MOVING TOWARD CITIZENSHIP:
A STUDY OF INDIVIDUALIZED FUNDING IN ONTARIO

In recent years, there has been wide-spread interest in new ways of providing support to people with disabilities. In several countries in the western world, numerous projects have been designed to combine person-centred approaches with individualized funding.

These projects, sometimes referred to as 'new paradigm' approaches, focus on values such as self-determination, citizenship, empowerment, and inclusion. They differ significantly from more traditional approaches that primarily focus on placement of the person in a program or service.[1]

Projects that have individualized funding as a key component start with the person's dreams and goals, and then build an individualized plan and budget to meet those goals. Jurisdictions that have implemented individualized funding have tended to combine independent planning and facilitation and other kinds of infrastructure support such as network development and support for individuals and their families to manage their personalized support systems.[2]

Generally, research to date on the effectiveness of new paradigm approaches has been quite positive. Studies show that costs for individualized funding are usually comparable — costs are similar to conventional supports, but quality of life outcomes are usually much better with individualized funding. Recent research suggests that the emphasis on self-determination in new paradigm projects is one reason for positive outcomes.[3]

A Study of Individualized Funding in Ontario

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This study was designed to increase our understanding of projects in Ontario that offer *individualized funding and planning support* to individuals and families. While some research has been done in Canada on these issues, more detail is needed as major policy changes are considered in Ontario and other parts of Canada.

We will be simplifying terminology and only using 'individualized funding,' without the word planning, although it is understood that planning is an integral part of the process. Individualized funding is a broad term that encompasses direct funding, which means that the funds go directly from the government to the person, and indirect funding, which means that the funding goes to the person through a transfer payment agency. In Great Britain, direct payments refer to individualized funding.

How We Conducted the Study

What was our Purpose

The *purpose* of this research was to document expenditures and experiences related to individualized funding arrangements in Ontario from 2001 to 2005. This four year period was chosen because of the relatively recent development of some projects, and to ensure that the study was manageable. Three *questions* guided the research approach:

1. How much individualized funding have people received for individualized support?
2. In what ways have individuals and their families utilized their individualized funding?
3. What is the experience of individuals and their families in regard to outcomes and participation?

Who Were Our Participants

To address the research questions, we chose four projects in Ontario that provided individualized funding to people with developmental disabilities. All projects received their primary funding from the Ministry of Community and Social Services (MCSS).

- *Four regions* of the province with organizations that offered individualized funding were selected. All projects in these regions provided individualized funding based on a support plan developed by the individual and their family. One project served mainly a rural population, while another was

based in a mid-size city. The other two projects were in large metropolitan areas. This geographical distribution in many ways represented the province, since most people in Ontario live in urban areas.

- 130 *individuals* with developmental disabilities, representing 40% of the people receiving funding, were chosen from the four sites. As much as possible, this was a purposive sample related to age, gender, disability, and the range of funding received. At two sites, this was possible. At a third site, because the numbers were small, all participants were selected. There were complications at the fourth site, resulting in a more limited sample. Table 1 outlines the demographics of our individual participants.

- 8 *facilitators / co-ordinators* at the four sites participated in the study. Each person had a facilitator.

- 18 *family representatives* were chosen from the 130 individuals. This purposive sample was based on criterion, including amount of funding received, complexity of the situation, and cultural background.

How We Collected Information

Several approaches were used to gather information related to the three research goals.

In *phase 1*, researchers completed three day long site visits to each region, using a protocol to examine each person's file. The protocol included demographic information (e.g., age, gender, cultural background, disability), goals of the support plan, budget (e.g., money asked for and received), how funds were used, and what the outcomes were for individuals.

Table 1

Who Were the Study Participants

Women:	48.5 %
Men:	51.5 %
Average age:	36
Age range:	9 to 82
Living with parents:	40.6 %
Living elsewhere:	59.4 %
English as primary language	93.0%

Also in *phase 1*, individuals' facilitators confirmed our interpretations of the files, filled in gaps that may have not been clear

in the files, and completed ratings from the protocol about the person in areas such as family involvement, social networks, and overall quality of life.

In *phase 2*, telephone interviews were conducted with families from the four regions. An interview protocol was developed that included questions related to families' experiences with individualized funding, facilitation, and the outcomes they had experienced. These phone interviews with families were completed with one parent and ranged in duration from 30 to 60 minutes.

How We Analyzed our Data

The following data analysis plan was used to organize and analyze the information we gathered:

- We analyzed the *quantitative* information from the 130 files with SPSS (a well-known statistical program).

- We analyzed the *qualitative* information from the 130 files by coding similarities and differences in people's responses. We used a similar coding approach with the 18 interviews we conducted with family members and identified patterns from the codes.

- The final themes and conclusions were drawn from both qualitative and quantitative approaches.

