clear that part of the success lies in the commitment to ongoing training, support, and supervision of local area co-ordinators as well as the direct consumer funding mechanisms, which are user friendly for consumers and families. These important details are imbedded in a structure which makes sense and is very cost effective.

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# New Hampshire Self-Determination Project

**The Transition of New Hampshire's Regional Service System:  Creating Access to Community Through Individually Determined Supports**

**Robert Wood Johnston Foundation**

## History

The project was funded in 1995 as part of a nation-wide project to implement self-determination for people with developmental disabilities. First we will describe the overall project and then we will provide 1 brief example of one of the projects which fall under this larger project, Monadnock, New Hampshire.

## Demographics

The state of New Hampshire is "geographically small with a relatively small population." Because of its size, information is disseminated more easily "making it possible to achieve the 'critical mass' of long term and ongoing values-oriented training which as contributed to an unusually high level of agreement about the mission of the state's service system." (New Hampshire Self Determination Project, n.d. a). The state also has traditionally believed in local control of service systems.  In addition, in the mid-eighties deinstitutionalization and increasing demands for supports from people who had never been institutionalized, left an increased need for

supports and consequently, a growing waiting list.

## Mandate/ Policy

The New Hampshire Division of Mental Health and Developmental Services has supported area agencies in their efforts to create new approaches to meeting the needs of people who have disabilities and their families.

## Rationale/Goals/Principles

The overall goal of the project is to support people with disabilities to be a part of their communities through increased choice and control over the services and supports they require. The project aims to gradually phase in system change that is long term and offers a wide range of flexible supports that are responsive to the needs of individuals. (New Hampshire Self Determination Project , n.d. a). State project goals are:

- 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 organizational change at all levels (state, area agencies, provider agencies).

- to reduce costs. (New Hampshire Self Determination Project, n.d. b).

The project is intended to build upon the pilot project.

**Who the Program is For**

- people with developmental disabilities

- individual budgeting was focussed on a minimum of 20 people in each region per year (three regions added per year)

**Criteria for Receiving Support Dollars**

Twenty consumers in each region were selected to participate in the project.

**Who Manages the Program? How Do They Do it?**

"Overall project leadership will be the responsibility of senior administrative staff within the Division of Mental Health and Developmental Services" (New Hampshire Self Determination Project, n.d. c). The project management team is 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. The team meets bimonthly. There is also a 40 member advisory committee made up of family members, consumers, state and regional service system staff, the Institute on Disability, advocacy organizations, Developmental Service Directors from other New England states, and members of the community. The committee met in December 1995 and in June 1996 in order to "clarify

the purpose of the grant, build a broad base of community support, and to share information. The utilization of a stakeholder approach creates a context for learning. It is characterized as an action learning process.

**Program Strategies and Infrastructures**

The project uses a stakeholder approach that includes ongoing leadership development for groups of stakeholders at the Browne Centre for Transformational Leadership. The training focuses on collaborative problem solving and communication skills. There is also training for case managers on budget development. Because the project is focused on systemic change, there are a number of working groups addressing different aspects of these changes (for example, education and training, community organization, and policy development).

**Support/Services Utilized in the Community**

One of the goals of the project is that new forms of community supports will result. These supports could include service brokerage, family support cooperatives, purchasing alliances, staff cooperatives, and other creative approaches to meeting needs.

**How the Person Manages the Money**

The project utilizes fiscal intermediaries (agencies that handle the money), although there appears to be flexibility in the system for management of funds (see above).

## Evaluation Research on the Program

Two evaluation tools were developed. The first is a survey developed by a statewide Quality Network Committee, working together with one of the project regions. It is designed to assess consumer satisfaction with services. The second is a survey called *"Who Decides?"* that was developed and administered by members of People First New Hampshire. This survey assesses consumer choice and control over services and is administered early in the participant's involvement in the project and then followed up at a later point. Other evaluation data includes documentation of organizational change, case studies of the participants, and cost reporting. Evaluation activities will take place annually and include consumers, parents, and staff. Methods include focus groups, interviews, surveys, document reviews, and observation.

## Successful Features/Lessons Learned

1.   A responsive service system depends upon the *involvement* of the people who use the services in "all aspects of system planning, design, and development" (Background report, p. 4).

