

# **Framework for Individualized Funding**

## **Individualized Funding: Background**

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## Individualized Funding: Backgrounder

### Table of contents:

<b>Introduction</b>	page 1
<b>Overview of Individualized Funding</b>	page 2
<b>Common Terminology and Equivalent</b>	page 3
<b>Specific models of IF</b>	page 6
1. <u>Individualized Funding – CLBC</u>	page 6
2. <u>Individualized funding – Alberta</u>	page 6
3. <u>Vela Microboards (BC)</u>	page 7
4. <u>In the Company of Friends (MB)</u>	page 7
5. <u>Direct payments (UK)</u>	page 8
6. <u>Individualized budgets (UK)</u>	page 9
7. <u>Local Area Coordination (Australia)</u>	page 10
8. <u>Self-determination (USA)</u>	page 11
9. <u>Cash and Counseling (USA)</u>	page 12
<b>Problems or issues</b>	page 13
<b>Reference list</b>	page 17

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### **Introduction**

Individualized funding, also known as self-managed care or funding, direct payments, Vela microboards and self-determination, is a relatively recent funding mechanism for providing supports and resources to people who are reliant upon publicly administered programs for health recovery, long-term or residential care, employment, day activities, or other publicly recognized social programs. Individualized funding initiatives exist internationally and across Canada under the guise of several different models and approaches. This document will identify the structures of these major models, and some of the problems or issues associated with individualized funding models.

Proponents and advocates for the use of individualized funding (IF) are strongly associated with the rights movement; indeed, the principle of self-determination is soundly entrenched in international and national human rights laws (e.g., Universal Declaration of Human Rights; International Covenant on Civil and Political Rights; International Covenant on Economic, Social and Cultural Rights; Convention on the Rights of Persons with Disabilities; Canadian Charter of Rights and Freedoms). In both the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights (incidentally these have been signed and ratified by Canada); the fundamental principle which lends support to IF and self-managed care is contained in the first Article:

All peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.

In the newly signed, but yet to be ratified, Convention on the Rights of Persons with Disabilities, Article 3(a) states the general principle of “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons.” Autonomy, freedom of decision-making and independence

## **Individualized Funding: Background**

are principles subscribed to by those advocating for a more broadly based utilization of IF in publicly administered chronic health and social services.

### **Overview of Individualized Funding**

Although there are many models of IF, each with its own terminology and specific guidelines which seems to obfuscate rather than illuminate (see Turnbull & Turnbull, 2006), there is a basic structure to IF with elements which are common to all models.

The principal components or key elements of IF include:

- a. Funding allocated to the individual (i.e., not to groups or agencies).
- b. Initial application and eligibility determination.
- c. Financial assessment or means testing (i.e., to identify the individual's charges or contribution to cost of plan).
- d. A system for financial administration, oversight and evaluation.
- e. Identification of the broad parameters or types of support/service areas (e.g., personal care supports, residential, employment) for the use of the funding.
- f. Formation of a personal support network.
- g. Identification of funding limits.
- h. Assessment or identification of needs and available resources.
- i. Personalized support plan.
- j. Approval of plan and the level of financial support.
- k. Negotiate and finalize the individualized contract.
- l. Funding allocation methods.
- m. Support network, including staffing mechanisms, for the utilization of the funds.
- n. Accountability guidelines (i.e., monitoring mechanisms) for the use of public funds and the protection of the person (i.e., risk management).
- o. Appeal or conflict resolution mechanisms.
- p. Review, audit, and evaluation processes.

## **Individualized Funding: Background**

### **Common Terminology and Equivalents**

Before presenting an overview of the specific IF models, a glossary (in the order of the above components, non-alphabetical) of the terminology with an indication of equivalent terms (listed below each section) will facilitate the identification of commonalities amongst the models.