What We Learned About Families

High Degree of Involvement

People receiving individualized funding for disability supports had very involved families. Facilitators rated 83.1% of people as having "high" family involvement, 6.5% as "medium," and 8.1% as "low." Families that were interviewed also felt that they were very involved. One father noted, "We have control over the funds, but you have to be really involved for it to work effectively." A mother commented, "It is about stewardship; you have to be involved."

Studies show that families play a major role in supporting their adult children with developmental disabilities.[4] Yet, these extraordinarily high ratings suggest something else at work here. At all four sites, facilitators worked with the people being supported and their families to develop goals and a support plan based on the dreams and interests of the person. Families and facilitators indicated that this takes time and, as one parent said, "It is not for the faint-

hearted." These findings indicated that families who chose individualized funding were very committed to improving the lives of their family members through person centred approaches.

Wide Range of Disabilities Served

Families who received individualized funding have sons and daughters with a wide range of disabilities. Sixty-three percent of participants had more than one disability. Table 2 shows the secondary disabilities beyond the developmental disability. Many families are supporting sons and daughters with complex needs.

Table 2

Participants with More Than One Disability

Secondary disability	%
Psychiatric/mental health	40.3
Physical disability	38.0
Autism	18.6

Cultural Diversity

Although 93% of families in this study identified English as their primary language, the multi-cultural nature of Canada was also somewhat reflected. Eighteen different countries were represented in the response of participants regarding their ethnic origin. Nevertheless, with only 130 families represented, we would not expect the full ethnic diversity of Ontario to be represented. Facilitators in the two urban sites indicated that they needed to be very conscious of this dimension and sensitive to cultural differences.

The Support Plan: Participation and Goals

Involvement in Development of Support Plans

Across all four sites, the vast majority of individuals and families developed support plans with the assistance of a facilitator. The support plan was used by facilitators and families for determining how much support funding might be required. Table 3 shows the degree of involvement of people with disabilities, families, and support networks.

Table 3

Involvement in Development of Support Plan

Who	%
People with disabilities	96.1
Families	96.8
Support networks	61.2

File information and interviews identified who was involved in developing the support plan. The high percentage of involvement from persons with disabilities and families showed that these sites were practicing the new paradigm, by engaging individuals and their families in the development of plans. Typical of the very few who did not participate was a family who said that their son was unable to be involved in planning when he came out of an institution. Although fewer people had active involvement of their support networks, this 61.2% is nevertheless notable. All sites are now actively encouraging involvement of networks. Finally, families commented on the importance of listening to the person while involving others in the development of individualized plans and goals.

Some research suggests that such participation is more likely to lead to meaningful goals and directions.[5]

Goals in Support Plans

Although support plans varied widely, they all identified goals or intentions that the person wanted to pursue. In Table 4, we have organized these goals into categories to show the diversity of goals and intentions. Goals within people's support plans demonstrated that people have a wide variety of interests. Most people had three goals in their plans but some had as many as five.

Table 4

Goals Identified in Support Plans

Goal area	*%*
Home related	83.6
Daily living	74.8
Recreation & leisure	73.2
Relationships	71.1
Employment	66.9
Community connecting	66.1
Behaviour support	59.8
Skills training/coaching	59.1
Education	23.6

During the file analysis, we took great care to assess each goal and its primary focus. For example, when a goal was primarily about being involved in an activity, it was rated as 'recreation and leisure.' A similar goal about activity may have been rated as a 'relationship' goal if the emphasis was to expand friendships through activity. 'Community connecting' referred to those

goals that were oriented to community participation, but not necessarily leisure oriented, such as "being more involved in my neighbourhood."

These goals showed people's desire to have an ordinary life living in the community. In home-related goals, for example, 83.6% of adults' plans focused on "moving away from home," "living on own with roommate," or "having more choice in where I live." In nearly all of the interviews, families indicated they were actively supporting their adult son or daughter to build a life in community that included moving into their own place or into an apartment in the family home. Similarly, daily living goals reflected people's desire to be more independent with things like cooking and shopping.

The goals also reflected the desire of people with disabilities to participate in citizenship roles. Community connecting, recreation and leisure, and relationship goals all represented people's intention to be part of the fabric of their community. Within community connecting, for example, goals in 42.6% of plans noted things like "to find meaningful activities in the community," and "to increase community presence." Relationship building goals were important for 71.1% of participants, and included "increasing the number of relationships," and "developing a support network or circle of support." Even some of the skills training/coaching goals focused on enhanced citizenship with areas such as literacy being a priority.

Over time, some goals remained the same, while other goals changed. Many people maintained one or two similar goals over four years. These tended to be goals related to maintaining friendships, expanding relationships, and building community connections. We also noted that many of people's goals were not static. Several families mentioned that some goals were always evolving. One parent said, "Our earlier goals were around behaviour… now it's mostly about relationships and home ownership."

Amounts of Funding Requested

At all sites, individuals and families were required to develop a support plan with a budget and submit it for funding. Most funding that people initially requested was to hire workers who

would assist the person to meet their goals. In some cases, funding was also requested for more specialized supports, such as behavioural therapy or counselling. The information about how much funding families initially requested for disability supports was limited; less than half of the files had this information. From this data, it is clear that the funds people asked for varied widely, depending on the needs of the person. Table 5 below shows the amounts of people's initial requests.