2.   *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. The result has been mutual support and improved day to day problem solving.

3. Area agencies are looking at the possibility of *creating individual budgets* for all consumers and not just those who are project participants.  In this way, the project is facilitating system change.

## Less Successful Features/Lessons Learned

1. Changes in staffing "led to some delays in implementation" of the project (Year 2 Report).

2. Another difficulty noted in the Year 2 Report was the fact that many agencies, consumers, and family members did not have access to the technology that would have provided them with the great amount of useful information being produced on the topic of self-determination.

3. A difficulty that was noted in the Year 3 project report was a disagreement between the area agency and the state division regarding the project evaluation.  It appears that collaboration between state regions has, at times, been difficult to accomplish (New Hampshire Self Determination Project, n.d. d).

## References

New Hampshire Self Determination Project (n.d. a) Website www.state.nh.us/sdp/puvs/annrpt96.html The Transition of New Hampshire's Regional Service System: Creating Access to the Community Through Individually Determined Supports.  Annual Progress Reports Years 1. Background to the Evolution of New Hampshire's Service System.

New Hampshire Self Determination Project (n.d.b) Website www.state.nh.us/sdp/puvs/annrut97.html The Transition of New Hampshire's Regional Service System: Creating Access to the Community Through Individually Determined Supports.  Annual Progress Report Year 2. (3)

New Hampshire Self Determination Project (n.d., c) The Transition of New Hampshire's Regional Service System: Creating Access to the Community Through Individually Determined Supports. Project Description. (4) website also

New Hampshire Self Determination Project (n.d., d). Website www.state.nh.us/sdp/puvs/annrut98.html The Transition of New Hampshire's Regional Service System: Creating Access to the Community Through Individually Determined Supports. Annual Progress Report Year 3.


# Monadnock Self-Determination Project

## New Hampshire

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In 1993, Monadnock Developmental Services received a grant from the Robert Wood Johnson Foundation for a three-year pilot project. The project's focus was to implement a system that gave control of supports to people with disabilities.

There are some unique features of New Hampshire and the Monadnock area that may affect the ability of the evaluation to be generalized. For example, "New Hampshire was the first state to completely end its utilization of public institutions for people with developmental disabilities" (Conroy & Yuskauskas, 1996, p. 13). Also, "the Monadnock area is small and somewhat rural" (p. 13) and was already deeply committed to transforming the service system to a more community-based way of offering supports.

The project had strong leadership from several factions. It received cooperation from the State's Director of the Division of Mental Health and Developmental Services. Project administrators and senior staff supported the changes required by the project. There were three over-arching goals to the program: enabling individuals and their families to control dollars without dealing with cash (hiring of "fiscal intermediaries"); changing the role of case management to personal agents chosen by the consumer and independent brokers of services; and organizing a coherent response to a managed care culture. Because of the importance of informal support networks in the lives of people with disabilities, the project had a community development component.

The program was for people who have developmental disabilities. It is "testing the theory that if people with major developmental disabilities and those who support them gain control of their lives… their quality of life will improve…." (Conroy & Yuskauskas, 1996, p. 2). The emphasis on support networks and on "major" developmental disabilities indicates that the program was open to those who did not self-direct. Another objective of the project was for individuals and support networks to "control the dollars without dealing with cash" (Conroy & Yuskauskas, 1996, p. 3).

The grant was awarded to Monadnock Developmental Services, a service provider organization. The project makes funds that would otherwise be provided to an agency through Medicaid, directly available to the person. The project is based upon four guiding principles: freedom, authority, support, and responsibility. It is a consumer-directed approach. Personal planning is done with the individual's informal support network. The

emphasis in the project was to provide control over the way dollars are spent without actually having to manage the money directly. In other words, the project allows for the utilization of fiscal intermediaries. Planning teams were mixed groups of paid and unpaid supporters. One result of the project was an increase in the number of unpaid supporters on the planning teams.

The evaluation utilized a pre-post design. A comparison group of non-participants was measured for similarity on several characteristics. Statistical similarity in all but two of these areas led the evaluators to believe that the outcomes of the project were generalizable to non-participants. Comparison group data will be collected at Time 3 (the current report covers measurements at Time 1 and Time 2 (18 months later). Several different scales were used to compare outcomes for project participants between Time 1 and Time 2.