- A.** Individualized funding – public funding provided directly to the person, or their support team, to enable the attainment of their goals and aspirations. (Duffy, 2007)
  - i.** Self-managed funding/Self-directed care
  - ii.** Direct payments (UK)
  - iii.** Vela microboards
  - iv.** Self-determination
  - v.** Cash and counseling
  - vi.** In the Company of Friends (Manitoba)
  - vii.** Individualized budgets/In Control Programme (UK)
  - viii.** Brokerage programs
  
- B.** Governance – the provincial government department or legislated authority responsible for the administration and delivery of the IF program and services.
  - i.** Local authorities (Note: This is a UK term and is equivalent to civic or municipal governments in Canada)
  - ii.** Purchasing authorities
  - iii.** Trusts
  - iv.** Social worker or case manager
  - v.** Legislated community based authority (e.g., Saskatchewan Health Authorities, Community Living British Columbia)
  
- C.** Support team – the people, consisting of families, volunteers, advocates, and/or agencies, who provide direct support to the person to obtain relevant program information, to contribute details to the assessment process, to guide and support the planning process, to participate in the budget negotiation, to assist in the employment and training of personal support staff, to assist with the use and administration of the funding, to participate in review processes, and to support the person in the attainment of their goals.
  - i.** Families or trusted advisers
  - ii.** Personal support network
  - iii.** Fiscal intermediaries
  - iv.** Service brokers
  - v.** Microboards
  - vi.** Living in Friendship Everyday Inc (LIFE) (MB)
  - vii.** Advocacy organizations
  - viii.** Independent agencies
  - ix.** Support organizations (Scotland)
  
- D.** Facilitators – government or agency staff who assist the support team with the assessment and planning processes, link the person and their support team to



## **Individualized Funding: Background**

- H.** Individual budgets – Negotiations take place in relation to how much funding will be provided to meet the costs identified in the individual plan. Most jurisdictions utilize the assessment to set the limits on the amount of funds available. Additionally some jurisdictions will hold back a percentage of the funding to cover off crises or unexpected events. The funds are usually paid out on a monthly basis into an account managed by the person, their support team, or a community agency which has a responsibility to fund the supports.
  - i.** Cash payments
- I.** Staff – Unless the funding is used to purchase all the services on a contractual basis from community agencies (Note: This is the model used for many of the individualized funding arrangements in Alberta and Manitoba.), most individual plans require the hiring of staff to provide or assist in the attainment of the goals. Although some jurisdictions allow funding to go to the close relatives of the person, there is still a need for the person and/or their support team to act in an employer-employee relationship with support workers. This includes recruitment, orientation and training, monitoring work performance, and managing payroll functions. Workforce development is a critical element of individualized funding.
  - i.** Personal assistants
  - ii.** Personal support workers
  - iii.** Self-employment contractors
  - iv.** Direct support professionals
- J.** Accountability mechanisms need to be identified prior to the implementation of an individualized funding system. In the UK, a branch of government, the Commission for Social Care Inspection, carries the responsibility for ensuring that direct payments are utilized as intended. Since the recipients of the government funding are individuals, it is important to utilize a ‘light touch’ monitoring system in order to avoid onerous and overly bureaucratic reporting requirements.
  - i.** Risk management procedures
  - ii.** Audits

## Individualized Funding: Background

### Specific models of IF

( Note: Only a brief overview will be provided of the following models since more extensive documentation is identified in this document and the references.)

#### 1. Individualized Funding – CLBC

In British Columbia, services for people with developmental disabilities were devolved from the provincial government in 2005 to a community board authority, Community Living British Columbia (CLBC). One of the plans of the CLBC has been to convert many of its funding supports to individualized funding. However this transition is being carried out on a voluntary basis and currently consists of a low percentage of the total caseload of over 20,000 children and adults.

In its model for IF, families and/or trusted advisers, together with CLBC Facilitators (if requested), support the person in developing an Individual Support Plan to identify personal goals, the support required to attain those goals, other sources of funding and/or supports which are currently available (e.g., trusts, community and generic resources, financial contribution from the family), the specific service and funding request, plans for crisis management, and additional information including a profile of the person. CLBC facilitators also provide information, advice and practical information for the attainment of the support plans.