This range of requests reflects the wide diversity of support needs among people with disabilities. With half of the participants requesting less than $36,000 per year, this data also shows the relatively limited size of people's requests. Only four (6 %) participants asked for more than $100,000 in disability supports. If we translate the $17,750 in Table 5 to the number of hours of support, it means that 25% of families requested less than 25 hours a week of paid individualized support.

Table 5

Amounts People Initially Requested for Yearly Disability Supports

Amount	%
$2600 to $17,750	25
$17,750 to $35,608	25
$35,608 to $58, 000	25
$58, 000 to $130,000	25

Amounts of Funding Received

Initial Amounts Received

The actual amount of individualized funding received by individuals and their families was considerably less than the amount people had requested. Table 6 below shows the actual amount of money received.

Table 6

Amounts People Initially Received for Yearly Disability Supports

Amount			%
$2,000	to	$ 9,996	25
$9,996	to	$17, 200	25
$17,200	to	$31,000	25
$31,000	to	$90,000	25

We again see a wide range of funding reflecting a diversity of needs. Facilitators at the sites pointed out that the funding allocation process was not entirely rational. The amount people received was often dictated more by the

total funds available and the total number of requests than by a clear allocation process based on goals and outcomes. We might conclude, based on these insights, that the wide range of funding reflects a diversity of needs, but also the incoherence of the system.

Funding Gap Over Four Years

On average, what people received was $16,692 less than what they had first requested. Several people we interviewed noted that this initial funding gap was quite challenging for families. In tracking the "amount requested" and "amount received" over four years, however, the difference between these two figures narrowed considerably each year. Table 7 shows the gap between funding requested and funding received over four years.

There are two explanations for why this gap between what people asked for and what they actually received grew smaller over four years. First, some families received slight funding increases over the four years as a result of overall budget increases by the MCSS. Second, many families told us that over time they moderated their demands to fit with what they thought they could reasonably receive. Families were basically learning to play the game.

Table 7

Average Gap Between Amount Requested & Amount Received Over Four Years

Year	Amount
1	$16,692
2	$ 8,617
3	$ 7,846
4	$ 4,574

More than half the family members we interviewed indicated that the amount of funding they were receiving was "adequate." People who indicated that their funding was "inadequate" described how they had to be creative to "make do," such as seeking subsidies for housing support, providing their own resources, and family members having to provide "extra support."

Sources of Government Funding

Nature of Sources

Funding for individualized funding came from three government sources. Two of the sources were from the same ministry. As outlined in Table 8, almost everyone

(94.6%) received funding directly (or through a transfer payment agency) from MCSS, and nearly 40% of participants also received Special Services at Home (SSAH), which is also part of MCSS. This money is available for families that have a person with a disability living in the family home. The reality is that MCSS has various pots of money, all with different parameters and rules. As well, 18.6% of families received some funding for disability supports from the Ministry of Health and Long Term Care. Such funding is earmarked for people with disabilities who have more complex support needs. This money is sometimes direct but often is designated only as "hours of support" that families must access through a community agency.

Table 8

Government Sources of Individualized Funding for Disability Supports

Source	% of families
Ministry of Community & Social Services	94.6
Special Services at Home (for the 40 % of people living at home)	39.5
Ministry of Health & Long Term Care	18.6

Multiple Sources

In some projects and jurisdictions, such as the Ontario Direct Funding Program funded by Ministry of Health and Long Term Care, the person with support needs receives individualized funding from one source. Because there is not as yet an official individualized funding program for people in Ontario with developmental disabilities, *people in this study tended to receive their funding for disability supports from a variety of sources***.** Table 9 shows the percentage of families that received funding from one or more sources.

Table 9

Number of Funding Sources for Individualized Funding

Number of Sources	%
1	48.4
2	35.9
3	15.6

Several families said they found the multiple sources of funding frustrating and time consuming, since each of the government programs had different applications and accountability approaches. However, most families were also very appreciative of the SSAH

funding because they had significant control over the use of the funds, but less appreciative of Ministry of Health resources that often came in hours of support, rather than direct funding.[6]

We now explore three key elements that emerged from this research that made individualized funding work: the unique application of the facilitator, network building, and effective support workers.

The Facilitator: Key to Individualized Funding

Positive Views of Facilitation

Facilitators at all four sites played major roles in the lives of individuals and their families. Interviews with families confirmed and gave depth to what facilitators say they do. All families were very positive about the importance and helpfulness of their facilitators. The strength of this theme gives credence to research that suggests that independent planning and facilitation are an essential infrastructure with individualized funding.[7]

Families described very positive relationships with their facilitators. A typical example of this comes from one parent who said, "Our facilitator is a treasure, so totally committed to people having respect and choices." Others said they appreciated that facilitators took the time to explain things and assisted the family in figuring out what kind of funding made sense. Families all said that their facilitator had a positive relationship with the person being supported.