- **Self Determination Scale** – 22 increases and 4 decreases, 11 of the increases and one of the decreases were statistically significant (see Table2, p. 7).

- **Personal interview and satisfaction** – on all nine dimensions participants rated a higher quality than one year previous.

- **Relationships and Integration** – number of close friends and frequency of visits stayed the same. Measurements at Time 1, however, were approximately "double the national average for people with developmental challenges." For participants who had Circles of Friends, the size of the circles had increased significantly (more than

doubled).

- **Planning Team Composition** – significantly more unpaid people were involved in planning at Time 2. Also, more planning team members had been chosen by the individual at Time 2.

- **Behavioural Changes** – [not a priority goal of the project, nor a predicted outcome] Adaptive behaviour scores stayed the same, while challenging behaviour scores decreased and productive behaviour increased.

- **Service and Support Indicators** – Although Time 1 scores were already high, participants were living in a more individualized, home-like setting at Time 2, and Individual Service Plans contained fewer goals. More time was being spent on educational or vocational activities as well.

- **Costs** – although existing methods of tracking costs were not based on individuals, costs were significantly reduced (between 12 % and 15%) for participants which translated to savings of approximately $10,000 per person per year (a conservative estimate).

With the Self Determination project, unpaid and invited community support increased. The decrease in challenging behaviour and increase in productive behaviour was attributed to the opportunity to make one's own choices and consequently having more responsibility for one's own life. The lack of change in adaptive behaviour scores points to the project's emphasis on support system change as opposed to the person changing. In

other words, self determination was seen as a right and not a privilege to be earned. Participants had an increased quality of life that did not have to be "earned" by learning new life skills.

## References

Conroy, J. W., & Yuskaukas, A. (1996). Independent evaluation of the Monadnock Self Determination Project. Ardmore, PA: Centre for Outcome Analysis.

# Michigan Self-Determination Project

## History

In 1996, Michigan received a three-year grant from the Robert Wood Johnson Foundation Self-Determination Project. Initially four counties were involved in the project. In 1998, four additional project sites, not funded through Robert Wood Johnson, joined the initiative. All but two of the project sites are Community Mental Health Services Programs (CMHSP's).

## Demographics

The larger community placement organizations (CMHSP's) are in urban centres. Midland is a small, homogenous community. Income and

education levels are high and people were experienced in person-centred planning and community building. There was a commitment to the principle of choice prior to the Self-Determination project.

**Mandate/Policy**

Because the state policy on managed care is based upon the principle of self-determination, it has enabled the development of a Medicaid waiver which allows a change in the direction of the flow of funding for supports and services for people who have developmental disabilities. Michigan's speciality Medicaid managed care plan for services for persons with developmental disabilities contains specially designed features which make it easy for agencies to provide consumer-controlled arrangements (Michigan Department of Community Health, 1999).

**Rationale/Goals/Principles**

Michigan's Self-Determination Initiative aims for major system change which assures that services and supports for people are not only person-centred, but person-defined and person-controlled (Michigan Department of Community Health, 1999). Some of the goals and objectives for the Michigan Self-Determination Project are:

• Demonstrate that the level of satisfaction with and quality of life can increase when individuals with disabilities are primarily responsible for the supports they choose as necessary to achieve their goals and dreams, and for controlling the disbursement of resources allotted for

their supports.

- Promote the development of living arrangements and acquisition of supports which center control with the person, such as "own home" independent living, and the development of consumer-controlled entities with provide needed personal supports and assistance chosen by the person.

- Apply Michigan's recently designed system of assessing consumer satisfaction with supports and services they receive, as developed under the Renewed HCBS Waiver, to all participants of this project.

- Demonstrate that individuals with developmental disabilities will make cost/benefit-effective decisions about the resources and supports they require, when given the opportunity to make informed, personal choices about them.

- Demonstrate that costs of services and supports can be contained (managed), if not decreased, when individuals with disabilities are able to exercise greater person choice over the activities in which they engage, and control over the resources available to conduct these activities.

- Identify and remove or resolve barriers inherent in current policy and practice which interfere with or reduce the potential of individuals with disabilities to define and achieve their dreams.