Once completed the Individual Support Plan is submitted to the CLBC Quality Service Analyst who is responsible to confirm eligibility for individualized funding and to identify the amount of funding that will be allocated. Whereas the CLBC Facilitators are decentralized throughout the BC regions, the CLBC Quality Service Analyst is a centralized function which is carried out separate from those involved with the planning. Priorities on funding include addressing health and safety risks, enabling individuals to move into less costly residential options, and to promote cost neutrality or reductions. Funding, once approved, is released to a fiscal intermediary. It is not clear from the literature reviewed whether the fiscal intermediary is a volunteer board or a community agency.

#### 2. Individualized funding – Alberta

Many funding arrangements in Alberta for adults with developmental disabilities are managed through individualized funding, although there are still several community NGOs which are funded directly through Contract Funding. While there are a number of examples (see <http://www.pdd.org/ourstories/default.shtml>) of the successful use of IF in Alberta, this is not generally the norm and most of the IF is directed to service organizations on an individual contract basis.

Since planning and funding is done on an individual basis according to the Principles for Determining Individual Support Needs (see CLD Jurisdictional Project, Blackman, 2004), there are no requirements for an assessment process to identify the needs. Funding is not capped; the individual's needs and plans are used to determine the level of funding. Funding arrangements enable flexible resources: home living supports, community living supports, employment, community access, specialized supports, and administrative supports. Although there is no cap on the funding, in 2002-2003, the median average monthly cost of support per adult client was \$4,027. Additionally, adults with disabilities are eligible for AISH funding with a maximum monthly living allowance of \$1,050.

## Individualized Funding: Background

More details on the Alberta system for people with developmental disabilities are available in the PDD 2005-2006/2007-2008 PDD Business Plan ([http://www.pdd.org/docs/prov/BusinessPlan\\_2005-06.pdf](http://www.pdd.org/docs/prov/BusinessPlan_2005-06.pdf) ).

3. Vela Microboards (BC) (see <http://www.microboard.org/>)

Vela is a non-profit society originally formed to offer subsidized housing to people with developmental challenges in the Greater Vancouver area of British Columbia.

A Vela Microboard is formed when a small group (micro) of committed family and friends join together with a person with challenges to create a non-profit society (board). Together this small group of people addresses the person's planning and support needs in an empowering and customized fashion. A Vela Microboard comes out of the person centered planning philosophy and is therefore created for the sole support of one individual. The Microboard's purpose is to ensure that the individual becomes a part of the fabric of community, thus safeguarding that person's future.

Vela Microboards provide the structure for the use of IF supports in that any funding can be paid to the microboard in support of the person. It should be noted that of the 450 Vela Microboards in British Columbia only about 80 are supported by IF.

4. In the Company of Friends (MB) (see <http://icof-life.ca> )

In the Manitoba program, In the Company of Friends (ICOF), funding is provided according to submitted budgets as approved by the Manitoba Family Services and Housing (FSH) to enable persons to become well connected and to participate in their communities. In 2006, the program served 47 individuals in 19 communities throughout Manitoba.

Living in Friendship Everyday Inc (LIFE) is a resource agency that was developed in August of 2000 to provide resource support to individuals involved with the ICOF and their support networks. Technical resource staff offer information, resources, training, ideas, and direction. Additionally they help the person and their support network to develop a budget based on specific needs and desires and assist with plans which focus on relationships, strengths, personal growth, dreams, needs and spiritual, emotional and physical well being.

The use of support networks is an integral part of the design of ICOF, and as such is not optional. Support networks provide assistance in decisions, the hiring of support staff, planning for the future, managing finances, and connecting to other people and resources. LIFE expects the person and their support network to work within the framework of the program, its philosophy, and objectives.

A planning tool, Planning Alternative Tomorrows with Hope (PATH), is used annually to create a vision and goals according to the principles of the Vulnerable Person's Living with a Mental Disability Act (1996). The budget that is developed on the basis of this plan with assistance from the Technical Resource staff and the support network gets submitted to FSH for prioritization and approval. If participants already receive money through FSH and it is comparable to the budget that was developed, the approval process can be expedited.

## Individualized Funding: Background

Through ICOF, participants receive a monthly cheque, based upon the established budget with a certain amount of flexibility, to purchase daily living and staff support needs. The recipient or a member of the support network is required to submit quarterly financial reports which show income and expenses, as well as the current bank account balance(s) and any investments to ensure budget suitability and for accountability. If reports are not received regularly funding may be affected.