Major Roles

Families described three facilitator roles that they experienced. *First, facilitators helped individuals and families plan.* As part of this planning role, facilitators often helped families develop a support plan and budget, as well as assisted with application forms. Sometimes this meant creating a life plan, while other times it meant building meaningful goals with individuals and their networks. Families noted that facilitators "kept us focused on the person," "helped us figure out how to access community resources," and "provided the information we needed to make sound decisions." Families agreed that planning support at first was quite involved and sometimes even intense. *Second, facilitators assisted people to develop and expand their support networks.* We saw earlier how important relationships were to

participants. One mother described her facilitator as "a catalyst" for network development. *Third, facilitators played an ongoing support role for implementation, including "checking in" on a regular basis*. Some families reported that their facilitator had a strong relationship with their support workers and was thus able to assist with ongoing monitoring and support. Some families called the facilitator their "guide," while others noted that feedback from facilitators often addressed things the family had not considered.

How Often Facilitators Met Individuals and Families

Families varied in how often they met with their facilitators. Some individuals and families met with the facilitator every second week, while others only met 2-3 times a year. *How often people met with their facilitator was determined by the individual's needs and capacities*. Some people seldom called on their facilitator because they had developed networks and support systems that worked well for them. Families stressed that facilitators deeply respected the self-determination of the person being supported and in all their meetings, put the person's desires "front and centre."

These themes strongly support the idea that families with a vulnerable member often need ongoing, unencumbered guidance and facilitation. Such independent planning support seems integral to the role of individualized funding**.**

Network Building: Key to Individualized Funding

Nature and Involvement of Networks

In the development of individual support plans, facilitators were quite involved. Part of this involvement included the development and facilitation of support networks. All sites made network development an "intentional" focus of their work. Sometimes referred to as "support circles" and other times as "personal networks," 54% of participants had support networks that met. In the first year, 73.2% of these networks were "very active" and 18.3% were "somewhat active."

The sites all had very similar views about the support network. It was seen as a group of people that were invited to be part of someone's life. Support networks or circles were more formal than simply inviting people to help with planning. Most families we interviewed indicated that they either had a formal support

network or had a couple of people they invited to assist with planning from time to time. Families with networks said they appreciated that friends, siblings, and other family members were quite willing to become involved. They indicated that it was meaningful to their son or daughter, increased their relationship possibilities, and helped with planning.

How Often Networks Met

Table 10 shows how often support networks met. Typically, one parent said, "Our facilitator helped us define and develop the support circle." Although most networks met on a regular basis in the early years, a typical parent noted, "We now meet when we need to," because "issues change depending on her life situation." Facilitators said that over the four years most families became comfortable with the approach that best suited their style, whether a formal network arrangement or a more informal approach. Regardless of which approach families chose, it was clear that the focus on networks and relationships was a unique and important part of projects that were trying to truly individualize supports.

Table 10

How Often Support Networks Meet (of the 54% with networks)

How often	%
bi-weekly	10.8
monthly	27.7
bi-monthly	23.1
3-4 times yearly	21.5
twice yearly	16.9

Support Workers: Key to Individualized Funding

Level of Satisfaction

One of the often stated benefits of individualized funding is that individuals and their families have control over the type of workers they hire and what people will actually do once hired.

All the families that were interviewed, except one, hired their own workers. There was a variety of hiring approaches from contract worker to hiring agency employees. There was a *high degree of satisfaction with the workers that were hired*. Families said they were "100% satisfied," "very satisfied," or "quite satisfied." There was wide agreement that, "It really makes a difference to be able to handpick your workers." Several

families noted that they had retained their workers for many years. One parent said, "You treat workers well, and they stay," while others stressed the importance of building strong relationships with workers. Part of the satisfaction was also related to people learning over time the best fit between their family member and their workers.

A minority of families also cited the infrastructure support (support provided by facilitators and local organizations) as being "helpful" in locating and training workers. However, most families indicated they trained their own workers and were satisfied in doing so.

Number of Support Workers

The number of workers hired by families is noted in Table 11. While the vast majority of families used 1-3 workers on a regular basis, a small percentage (2.5%) only used facilitation support, and a number (20.9%) had four or more workers.

Table 11

Number of Support Workers Used by Individuals

No. of workers	%
0	2.5
1	22.7
2	30.4
3	23.5
4 +	20.9

Interestingly, there was no relationship between the number of workers people used and the amount of funding they received. As an example, there were people with a small amount of money who had two part-time workers, and people with a large amount of funding also with two workers, one of whom might have been full time.

Roles of Support Workers

Support workers played a variety of roles, depending on the needs of the person being supported. Table 12 shows the types of support provided. Many people hired their support workers to provide "practical support" in the home. Though 69% of people received support for meal preparation, people who lived away from their parents were more likely to receive this kind of support.