- Apply the principles and practices of self-determination to the evolving managed care planning for Michigan's system of services and supports for persons with developmental disabilities. (Robert Wood Johnson Foundation, n.d.)

**Who the Program is For**

The program is for people who have developmental disabilities. It has been focussed on people who are having problems with their current support arrangements.

**Criteria for Receiving Support Dollars**

Person-centred planning is a requirement for involvement in the program. Chosen family members or unpaid allies who have been chosen by the individual are involved in planning.

**Who Manages the Program? How Do They Do it?**

Each project site manages its own program. While there is no set limit on the amount of money an individual may receive, the agency must negotiate each individual service plan.

**Program Strategies and Infrastructures**

As stated above, person-centred planning is a requirement. The host agencies support this planning process. For those people who do not have

family or friends with whom to engage in the planning process, the agency will assist in assembling a group of people to do the planning.

**Support/Services Utilized in the Community**

Funding covers supports and services required by the individual to live in the community. The exceptions are housing and recreation. However, a housing subsidy is available. The support plan is predicated on the needs of the individual and what is available, however the project has tried to focus on fiscal conservatism.

**How the Person Manages the Money**

The money is managed by fiscal intermediaries, who operate at arm's length from the government. Individuals enter into an agreement with the "host agency" and develop individualized budgets using a person-centred planning process. "The host agency authorizes the budget in accordance with mutually agreed-upon estimates of the amount of money needed to accomplish the person's plan" (Michigan Department of Community Health, 1999).

**Evaluation Research on the Program**

Michigan is conducting an independent evaluation of the project using the Quality of Life protocol developed by James Conroy, the national evaluator. The evaluation is a pre-post, comparison group design focussed on outcomes for individuals involved in self-determination. Evaluators have

been collecting baseline data since 1997 and data on over 800 individuals has been collected.

**Successful Features/Lessons Learned**

1. Preliminary evaluation data has confirmed that quality of life increases as people become more self-determined. In addition, cost savings of between 6% to 8% have been realized through self-determination.

2. Much of the success of the Michigan Self-Determination Initiative may be attributed to a commitment to the principle of choice on the part of the state and community agencies. As Michael Head, the state project coordinator said (personal communication, 2000), "We were already going in this direction – the idea of individualized budgets came with [the] Robert Wood Johnson [Self-Determination Project]."

3. The process and practice of self-determination, once begun, tends to spread. The Department of Community Health is currently developing self-determination for other populations they support.

**Less Successful Features/Lessons Learned**

"Much of the local thinking about what managed care is, and how local systems should be realigned is built on managed care models which deal with persons who are in acute medical or mental illness episodes....However, some are trying to apply the tenets of 'traditional'

managed care to planning and decision-making for persons with developmental disabilities who require long-term support, and where quality of life is a primary outcome….Thus, self-determination has been viewed as less important than the planning for managed care being conducted at the local level. The irony is that self-determination is more directly related to managed long-term care than are the tools of the model applied to persons in acute stages of a medical or mental illness" (Robert Wood Johnson Foundation, undated).

In terms of project implementation, Michael Head (personal communication, 2000) identified the following learnings:

1.     It takes a long time.

2.     It is hard to change people's minds.

3.     Many people find self-determination hard to understand.

4.     Many people do not know about the option of managing their own supports/services (organizations are developing brochures to increase awareness about the project).

5.     When you hire back the service provider people's lives do not change much.

6.     While there is no limit on the amount of funding a person may receive, project sites must "triage" with available funds.

7. Important implementation features include getting the system out of the way, building self-advocacy, and building community.

## References

Head, M. J. (February 22, 2000). Personal communication with Project Manager, Michigan Dept. of Health, Lansing, MI.

Michigan Department of Community Health (1999). *Michigan's self-determination initiative.* Unpublished document. Lansing, MI: Author.

Robert Wood Johnson Foundation (undated). *The Michigan State plan.* Common Sense Newsletter, www.self-determination.org/newsletter1249.

# Chapter V:

# Final Reflections: Building on the Lessons

This Review of Individualized Funding has identified themes and lessons from several projects in different parts of the world. Despite the diversity of locations of these projects, our analysis has identified several common themes related to individualized funding and disability supports. These "lessons" reflect new paradigms of disability and community. *Initiatives that focus on individualized support and funding reflect the new paradigm in several ways.*

- The goal is to empower and build the capacity of individuals, families, and communities.

