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Individualized Funding in Ontario: Report of a Provincial Study

Abstract

Individualized funding for people with developmental disabilities is increasingly being seen as valuable for self-determination and inclusion. Recently, the Individualized Coalition of Ontario commissioned a study to explore the practice of individualized funding. The researchers examined 130 files of people receiving individualized funding and interviewed 18 families. The results showed that people with individualized funding experienced positive outcomes. The support plan provided a foundation for building a good life. Facilitators played a major role in assisting people with planning and network development. Individuals and families generally received less funding than they requested and funding often came from multiple government sources. Although families were generally very satisfied with individualized funding, they raised a number of concerns.

In recent years, there has been a growing interest in self-determination of citizens with disabilities (Laragy, 2004; Wehmeyer & Schwartz, 1999). Self-determination implies that people have autonomy, freedom, and choice accorded by citizenship (Stancliffe, 2001; Turnbull & Turnbull, 2006). Not surprisingly, many people with disabilities have been denied an inclusive life in the community that supports self-determination (Pedlar & Hutchison, 2000; Stienstra & Wight-Felske, 2003). However, a new paradigm, focused on a social model rather than a deficit model, is now in the process of evolving to address this exclusion (Lord & Hutchison, 2007). In Canada, much of this work was originally spearheaded by the G. Allan Roeher Institute (1991). In their work with the Institute, Bach & Rioux (1996) identified self-determination, equality, and democratization as key components of social well-being. More recently, other national and provincial groups have also been calling for new approaches in the provision of disability supports (Council of Canadians with Disabilities, 2005). Some researchers suggest that the social model contributes to self-

determination by its focus on rights and community opportunities made available to adults with disabilities (Bach, 1998; Wehmeyer & Bolding, 2001).

Individualized funding is often seen as one viable strategy to maximize self-determination and citizenship (Dowson & Salisbury, 2000; Stainton, 2005; Stancliffe & Lakin, 2005). Individualized funding or direct funding is the allocation of financial resources to individuals and/or families by government (in contrast to block funding to agencies) on the basis of the person's specific disability related needs and support requirements, enabling the person to acquire services and supports of their choice (Dowson & Salisbury, 2000). Individualized funding operates with the parameters of funding agreements determined by policy and typically includes various funding levels as well as funding limits.

Research completed to date on individualized funding captures the possibilities and dilemmas of this approach to funding disability supports. Some research shows that using this method for disability supports is cost effective because better outcomes are often achieved with individualized funding (Laragy, 2004; Stainton, 2006; Stainton & Boyce, 2001). Evaluations completed with the Western Australia Local Area Co-ordination and Direct Funding Project over more than fifteen years show that outcomes create "value for money" (Bartnik & Psaila-Savona, 2003; Lewis, 1996). Using a comprehensive experimental design, Lewis (1996) identified twenty discrete positive outcomes related to individualized funding and independent planning and co-ordination. Related research shows that self-determination is enhanced when individualized funding enables people to access community supports for inclusion (Wehmeyer & Bolding, 2001; Spandler & Vick, 2006). In a study that looked

at people with individualized funding and strong social networks, Pedlar, Haworth, Hutchison, Taylor, and Dunn (1999) found that individualized funding enhanced citizenship by providing options for truly individualized support. Studies show that users of individualized funding are generally very positive about individualized funding, especially in comparison with traditional service approaches (Glasby & Littlechild, 2002; Lord, Ochocka, & McGeown, 1993; Stainton & Boyce, 2001).

Some researchers also raise cautions about individualized funding. Lyon (2005) noted that we need to see the impact of direct funding on the social service system, not just its impact on individuals. O'Brien (2001) pointed out that there are many system barriers to the implementation of individualized funding and in reality it is very difficult to customize supports. Leece and Leece (2006) noted the danger in the UK is that direct payments or individualized funding is creating a two-tiered service system. Although ten years of individualized funding in the UK demonstrates several positive results, Leece (2004) showed that using this market approach to disability supports is also leading to the commodification of community supports. Spandler (2004) concurred with this concern and showed how the hiring of personal assistants can be empowering or problematic. As Callahan (2001) found in a study of personal budgets, many participants found the whole procedure confusing and complex. Stainton (2002) found that structural constraints often limit how professionals can support individualized funding, despite their best intentions to support a rights based approach. Dowson and Salisbury (2000) cautioned that individualized funding is complex and should be implemented incrementally and very carefully. A study in the state of Victoria in Australia confirmed

the idea that not everyone wants full individualized funding and that this approach to disability supports needs to be implemented cautiously (Laragy, 2001).