While workers routinely supported people with "little decisions," like meal planning, 40.3% of workers also assisted with larger decisions, such as what community activities to connect with, or

Table 12

Roles Played by Support Workers

Area of Support	% of People
Practical Support in the Home	
Personal Care	61.2
Meal Preparation	69.0
Health	61.2
Communication	42.6
Decision-Making Support	
Little decisions	76.0
Big decisions	40.3
Present & interpret	59.7
Support for Community Participation	
1:1 in activities	76.0
coaching/connecting	70.5

even the types of vacations the person might want to take and with whom. Support workers spent a lot of time providing 1:1 support connecting people in the community. The finding that 70.5% of support workers spent time "coaching or connecting people" with the community sheds light on a relatively new role of support workers. *Connecting people to community activities also built on the goals of participants,* many of which were citizenship and community oriented. Our discussions with facilitators and families also emphasized this role. The facilitators in some sites were instrumental in "coaching" support workers to learn better ways to connect people with community life.

All of the families we interviewed said that they were the ones who decided when their workers came to work with the person**.** *People were very pleased to be able to determine when the support could most benefit the person and the family.* Many families praised the organizations that provided facilitation support. Some parents expressed appreciation for the "flexibility" and "sharing of ideas" that personified this approach to providing individualized support. Families admitted that there were times when a worker did not work out, but it appeared that over time and with support, families got better at finding and retaining workers that understood individualized support and could provide consistency.

We can conclude that the flexibility of individualized funding enabled individuals and families to build creative supports using their workers.

Outcomes Experienced with Individualized Funding

Individuals and families experienced a wide variety of outcomes as a result of individualized funding. Most notably, *people met many, although not all, of the goals outlined in their support plans.* Our data also showed that *people were experiencing extensive participation in community life as a result of individualized funding.* For each of the outcomes identified in the file reviews or in conversation with facilitators, the number of participants who met each outcome is noted in Tables 13 to 17.

Table 13

Outcomes Experienced with Individualized Funding

Outcome Area	% of people
Home	
Moved from family home	38.0
Changed living situation	51.2
Daily Living	
Goes shopping	79.8
Directs support	75.2
Indicates preferences	84.5

Moving Away From Home & Daily Living

A number of participants were able to meet their goal of moving away from the family home. This outcome (38%), achieved over four years (see Table 13) is noteworthy, given the importance of this goal to so many people. As well, there was no correlation or relationship between "moving away from home" and "amount of funds received" for support. In other words, people at all ranges of funding support were able to move away from home. Some families in interviews indicated they did not have sufficient funds to meet this goal, while others were very creative in achieving this goal. An even larger number of participants (51.2%) had some change in their living situation, which included things like "more independence at home," "more time spent without parents," and "more participation in meal preparation."

Daily life also improved for many participants, with almost 80% going shopping on a regular basis. Combined with the fact that most people also had increased choices and preferences, going shopping took on a new light. With much of the individualized support being provided by paid workers, it was interesting to note, that according to facilitators, 75.2% of participants provided some direction to their workers. In some studies, this has been an important indicator of the person's empowerment.[8]

Employment & Making a Contribution

In Table 14, we see that a number of participants found jobs (38.8%) or volunteer work (42.6%), indicating that *the vast majority of people met their goal related to working in the community*. Although most of the employment appeared to be part-time and low paid, this finding indicated that people with individualized funding were gaining partial entry to employment. Several families described their son or daughter's life that often included volunteer work and some paid employment.

Table 14

Outcomes Experienced with Individualized Funding

Outcome Area	%
Employment & Making Contribution	
Found a job	38.8
Found volunteer work	42.6
Makes a contribution	62.0

Also, many people (62%) were seen as making a contribution in some way to their community. This outcome fits with people's citizenship goals outlined earlier. Several family members talked enthusiastically about people now having more fulfilling social lives in the community, and being able to contribute in lots of small ways that previously parents never dreamed possible. As one facilitator pointed out, these small things in fact can add up and can make a huge difference in a person's life.

Independence/Skills/Behaviour

In Table 15**,** the file review and facilitators' assessments showed that the majority of people being supported with individualized funding were more independent (76%), more confident (69%), and had fewer behavioural issues (58.1%).

Table 15

Outcomes Experienced with Individualized Funding

Outcome Area	%
Independence/ Skills/ Behaviour	
More independence	76.0
More confidence	69.0
Fewer behavioural issues	58.1
People see more capacities	51.9

Interviews with parents confirmed these findings, with families and support network members now seeing more *capacity* in the person than they had previously. Some parents attributed this finding to the fact that the projects used a "strengths-based approach" to facil-

itation and support, which helped families move away from seeing only deficits and problems.

Relationships & Community Connections

As shown in Table 16, people were more involved in their communities. This was reflected by the fact that 76.7% of participants went more places in the community. Interviews with families confirmed that most people had very active lifestyles.