Participants of ICOF are eligible for a one-time payment of up to \$2000.00 when they join the program. This money is intended to assist with the purchase of necessary furnishings and household items. This request is submitted along with the budget.

Any income over \$100.00 monthly in gross earnings must be reported. The formula used is: the first \$100.00 in gross earnings plus one-third of the remaining gross income can be kept. The remaining two-thirds of gross income is factored against the funding received.

Getting started under ICOF is not easy and requires an effective support network. The participant or their support network will have to set up as a business (to pay employees), obtain Worker's Compensation coverage, apply for a medical benefits plan, and establish a payroll system. Additional staffing functions include interviewing, and establishing job requirements and descriptions as well as employee agreements.

5. Direct payments (UK) (For more information see <http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Financeandplanning/Directpayments/index.htm>)

Direct payments are cash payments given to service users in lieu of community care services they have been assessed as needing, and are intended to give users greater choice in their care.

Assessment of need is no longer about to which service a person should be referred, but about individualizing the support a person can receive. For anyone seeking any care service this starts with the single shared assessment (SSA) which should include some self-assessment work. One professional carries out the assessment with the individual, often with contributions from other professionals and carers, and results are shared with all those who have an interest to avoid the need for several professionals to undertake separate assessments. In the self-assessment process, individuals are encouraged to consider for themselves what care and support they might need.

Payments are given to individuals so that they can organize and pay for the social care services they need, rather than using the services offered by their local authority or council. The payment must be sufficient to enable the service user to purchase services to meet their needs, and must be spent on services that users need. Direct payments increase people's independence and choice by giving them control over the way the services they receive are delivered. There is now a duty on councils to make Direct payments available to people who want them.

Like commissioned care, they are means-tested so that, in many cases, people will contribute to the cost of their care.

Direct payments confer responsibilities on recipients to employ people or commission services for themselves. They take on all the responsibilities of an

## Individualized Funding: Background

employer, such as payroll, meeting minimum wage and other legislative requirements and establishing contracts of employment. Some of these services can be contracted out and many councils have commissioned support organizations to help service users handle these responsibilities.

In the current social care system, direct payments generally involve the transfer of funds into an individual's bank account by the local authority. There are some exceptions such as the use of trusts and third party organizations. What is important is that there is a transparent allocation of resources to the individual based on an assessment of need and that the individual is able to control how the resources are used, if not the money itself.

Direct payments can buy support for a person to live in their own home, such as having a bath or getting washed and dressed. Out of the home it could be to support an individual in college, or to enjoy leisure pursuits more. It may also be used to pay for someone to provide care and support to enable them to take a short break with the person. In summary, it is an opportunity to meet the assessed needs of the whole person in creative and flexible ways.

Take-up of direct payments has risen significantly in recent years but still remains low as a proportion of people receiving services. As of March 31, 2006, 32,000 adults and older people in England were receiving a direct payment, up from 22,100 the previous year. In Scotland, payments rose from 1438 to 1829 between 2005 and 2006. However, just two per cent of the 650,000 eligible older people in England were receiving a payment in March 2006. In Scotland during 2006, there were 424 people with learning disabilities who received direct payments. (This is out of a total of 18,000 to 20,000 people with learning disabilities in Scotland.)

While savings were made through service users taking responsibility from care managers for funding and administering care, the research found that these were more than offset by the costs of supporting users (e.g., higher regulatory costs, providing advice and guidance) and providing training to council staff (Audit Commission, 2006 in Samuel, 2007). The costs per user of implementing direct payments ranged from a low of \$400 in a rural setting to a high of over \$3,500 in a suburb of London (Audit Commission, 2006 (**Note some useful content in:** Appendix 2: Illustrative good practice from our case study sites. Full case studies can be found at [www.audit-commission.gov.uk](http://www.audit-commission.gov.uk) ).