Ontario has had individualized funding for some time for people who have developmental disabilities. Special Services at Home (SSAH) was started in 1982 and provided families with an option to self-administer their disability supports (Rooke, 2003). A 1993 evaluation of the SSAH program identified positive outcomes for individuals and families. Despite the appreciation of families for this individualized funding approach, this evaluation showed that the lack of infrastructure and the small amounts of funding provided were serious limitations to this program (Lord et al., 1993). Infrastructure support designed to enhance individualized funding and individualized approaches includes independent planning and facilitation, sometimes referred to as brokerage (Bach, 1998; Hutchison, Lord, & Salisbury, 2006). "Independence" of facilitators is often seen as important because it means that facilitators are free of conflict of interest (Community Living British Columbia, n.d.; Individualized Funding Coalition for Ontario, 2006; Smith, 2003; Torjman, 2000).

In 1997, the Individualized Funding Coalition for Ontario was established. In 2000, the Coalition sponsored a Round Table on Individualized Funding (Individualized Funding Coalition for Ontario, 2000). The Round Table highlighted lessons from other jurisdictions including British Columbia where transformation in the developmental disabilities sector has lead to the development of seventeen centres that house independent facilitators (Salisbury & Woollard, 2007). In response to concerns about individualized funding, the Coalition and others propose related infrastructure supports that families

and individuals may require, including things such as payroll support, pools of workers, and training for workers on the new paradigm (Individualized Funding Coalition for Ontario, 2000; Lord & Hutchison, 2003; O'Brien, 2001).

This current study was commissioned by the Individualized Funding Coalition for Ontario in order to explore the practice of individualized funding in the province. More specifically, the Coalition worked with the researchers to identity research questions, including: how much individualized funding families and individuals receive for individualized support, in what ways they utilize this funding, and their experience with regard to outcomes and participation. The rationale of the study was that this research would increase our understanding about individualized funding projects in Ontario for individuals with developmental disabilities and families, and possibly point to policy implications. The concept of individualized funding could have greater prominence in major developmental disability literature (Brown & Percy, 2003).

Methods

Participants and Procedures

In order to study individuals and families who received individualized funding, it was necessary to select sites that provided this option, of which there are only a few in Ontario. Ideally, sites chosen had individualized funding and independent planning and facilitation. There was no limit on the number of possible sites. Only four sites within four separate regions of the province met both criteria, although the independence part was somewhat limited in one case. However, all sites had well trained facilitators who were at least "separated" within their agencies from any service functions. One site served

mainly a rural population, another in a mid-size city, and two others were in large metropolitan areas.

Random sampling was used to select the files of individuals with disabilities receiving individualized funding where possible. A total of 130 files from a possible total of 329 were chosen from the four sites. In addition, a purposive sample identified 18 families from the four regions for the purpose of completing in-depth interviews about people's experience with individualized funding. The four to five families chosen from each site represented families with a range of funding and diverse outcomes.

Researchers conducted two to three visits to each site, each lasting a day. A protocol developed for analyzing participant files included demographic information (age, gender, cultural background, disability, etc.), goals of the support plan, budget (money asked for and received), how funds were used, and outcomes that were achieved. Two researchers worked together to extract information from the files. During this file analysis, researchers met with the individuals' facilitators to confirm their interpretation of the file information and to fill in gaps that may not have been clear in the files.

Telephone interviews were then carried out with the 18 families (at least one parent). An open-ended interview protocol included questions about the development of the support plan, role of individualized funding, nature of relationship with the facilitator, and goals and participation of the person. Interviews ranged from 30 to 60 minutes. Standards of ethics were followed at all stages of this community-based study pertaining to informed consent, confidentiality of subjects, anonymity, participant withdrawal, and feedback of results.