- Power and decision-making related to disability supports is shifted from service systems to individuals and families.

- The focus of personal planning is community involvement, self-determination, and individualized support.

- The development of supports is based on each person's unique personal plans, not on what is available in the formal service system.

- Infrastructure supports for individuals and families, such as facilitation for planning and network building, are independent/separate from the service system.

- A policy framework, such as that proposed by the Ontario Round Table on Individualized Funding, provides principles, a direct funding mechanism, and implementation guidelines for local communities and government.

*In the last decade, there has been a notable expansion in the number and quality of projects and programs that offer individualized support and funding.* Ontario, like other provinces and states, has been moving slowly toward the new paradigm of disability and community. The Federal-Provincial agreement, *In Unison: A Canadian Approach to Disability Issues,* sets out a blueprint for promoting the integration of persons with disabilities. It emphasizes several policy directions such as policies should enhance more consumer control, flexibility, and responsiveness in the provision of disability supports. In addition to this broad framework, Ontario already has regulations that allow grants to be provided directly to persons with disabilities for attendant services. These regulations are based on the 1994 regulations of the *Ministry of Community and Social Services Act.*

This Review has also shown that Ontario has extensive practical experience with individualized support and funding. Thousands of families that have accessed Special Services at Home know what it means to have power and control over valued resources that are available to support their

sons and daughters. Many of these parents have built support networks, hired staff, and have thought long and hard about their children's futures. Leaders interviewed for this Review stressed that this new generation of parents have very high expectations for their children with disabilities and for the resources that are available for them. Increasingly, these families expect individualized support and funding.

Other trends are also having an impact. The Ontario Direct Funding Project has enabled many adults with physical disabilities to access direct funding. Most of the individualized funding pilot projects throughout Ontario have become permanent programs. Some regional offices of MCSS have been quite supportive of individualized support and funding. The amount of learning from these experiences has been significant, and the outcomes for individuals and communities have been very positive.

*Despite encouraging trends toward individualized support and funding, current policy and projects in Ontario are quite limited.* The reality is that there is no provincial policy framework, no regulations or guidelines for regional offices of MCSS to promote IF, and no direct funding mechanisms for adults who are unable to self-direct. As a result, individualized support and funding tends to be ad hoc and look like a patch-work approach. If you live in Windsor and have a developmental disability, you might be able to access individualized funding and support. But if you live in Kitchener-Waterloo, you are out of luck!

We are encouraged by the Ontario Round Table Report on Individualized Funding. For the first time, we have a document in Ontario

that helps people to conceptualize, plan, and implement a comprehensive approach to individualized support and funding. Already, some regions are utilizing the Round Table Report to help with their planning. It is hoped that this Review will serve as a supplementary document to the Round Table Report. This Review contains more detailed analysis and reflections on the principles and policy directions outlined in the Round Table Report.

*More meaningful change toward individualized support and funding will require local and provincial commitments, knowledge, and wisdom.* As outlined in this Review, there is now a large body of knowledge that can be used for education and planning. Local communities now need encouragement from local government officials and leadership from individuals, families, and service providers. The provincial government needs to develop a policy framework and begin to allocate money specifically for individualized supports and funding. We agree with the recommendations of the Round Table Report, that a new initiative will be required to ensure equity and accessibility for all people who want individualized supports and funding. We hope that wisdom will prevail as governments and communities work together to create more genuine options for citizens with disabilities.

# Endnotes

1  In recent years, there has been extensive writing about paradigm shifts in the disability field. While most authors have presented philosophical arguments, some have studied what the paradigm shift means in practice. For a thorough study of shifting paradigms, see;

> Al Condeluci (1991). Inter-dependence: The route to community. Winter Park, Florida: PMD Publishers.

> Yvonna Lincoln (Editor) (1985). Organizational theory and inquiry: The Paradigm Revolution. Newbury Park, CA.: Sage Publications.

> Geoffrey Nelson, John Lord, and Joanna Ochocka (2000). Shifting the paradigm in community mental health: Toward empowerment and community. Toronto: University of Toronto Press.