(**Note:** The document, Direct Payments For Self-Directed Care: Draft Policy and Practice Guidance (Sept., 2006), from the Scottish Executive provides the new draft guidance on direct payments. Once finally approved the new guidance will be issued under Section 5(1) of the Social Work (Scotland) Act 1968 and will replace the earlier policy. (see <http://www.scotland.gov.uk/Publications/2006/09/28113843/0> ) )

6. Individualized budgets (UK) (see <http://individualbudgets.csip.org.uk/index.jsp> <http://www.ncil.org.uk/individual-budgets.asp> [http://www.in-control.org.uk/home/index\\_sc.php](http://www.in-control.org.uk/home/index_sc.php) for more information)

Individual Budgets are an outgrowth of the Direct Payment scheme. Individual budgets differ in two respects from direct payments. First, they go beyond social care, to cover Supporting People, Disabled Facilities Grant, Independent Living Fund, Access to Work and community equipment services. And second they set an overall

## Individualized Funding: Background

budget for all of these services, which users can choose to take as cash payments, services, or a mixture of both. Where an individual's support needs are extremely complex, a budget can be used to purchase case management, the difference being that the case manager is employed by the individual not an agency and must, therefore, respond to his or her needs.

Individual budgets were first proposed in January 2005 in a paper by the Prime Minister's Strategy Unit, and seen as a way of personalizing services. However, at the time a similar idea was already being piloted by the In Control Programme, which was set up in 2003 by Mencap and the Department of Health's Valuing People Support Team and initially targeted at people with learning difficulties.

In Control is based on allocating a budget to an individual, on a self-assessment of their care needs, and enables them to choose the best mix of services and/or cash to suit their needs or wishes.

The Department of Health established pilots, due to conclude in 2008, of Individual Budgets in 13 councils. The pilots are receiving support from a team from the DH's Care Services Improvement Partnership and people who have been involved with the In Control scheme. The pilots are also being evaluated by a team from the Personal Social Services Research Unit, York University's social policy research unit and King's College London's social care workforce research unit.

Care managers usually consider multiple funding streams to make up the individual budget (IB) to meet a person's assessed support needs. Besides the local authority care budget, funding for equipment and temporary adaptations and Supporting People, there may be Free Personal Care, the Independent Living Fund, Access to Work, Disabled Students Allowance (SAAS), Disability Living Allowance (DLA), Carer's Allowance (CA) and health monies to meet continuing health needs. The funds are combined within one bank account and monitoring done as a whole. The care manager is best placed to perform this brokering function as the process is integral to assessment. Their skills and creativity helps them know about an individual's aspirations and wishes, work with them through times of change and help them attain choice and control.

7. Local Area Coordination (Australia) (for more details, see <http://www.disability.qld.gov.au/publications/#support> )

This is an approach for supporting people with a disability and their families living in local communities. The local area coordinator works to facilitate positive changes that assist people with a disability live and participate in the community and assist families and their continued provision of care.

Within Local Area Coordination, a basic principle of providing funding support is that this should complement and strengthen, not replace, the support provided by families, communities and natural caring relationships. Funding is a strategy of last resort, used only when the extent and level of need is unable to be met in any other way. Funding when available is directly managed by individuals or families who purchase services and supports within their local community. Two types of funding are available: untied and tied. Untied comes from the budgets of the local area coordinator and is intended for one-time funding only. Tied funding links to government funding that may be available to people with disabilities (e.g., adult

## Individualized Funding: Background

lifestyle support funding, moving ahead post-school options funding, family support funding).

In the Australia Disability Services Queensland 2001 publication, *Essential Elements of Local Area Coordination*, the final point emphasizes that “funding of individuals and families is a strategy of last resort.” This means that Local Area Coordination is primarily a support mechanism and not a funding system.

8. Self-determination (USA) (see <http://www.self-determination.com/> <http://www.selfdetermined.org/> or [http://www.self-determination.com/articles/tash03\\_04\\_2005.pdf](http://www.self-determination.com/articles/tash03_04_2005.pdf) )

The Robert Wood Johnson Foundation funded the first demonstration project on self-determination (the term here refers to self-determination funding) at Monadnock Developmental Services in New Hampshire (Turnbull & Turnbull, 2006). This model focused on the development of individual budgets for adults with disabilities that were developed and implemented through the process of person-centered planning.