Table 16

Outcomes Experienced with Individualized Funding

Outcome Area	%
Relationships & Community Connecting	
More relationships	70.5
Expanded network	65.9
Goes more places	76.7
Takes Courses	9.3

For many people, this included expanding their relationships (70.5%) and networks (65.9%). *It appeared that the "intentional" focus of the projects on network development paid off for many people.* This finding that people with developmental disabilities had increased their relationships is encouraging, given the research showing that people with disabilities generally have fewer relationships and are often isolated and lonely.[9]

On the other hand, few people (9.3%) accessed courses and educational opportunities in the community. Only some people had this as a goal (23%). Why people did not see this as an important goal could not be answered with this data.

Recreation and Leisure

Recreation and leisure participation had notable outcomes. The vast majority of people were quite active in their communities. As shown in Table 17, 87.5% of participants were involved in formal (e.g., referred to program) and informal (e.g., visiting library) integrated recreation and leisure settings and activities. In the research, formal and informal were combined. In addition, 47.7% participated in segregated activities, both formal (e.g., dance with others with disabilities) and informal (e.g., dinner with group home residents).

However, *people participated in integrated leisure far more than segregated settings*. On average, people participated in 3.1 integrated community activities, while on average they participated in only .81 segregated activities. Some of the "segregated" activities were actually mutual aid groups, such as People First participation (8.7%). People First is a mutual aid group of people with developmental disabilities that involves people in self-advocacy and education about their rights.

As noted in Table 17, some integrated activities were quite popular, like swimming, fitness, church, and library. People participated in *123 different community activities*. This broad participation covered the range of leisure participation, from physical activity, the arts, to serious leisure such as clubs. Combined with the fact that less than 10% of adults attended segregated day programs, this finding shows that people with individualized funding are beginning to build inclusive lives in community. We mostly used the word 'integrated' in this study because our data only hinted at the extent to which full 'inclusion' was actually happening.

Table 17

Outcomes Experienced with Individualized Funding

Outcome Area		% of people
Recreation & Leisure		
Integrated settings/activities		87.5%
Segregated activities		47.7%
Number of Activities per Person		
Integrated activities	average	3.1
	Range	0-8
Segregated activities	average	.81
	Range	0-4
Highest Participation Activities		
Integrated		**% of people**
Swimming		26.9
Fitness/gym		26.9
Church		23.0
Library		18.5
Segregated		
Bowling		16.6
Swimming		9.8
Day programs		9.8
Mutual Aid Groups		
People First		8.7

Potential of Individualized Funding

This research showed that individualized funding has potential to contribute to the new paradigm of disability support. There were three themes that helped us understand this potential.

Values Create Foundation for Good Things to Happen

All four sites were very clear about the values that must guide individualized funding. Facilitators continually expressed commitments to self-determination and full participation of people with disabilities. We noted that these values were reflected over and over by the families we interviewed. Not one family wavered from a desire to build an inclusive life for their son or daughter. The strong beliefs and intentions of people and projects give a much broader meaning to individualized funding than simply the mechanics of transferring money to individuals. Values clearly create a foundation for good things to happen for people.

Family Involvement Builds Capacity of Individuals and Their Families

This research showed that families of individuals receiving individualized funding were very involved in the life of their son or daughter. This commitment of families certainly enhanced their participation. In turn, families appreciated the potential of individualized funding. The most predominant theme was that of "having control" over the resources for disability supports. This was particularly important for those individuals that used their funding to move from a congregate or segregated setting. Some families said that the combination of facilitation and funding enabled them to "look at life in a different way." There was a strong sense in the family interviews that people had slowly learned the value and principles of "individualizing support."

In a related theme, many families talked about how individualized funding enabled them to build more creative supports with their son or daughter. As we have seen, families identified positive outcomes in several areas. Many of these outcomes were about building the capacity of the person's skills, networks, and community connections. It was clear from this study that families also expanded their capacity to help their loved ones build a life in community.

Individualized Funding Contributes to Quality of Life

This research showed that individualized funding combined with strong facilitation contributed to quality of life. In assessing the overall quality of life of participants, we looked at four indicators which were based on the determinants of health literature.[10] At the end of each file

review, as a way of trying to summarize a few of the most important indicators, facilitators were asked to rate how individuals were doing on these four factors. These are summarized in Table 16.

Table 16

Indicators of Quality of Life

Area	% of people
Person makes self-determined choices	85.0
Most of person's goals met	86.6
Strong community participation	70.1
Many relationships (6 or more)	50.9

Facilitators indicated that 85% of participants were making self-determined choices. Making self-determined choices was similar to "having control" and has been shown to be an important determinant of health. Comments of families and facilitators noted that over four years, most people were making more choices in all areas of their lives.

Facilitators' comments and files indicated that over four years 86.6% of people were meeting most goals of their support plan. As a determinant of health, meeting goals was an indication that people have purposive activities, which increases meaning and well-being. This finding also shows that people's goals were within reach and that individuals, families, and networks worked very hard to achieve them.