2 Individualized Funding Coalition (1999). Individualized Funding: A New Vision. Author.

3  John Lord, Peggy Hutchison, and D'Arcy Farlow (1988). Today's Dream, Tomorrow's Reality: Review of Ontario Support Services.
Toronto: Ministry of Community and Social Services.

4  In 1998, the federal and provincial governments signed an agreement, entitled In Unison, which identifies citizenship and several other progressive directions for enhancing disability supports.

5  Groups that have positions on this issue include: Ontario People First, Canadian Association of Independent Living Centres, and the Council of Canadians with Disabilities.

6  For further insight into this issue of vulnerability and health, see John Lord and Peggy Hutchison, Living with a disability in Canada: Toward autonomy and integration, Determinants of Health, Canada Health Forum. Ste.Foyes, Quebec: Editions Multi Mondes.

[7] Bruce Uditsky (1999). The erosion of individualized funding. Edmonton, Alberta: Alberta Association for Community Living, p.11.

[8] Roeher Institute (1997).  A literature review on individualized funding. Self-managed attendant services in Ontario: Direct funding pilot project . Toronto:  Author

[9]  Individualized Funding Coalition (1999). Individualized Funding: A New Vision.  Author.

[10]  Round Table on Individualized Funding (2000). Individualizing Supports and Direct Funding: Making Money Work for People. Toronto: Individualized Funding Coalition.

[11] B.C. Coalition of People with Disabilities (1997).  Report on the individualized funding conference.  Vancouver:  Author.

[12]   John Lord (1998).The NABORS experience: Lessons in community building. Toronto: Green Dragon Press.

[13]  Geoffrey Nelson, John Lord, and Joanna Ochocka (2000). Shifting the paradigm in community mental health: Toward empowerment and community. Toronto: University of Toronto Press.

[14]   See Roeher Institute (1997). Final evaluation report. Self-managed attendant services in Ontario: Direct funding project. Toronto: Centre for Independent Living Centre in Toronto (CILT), Inc.

[15]  Community Brokerage Service Society (1996).  Towards empowerment: A glimpse of the future.  Burnaby, BC:  The Little Printer.

[16]   Bruce Uditsky (1999). The erosion of individualized funding. Edmonton, Alberta: Alberta Association for Community Living.

[17]  This conclusion is based on interviews with leaders from Australia, and on an analysis of very comprehensive evaluations that have been completed on the Western Australian project.

[18]  See, Dan Rossiter and Dennis Harkins (2000). Dane County Wisconsin offers individualized funding option to all adults receiving service, Community Living: British Columbia Association for Community Living Newsletter, 18:1.

[19] Roeher Institute (1997). <u>A literature review on individualized funding. Self-managed attendant services in Ontario: Direct funding pilot project</u> . Toronto: Author

[20] Kubiski & Associates (1996). <u>Review of the literature on individualized funding: Projects & concepts</u>. Mississauga, Ontario: Author.

[21] John Lord, Mary McGeown, and Joanna Ochocka (1993). <u>Family Directed Support: Diversity, Hopes, Struggle, Dignity: Special Services at Home Evaluation</u>. Toronto: Ministry of Community and Social Services.

[22] Elizabeth Bloomfield (1999), Andrew of Guelph: A case study in person-centred planning and individualized funding. Author.

[23] John Lord (1998).<u>The NABORS experience: Lessons in community building</u>. Toronto: Green Dragon Press.

[24] See write-up in Chapter 5, and, Policy and Planning Branch (1996). <u>In the Company of Friends Pilot Project: Evaluation Final Report</u>. Winnipeg: Manitoba Family Services.

[25] Michael Bach (1991). Giving choice to people with mental disabilities. <u>Perception</u>, 15:3, p.5-8.

[26] The Council on Quality and Leadership in Supports for People with Disabilities in the United States has developed several resources for understanding and measuring personal outcomes. In Ontario, the Accreditation Council uses these materials and offers training and reviews for organizations and individuals. The OFCP and OACL are both very involved in the Council.

[27] Alison Pedlar, Larry Haworth, Peggy Hutchison, Peter Dunn, and Andrew Taylor (1999<u>). A textured life: Empowerment and people with developmental disabilities</u>. Waterloo: Wilfrid Laurier University Press.