The Self Determination initiative was a nineteen state demonstration that aimed to give individuals with developmental disabilities and their families greater control over the services they received. Funded by the Robert Wood Johnson Foundation, it began in New Hampshire in 1993 and was subsequently extended to cover initiatives in eighteen other states. Since these original demonstrations, regulatory changes have meant that consumer-direction can be pursued through various routes and many states now have programs that serve a small proportion of the eligible population.

Many states and local areas have policies and practices that enable individuals, with support from family and friends to exercise control over their services as well as the Medicaid funds allocated for their services. Exercising control over services and funding usually includes developing a person-centered plan, developing a budget and spending plan, serving as the employer of record (recruiting, hiring, supervising and scheduling support staff), identifying and purchasing needed goods and services, and working with a support team which usually includes a case manager, support broker, fiscal intermediary, and family and friends.

The diversity of goods and services purchased under consumer-directed programs does not mean that consumers can use their money any way they please. Most programs have a list of prohibited goods and services. Other items have to be approved, most often by the individual’s counselor or support broker. Where the counselor is in doubt, the decision will be referred to a higher level, for example to the county or state, and the individual will be expected to justify how a particular purchase supports his or her long term care needs. (Alakeson, 2007)

It should be noted that Self-Determination isn’t available in all states nor are the policies and structure the same. In a 2005 TASH report, several problems were identified with this system: difficult to implement; labour intensive at the personal and family level; state pre-determined individual budget allocations; confusing terminology and rhetoric; complicated and dissimilar structures; insufficient quality control for health and safety of the users; and severe programmatic issues with the USA Medicaid system.

Currently, the Center for Self-Determination (CSD) and the Centers for Medicare & Medicaid Services (CMS) are collaborating on an exciting new project to advance

## Individualized Funding: Background

the philosophy and implementation of self-determination. With an Advisory Group providing input, CSD/CMS will jointly develop a resource guide for State Medicaid Agencies and Medicaid programs serving all disabilities and aging. This guide will include elements such as how self-determination can foster independent living in the community, best practices of programs already incorporating self-determination, challenges States have faced in designing and implementing self-determination-focused programs, and how self-determination can be funded under the Medicaid statutory and regulatory framework. It will also include sections on rethinking quality and income and asset development to overcome the effects of personal impoverishment. (see [www.self-determination.com](http://www.self-determination.com))

9. Cash and Counseling (USA) (see [www.cashandcounseling.org](http://www.cashandcounseling.org) )

Cash & Counseling is a national program sponsored by The Robert Wood Johnson Foundation, the Office of the Assistant Secretary for Planning and Evaluation in the United States Department of Health and Human Services, and the Administration on Aging. In addition, the Centers for Medicare and Medicaid Services (CMS) reviews states' home and community based services (HCBS) waiver program applications and provides continuing oversight and technical assistance in the waiver process. Recently the CMS has introduced the Independence Plus Program to support self-directed services.

The Cash & Counseling approach provides a flexible monthly allowance to recipients of Medicaid personal care services or home and community based services. Participants use an individualized budget to make choices about the services they receive and they are able to make sure these services address their own specific needs. In the Cash & Counseling program, the participant, instead of an agency, decides who to hire and what services they would like to receive. Participants also have the option of using their budget to purchase labor saving devices or to make home modifications to help them live independently. In addition, this innovative program offers counseling and fiscal assistance to help consumers manage their allowance and responsibilities by themselves or with the aid of a representative. These main features are adaptable to consumers of all ages with various types of disabilities and illnesses. Cash & Counseling intends to increase consumer satisfaction, quality, and efficiency in the provision of personal assistance services. (<http://www.cashandcounseling.org/about> )

## **Individualized Funding: Background**

### **Problems or Issues Associated with Individualized Funding**

Many benefits have been attributed to IF, including: person-centered planning; freedom over one's life and goals (i.e., self-determination); the person together with their support network, if necessary, directly manages their own funding to develop and/or purchase the services to achieve their goals; a greater reliance upon natural supports and generic services; avoidance of trying to fit the individuals into groups with whom they are incompatible; ability to structure the necessary supports around the person, especially for those with challenging behaviors; promotion of integration and full inclusion of the person within their community; responsibility for success or failure assigned to the individual and their support network; creative programmatic solutions; and potential cost reductions and/or benefits.