Analysis

The quantitative data from the 130 files was analyzed using SPSS, and descriptive statistics were generated. In addition, a qualitative methodology was used to analyze information from people's support plans from the files as well as interview information from 18 selected family members. Open coding was completed, and the resulting categories were then reduced using constant comparison. Common themes that summarized the data were determined. Themes from both the qualitative and quantitative data were then combined to build the final themes. Early themes were sent to a few facilitators and leaders from each site to confirm the findings.

Results

With respect to the participants with disabilities, the file review revealed that there were approximately equal numbers of men and women ranging in age from 9 to 82, with the vast majority of participants in the age group of 20 to 40 years. 40.6% of participants were living with their parents and 59.4% were living elsewhere. Most participants had a developmental disability (97.7%), but many (63%) also had another disability; commonly reported were psychiatric/mental health (40.3%), physical disability (38%), and autism (18.6%). This study had five major findings.

Network building was an intentional focus of families that had facilitation and individual funding. All sites made network development an "intentional" focus of their work. Sometimes network development was referred to as "support circles" and other times as "personal networks." Of the 54% of participants who had support networks that met regularly, 10.8% met weekly, 27.7% met monthly, 23.1% met bi-monthly and 21.5% met 3-4 times a year.

Most networks met on a regular basis in the early years. In the first year, 73.2% of these networks were "very active" and 18.3% were "somewhat active." Some parents noted, "We now meet when we need to," because "issues change depending on her life situation." For many individuals and families, the support network was put in place prior to the development of the support plan.

The support plan provided a foundation for individuals and families' application for individualized funding. The support plan provided the basis for facilitators and families to determine how much funding for support might be required. An analysis of the goals in the support plans revealed nine categories from the highest – home related (83.6%), to recreation and leisure (73.2%), relationships (71.1%), employment (66.9%), behaviour (59.8%) – to the lowest, education (23.6%). The goals identified within support plans showed that people had a wide variety of needs and interests. These support plans were the result of a collective effort from diverse stakeholders such as the families (100%), facilitators (96.8 %), and the person's informal support network (61.2 %).

Facilitators played a major role in assisting families and individuals. All families who were interviewed were very positive about the importance and helpfulness of their facilitators. One important facilitator role at all four sites was to help individuals and families plan. Sometimes this meant creating a life plan, while other times it meant building meaningful goals with the person and their network. 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."

Facilitators also assisted people to develop and expand their support networks. Typically, one parent said, "Our facilitator helped us define and develop the support circle." Several families expressed appreciation that the facilitator had helped their son or daughter develop a support network and expand relationships.

Finally, facilitators played an ongoing support role for implementation, including "checking in" on a regular basis. Some families called the facilitator their "guide," while others noted that feedback from facilitators often addressed things the family had not considered. Families varied in how often they met with their facilitators. Some families met with the facilitator every second week, while others only met 2-3 times a year. Families all said that their facilitator had a positive relationship with the person being supported.

Individuals and families generally received less funding than they requested, and funding often came from multiple government sources. At all sites, funding required a support plan and a budget. Only 6% of participants asked for more than $100,000. On average, people received about $16,692 less than what was initially requested. Several families we interviewed noted that this initial funding gap was quite challenging for their families. In tracking "amount requested" and "amount received" over four years, however, the difference between these two figures narrowed considerably (year 2 - $8,617, year 3 - $7,846, year 4 - $4,574). Explanations for why the gap decreased over four years included: there were some slight funding increases over the four years for some families; and some families moderated their demands to fit with what they thought they could reasonably receive.

Since there is not as yet an official Ontario individualized funding program for people with developmental disabilities, many people tended to receive their government funding from a variety of sources (one - 48.4%, two - 35.9%, three or

more - 15.6%), including Special Services at Home, Ontario Ministry of Community and Social Services, and Ontario Ministry of Health & Long Term Care.

People experienced a variety of positive outcomes when they had individualized funding and ongoing facilitation. People met most of the goals outlined in their support plans. Many people were able to move away from home (38%), and there was no relationship between "moving away from home" and "amount of funds received" for support. In other words, people with all levels of funding found it possible to move away from home, although several families did indicate that this required a lot of financial and other support from the families themselves. Daily life also improved for many participants, with almost 80 percent going shopping on a regular basis. Many participants found jobs (38.8%) or volunteer work (42.6%). A majority of people attained more relationships (70.5%), expanded networks (65.9%), and made a contribution to their community in some way (62%). 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 parents previously never dreamed possible. Families noted that it was the funding and the ongoing facilitation that made all these things possible.