Similarly, 70.2% of participants were rated as having "strong community participation." This was supported by the extensive outcome data related to community involvement. All sites had a focus on "community as a first resort," meaning that planning and support revolved first around community and second around services only when necessary. Most plans we reviewed, for example, emphasized community involvement as a major intention. Community participation is an important determinant of health and relates to civic engagement and sense of community.

Facilitators' ratings showed that over four years, most people developed more relationships. Approximately 50% of participants were rated as having many relationships (6 or more). It will be recalled that more than 70% of participants had "relationships" as one of

their goals. 22.4% of participants were rated as having some relationships (3-5) and 25.9% as having few (0-2). Social networks are one of the most important determinants of health because research shows that rich networks and relationships are strongly associated with health, well-being, and quality of life.

These four indicators point to people with individualized funding and independent planning support having reasonably good quality of life.

Dilemmas of Individualized Funding

This research identified some very positive findings about individualized funding as a mechanism for enhancing disability supports. Nevertheless, several issues and dilemmas emerged from this research that could benefit from reflection and further action.

Lack of Coherent Provincial Policy

Since individualized funding is not yet a province-wide program for people with developmental disabilities in Ontario, there were wide differences among the four sites in terms of the application process for individualized funding, the degree of independence of facilitators, and allocation of funds. *None of the sites had all the components of a fully fledged "new paradigm" approach in place.* A new paradigm of disability supports includes clear values of citizenship and inclusion, a mechanism for individualized funding, independent planning and facilitation, allocation processes that are fair and equitable, and infrastructure that provides families with choice, information, and support. That sites did not have all these components in place was understandable, given the absence of provincial policy. A coherent provincial policy based on this research would ensure that facilitators were truly independent and that clear principles and processes would guide both application and allocation procedures.

Role of Facilitators

Support plans varied widely across the four sites in terms of detail and documentation. At some sites, facilitators recorded clear goals and the individuals' progress, while at other sites, details of progress were seldom written down and regular reviews were rare. One site leader wisely pointed out that documentation enabled her staff to be "reflective practitioners." Such

practice enabled everyone to keep growing and learning.

While people appreciated the facilitators and the work they accomplished, there were some dilemmas at the sites about facilitation. At some sites, facilitators played a major role in helping people negotiate systems, while at other sites this was not the case. Most facilitators knew the people they supported very well, but this was not always true. Most facilitators had a clear set of principles by which they worked, but some did not. Some facilitators did community development as part of their work, while others did not. Such differences among facilitators suggested *the importance of ongoing, consistent province-wide facilitator training and support.*

Challenges for Families

While almost all families were very active in the lives of their sons and daughters, some families expressed "tiredness" with the systems that were in place for people with disabilities. A minority of families admitted that it took a lot of time and effort to manage the money and planning. Other concerns revolved around the narrow, deficit-focused application forms, the uncertainly of funding, the multiple sources of funding, and the gap between what funding was required and what was received. Some families expressed worry that the funding only went from year to year. While most families had very positive experiences with their workers, a few said it was a challenge to find and keep good support workers. At one site, the requirement that families put their individualized funding through a transfer payment agency was a concern to some families. These are issues that demand effective and coherent provincial policy.

Sites were emphatic that active families were crucial to the effective utilization of individualized funding. While our data supported this insight, this finding raises important questions. What about families that cannot be active, but want individualized funding as an option? What about individuals who do not have family, but want facilitation and funding tailored to meet their needs? Some sites have grappled with these questions and are deepening their insights. At the same time, sites are limited in their response to these concerns until there is adequate infrastructure in place to provide intensive facilitation and support to

individuals that do not have strong family ties.

Conclusion

The findings and themes from this research show *participation to be central to the implementation of individualized funding*. We found that parents participated fully in the life of their son or daughter. We found that individuals and their support networks participated in the development of goals, community connections, and relationships. We found that facilitators participated with families and individuals by providing information, engaging people in the process of planning, and serving as a "touchstone" for families in their journey to build a life in community. We found that the four organizations participated with families, listened deeply to them, and stood with them as they worked to create alternative visions and supports.

Individualized funding as a concept has become well accepted in the world of disability supports. *As Ontario moves to create a province-wide approach to individualized funding, it can pay heed to the lessons emanating from these four sites.* Although imperfect in their design and implementation, they can serve as "development sites" for the entire province. There is a strong sense at all sites that people are "learning as they go." Both the strengths and dilemmas of these sites can contribute to the development of coherent provincial policy.

In this study, there were a large number of positive outcomes achieved by individuals. While this research was not designed to fully analyze the exact causes of the positive outcomes, *we can speculate from our data that the outcomes can be attributed to four conditions*: strong facilitation and unencumbered planning, active and involved families, networks of support, and individualized funding. As already noted, the importance of values must be considered as well. Insights about these five ingredients at all sites can contribute to the growing theory related to the new paradigm of disability supports. This work suggests that inclusion and a textured life can be enhanced through individualized funding in conjunction with other personalized infrastructure supports.[11]

The results of this research emphasize the need for future research. While we found that participants had enhanced quality of life and many integrated community experiences, it was difficult to determine the extent to which people's lives were fully inclusive. Future studies should look more deeply at people's actual participation in the community and how inclusive it has become.