In their newsletters and publications, proponents of IF cite many successful case examples. According to a report done for the Canadian Labour Congress (2000), "studies have tended to be case studies utilizing anecdotal evidence and may be biased to reporting favourable accounts." Very limited systematic research was located which studied the overall quality, benefits, and deficits associated with self-managed funding and services. One study which promises to be useful with its report to be released in December, 2007 is being conducted by the University of New South Wales on the outcomes associated with a pilot program into Australia on direct funding for attendant care (Fisher, Anderson & Muir, 2007).

Nevertheless several problems and issues have been identified concerning self-managed funding and services for which, especially for vulnerable people, adequate solutions have not been developed thus resulting in compensatory measures which differ amongst the jurisdictions which offer IF programs.

#### **1. Philosophical/political issues**

Many proponents of IF view it as the total service delivery system versus just one part of the continuum of services. Much of the literature by advocacy organizations promotes the use of self-managed funding as the sole mechanism to provide programs and services for the individuals who require these public supports. Because of their philosophy on this funding, there is an emphasis on the total overhaul of the way publicly administered supports and services are offered. This has produced a strong counter-reaction from community organizations and agencies, government officials, and professionals. As such, much resistance has developed towards the introduction of any form of IF.

One of the problems of a total reliance upon IF is that it eliminates alternate services for individuals and/or families who are either not interested or not capable in using self-managed funding and services. IF is not suitable for everyone.

In reality, and officially in Scotland, IF is presented in all jurisdictions as one of the many systems to provide the services and supports to individuals.

#### **2. Quality and Risk management**

Protection of the users and of the funding are crucial elements of IF programs. Of concern is the victimization of the individual through theft, intimidation, and mismanagement of funding and the fraudulent misuse of the IF.

For those users who directly self-manage their funding, appropriate controls are required to prevent the victimization of the person and the unscrupulous use of their

## Individualized Funding: Background

funds. These can include the use of direct deposits, debit withdrawal limits, and other forms of banking controls. Such issues are vastly reduced when the IF is paid directly to contracted service providers.

In a 2004 study for the BC Ministry of Children and Family Development, the Internal Audit and Advisory Services identified three risks for funding misuse: some families may lack the capacity to manage funds and/or treatment; expectations for the families may not be clear; and some families might misuse program funding. It was ascertained that there was a widespread lack of compliance with program accountability requirements and that several instances occurred where funds were being misused. It was noted that families with limited financial resources were particularly challenged by the IF programs. Additionally Ministry staff lacked the time and resources to follow up on these problems.

The BC study noted that the program materials provided very limited information on how to develop and manage programs for the individuals concerned. As a result, choices were being made which had a negative impact on the family well-being and the children's outcomes.

### 3. Support systems

For vulnerable and/or communication-challenged people, the successful use of IF requires a support system or network to assist the individual. Problems arise when there is a lack of committed and/or capable people (i.e., family, relatives, friends, trusted advisors or advocates) who are available to support these individuals. Additional problems occur through the restrictive or patronizing attitudes about the capabilities of people who might use IF.

The onus of supports requires families to increase their engagement with the family member which may be a strain on their personal resources. Family members may not always be prepared to assume responsibility for managing funding or employing caregivers. Similar difficulties occur amongst families and/or other supporters with limited personal resources or finances and/or those for whom English is a second language.

Somewhat related issues concern inadequate support and advocacy services. Those available to provide support to the individual require training and support on person-centered planning, the essential elements of IF, methods to include the individual in their community, methods for crisis management, financial and case management, accountability measures, and access to existing community services. Training materials and educational seminars should be provided in alternate formats and languages.

### 4. Labour market and staffing issues

The successful use of IF is dependent upon the availability of personal support workers. The individual and/or their support network are usually expected to provide such employer functions as the recruitment of qualified staff (this may involve the employment of relatives); orientation and training; scheduling; retention of staff including benefits and employee perks; performance management; payroll functions; termination; and other management responsibilities (e.g., documentation). Often there is a high turnover of staff as a result of high expectations, low remuneration, and applicants being drawn into other areas of work. Prospective staff want proper

## Individualized Funding: Background

employment conditions, which recognize their needs and rights and suitable opportunities to develop their skills and competencies.