Recreation and leisure participation was the most impressive outcome. More people were involved in integrated recreation and leisure settings and activities (87.5%) than segregated options (47.7%). On average, people participated in 3.1 integrated community activities, but only .81 segregated activities. People participated in a total of 123 community activities, for an average of 3.1 community activities per person. This broad participation covered the range of leisure participation, from physical activity, the arts, to serious leisure such as reading. Finally, there was

participation in mutual aid groups, such as People First, a group for people with developmental disabilities that focuses on self-advocacy and education about their rights.

The most predominant outcome for families was that of "having control" over the resources for disability supports. Some families said that the combination of facilitation and individualized funding enabled them to "look at life in a different way." Many families talked about how individualized funding enabled them to build more creative supports with their son or daughter. Many of the individual outcomes were in fact about building capacity of the person's skills, networks, and community connections. It was clear from this study that families had also built their capacity to help their family member build a life in the community.

In response to a question about the limitations or drawbacks of individualized funding for their families, several families discussed concerns that fell into four main areas. There were frustrations and tiredness with procedures, multiple sources of funding, deadlines, and contracts with scheduling workers. There were also fears and uncertainty about having to re-apply for funding every year. Some families indicated there was not enough money, resulting in things like not being able to go on a holiday or high turnover of staff (low wages, no mileage for the workers). Finally, the funding in most cases was not portable, which limited people's ability to move or to take their money to a different city or agency.

Discussion

The results of this study showed that individualized funding tends to be used by individuals and families in ways that were set out in their support plans. Most people were able to meet the goals they had developed. Families identified

many positive results associated with individualized funding, but did have concerns about some of the procedures and the levels of funding. Further, this study found evidence of increased self-determined choices, purposeful activities, strong social networks, and community participation. Since these outcomes are all determinants of health, it might be assumed that overall individual and family quality of life was enhanced (Laragy, 2004; National Forum on Health, 1998; Pedlar et al., 1999; Renwick, Brown, & Nagler, 1998).

Facilitation in this study was an important component of individualized funding (Bartnik & Psaila-Savona, 2003). At all four sites, facilitators participated with families and individuals by providing information, engaging people in the process of planning, developing goals and a support plan based on the dreams and interests of the person, developing a plan for funding, helping people build networks of support, and serving as a "touchstone" for families in their journey to build a life in their communities. Families understood the importance of having someone independent of the family and services in this journey. Families appreciated that facilitators were more than planners and were very creative in a variety of areas. It was clear from these four sites that facilitators can be effective when they are supporting a reasonable number of individuals and families.

None of the sites have all the components of a fully fledged "new paradigm" approach in place. For example, the struggle that some families experienced with "finding workers" may be attributed to the limited infrastructure supports available to families. The paradox is that one of the often stated benefits of individualized funding is that individuals and families have control over things such as the kind of support workers hired and the roles

of workers (Williams et al., 2003). It is no doubt challenging for these sites to address all these kinds of issues in the absence of policy. These are issues that demand effective, coherent provincial policy (Dowson & Salisbury, 2002).

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, these projects can serve as "development sites" for the entire province. The challenge for provincial transformation will be to figure out how to move from small pockets of innovation to system wide innovation where a greater number of people have access to individualized funding and facilitation. Other jurisdictions have found that it is important to have a coherent framework based on values and principles and a clear understanding of the importance of separate functions, such as independent planning and facilitation (Bartnik & Psaila-Savona, 2003; Individualized Funding Coalition for Ontario, 2007; Salisbury & Woollard, 2007). This study is consistent with a growing body of research that shows that people receiving individualized funding have better outcomes and more control over important aspects of their lives (Stainton & Boyce, 2004). Although there is clearly a role for greater research, Ontario policy makers are fortunate to have some very constructive projects provincially, nationally, and internationally from which to learn.

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Ontario Association on Developmental Disabilities

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