In this study, we have come to understand the lives of people with developmental disabilities through the file reviews and the words of facilitators and families. Future studies must explore some of these research questions with people with disabilities themselves. As we learn more about new paradigm approaches, we need to ensure that people with disabilities are front and centre to theory building and best practice. The real pioneers of individualized funding are people with disabilities who have shown that they have the capacity to dream, make choices, keep relationships, and live full lives in our communities.

Endnotes: References for Related Research

[1] See Alison Pedlar, Larry Haworth, Peggy Hutchison, Peter Dunn, & Andrew Taylor (1999). *A Textured Life: Empowerment and Adults with Developmental Disabilities.* Waterloo: Wilfrid Laurier University Press.

[2] For a thorough analysis of existing programs that use individualized funding, see John Lord, Barb Zupko & Peggy Hutchison (2000). *More Choice and Control for People with Disabilities*, a summary of ten projects in three countries. *Common Vision for Real Transformation* was developed by four provincial organizations in Ontario and outlines key principles of individualized funding and independent planning and facilitation. Both of these documents are on the Individualized Funding Coalition for Ontario website; www.individualizedfunding.ca
British Columbia has recently implemented legislation that gives families and individuals an opportunity to choose IF and facilitators who are independent of the service system. See www.communitylivingbc.ca

[3] For a summary of IF research, see John Lord and Peggy Hutchison (2003), Individualized support and funding: Building blocks for capacity building and inclusion. *Disability and Society,* 18:1, 71-86. Also see Tim Stainton (2005), *Individualized Funding*, Presentation to Policy Forum of Ontario Ministry and Community Services, March 30 www.individualizedfunding.ca
For further research on IF and self-determination, see Roger Stancliffe & Charlie Lakin(2005). *Costs and Outcomes of Community Services for People with Intellectual Disabilities.* Baltimore, MD: Paul H. Brookes Publishing.

[4] For an analysis of the role that families can play, see Canadian Association for Community Living (2005) *Family Policy Newsletter.* Toronto: CACL.

[5] See Steve Holburn & Peter Vietze (2002). *Person-Centred Planning: Research, Practice, and Future Directions.* Baltimore, MD: Paul H. Brookes.

[6] Studies show that families and individuals rate “control over resources and supports” very highly. This was the case in the provincial evaluation of the Special Services at Home program. See John Lord, Mary McGeown, & Joanna Ochocka (1993). *Family Directed Support: Diversity, Hopes, Struggles, Dignity.* Toronto: Ministry of Community and Social Services.
In a new British book on individualized funding, several chapters emphasize the importance of autonomy and self-determination in the UK system known as “direct payments.” See Janet Leece & Joanna Bornat (Editors) (2006). *Developments in Direct Payments*. Bristol, UK: Policy Press, University of Bristol.

[7] See John Lord, Barb Zupko & Peggy Hutchison (2000). *More Choice and Control for People with Disabilities*, a summary of research on ten projects in three countries that includes an analysis of the role and importance of independent planning and facilitation. This Report can be found on the Individualized Funding Coalition website; www.individualizedfunding.ca

[8] Empowerment has long been considered a key element in the move to more community living for people with disabilities. See Roger Stancliffe (2000), Outcomes and costs of community living: A matched comparison of group homes and semi-independent living, *Journal of Intellectual and Developmental Disability*, Vol. 25:4, 281-305. For a qualitative analysis of empowerment indicators, see Geoffrey Nelson, John Lord, & Joanna Ochocka (2001). *Shifting the Paradigm in Community Mental Health: Toward Empowerment and Community.* Toronto: University of Toronto Press. For a practical analysis of the use of empowerment in the relationship between the person and the support worker, see Michael Kendrick (2004). *Discerning Actual Levels of Substantive Empowerment.* Article available from www.kendrickconsulting.org

[9] See Pedlar, *Textured Life* referred to above.

[10] For research into determinants of health, see National Forum on Health (1998). *Determinants of Health.* Ottawa: Les Editions Multimondes. For further insights into quality of life, see R. Renwick, Ivan Brown, and Mark Nagler (1998). *Quality of Life in Health Promotion and Rehabilitation: Conceptual Approaches, Issues, and Applications*. Thousand Oaks: Sage Publications.

[11] See Pedlar, *Textured Life* and *Common Vision for Real Transformation* referred to above.

Thank You !

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For further information on research and experience with individualized funding and independent planning:

Individualized Funding Coalition for Ontario
www.individualizedfunding.ca

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research and writings
www.johnlord.net

Copies of this study are available on both of these web sites.

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There is nothing more

powerful than an idea

whose time has come.

Victor Hugo