### 5. Devolution

Concerns expressed by unions and community agencies are that the market-driven nature of individual funding schemes may increase privatization and result in a low wage sector. Historically the introduction of IF programs has been in the midst of government downsizing, budget restrictions, and devolution of services. The proponents of IF have contributed to this problem by their consistent claims that IF models result in cost efficiencies and budget reductions. However this argument has been somewhat circular in that the funding for IF has been based on budgets which are calculated to be less than those provided through community agencies and are highly dependent upon an active personal support network. Additionally the administrative costs and personal contributions from families are typically not considered when calculating the financial efficiencies of IF.

### 6. Assessment

The categorization of people based on limitations and weaknesses produces its own set of issues and has received criticism from the users of IF programs. Rather they recommend the quantification of those supports required for various needs and goal attainment. For example, the creative use of IF to promote self-employment (e.g. (from Alberta), sheep raising, delivery truck driver's training, lawn and garden services) and thus to reduce dependence upon public funding is vastly reduced by basing funding on needs assessments.

An area of assessment that is often missed is that of identifying the capability of a person's family and/or support network to appreciate and manage the complete IF program.

### 7. Accountability measures

Since IF is a publicly administered and funded program, appropriate measures are required to ensure that funding is being utilized for the benefit of the individual and within an accountable framework. However there is a need to avoid complex administrative bureaucracy, restrictive regulations, and overly complex paperwork requirements. A report from the UK (Platt, 2007) stated that auditors need to change their approach from 'you can't do that' to 'this is how'. Such an approach builds capacity amongst the people involved with using and supporting IF programs.

### 8. Knowledge management

Since the introduction of IF models, a plethora of different systems and terminology has arisen with the resultant confusion amongst potential users and/or supporters. There is a lack of clear information on the IF options and requirements. Internet searches using Google resulted in over 21,000 hits for 'individualized funding', over 39,000 hits for 'cash & counseling', over 1 million hits for 'self-determination' including the term, 'funding', and, similarly, over 1 million hits for 'direct payments' including the term, 'UK'. Clearly this results in information overload for people accessing such programs.

This is clearly an issue of promotion and training which governments will need to address. In a recent report to Health Canada, it was noted that in all jurisdictions it proved difficult to access information about self managed care programs (Spalding,

## Individualized Funding: Background

Watkins & Williams, 2006). The problem of accessing relevant information is likely to pose a significant barrier for consumers, particularly those experiencing cognitive, language, or functional challenges.

### 9. Resistance to change

Problems include the reluctance of government administrators and staff to promote IF and patronizing attitudes on the part of staff about the ability of people to manage a direct payment. Additionally there is a reluctance to devolve power away from professionals to the people who use services. To some extent these issues can be addressed through training, education, and promotion.

### 10. Equity

From the experience of direct payments in the UK, there was difficulty ensuring equity of funding amongst different user groups. This results from the use of different assessment methods and through the strength of the various advocacy organizations associated with the users. At issue is the public perception of government programs and services being equally available for all persons.

### 11. Contracted services

In a framework where the majority of community organizations are block-funded directly by government, there may be a lack of commitment by these organizations to provide service on an individual, contractual basis.

### 12. Advocacy supports

Various reports (e.g., Riddell, Priestley, Pearson, Mercer, Barnes, Jolly, & Williams, 2006) from the UK noted that advocacy organizations which became involved with the direct service provision (e.g., support networks, coordination) of IF became less able to carry out their advocacy functions and lost some of their original connectivity to their financial supporters. This matter raises concerns about the sustainability of advocacy supports to users and the ongoing financial stability of such organizations.

## Conclusion

*Reasonable risk is about striking a balance in empowering people who use services to make choices, ensuring that the person has all the information, tailored to their specific needs, in the appropriate form, to make their best decisions. (UK Department of Health, May, 2007)*

## Individualized Funding: Backgrounder

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