Individualized Funding
A Framework for Effective Implementation

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Executive Summary

The *United Nations Convention on the Rights of Persons with Disabilities* notes, as its first principle, "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons".[1] Individualized Funding (IF) represents a significant tool through which to advance the goals and values of the UN Convention and the needs and aspirations of Canadians with disabilities, by providing individuals with more choice and control over their supports and services.

Individualized Funding already exists in six Canadian provinces, as well as in the United States and Australia. The National Individualized Funding Discussion Group has developed this document to support the understanding and development of IF.

Individualized Funding recognizes that funding, services and supports should not define the individual's needs, but should respond to, and be built around them. Further, it recognizes that these needs must be identified by the individual, and not by the professionals around them. Choice and greater control by individuals over the supports and services that are a part of their lives are key aspects of IF.

Key framework elements identified within this report include:

- **Eligibility** - criteria is fair and transparent and is based on disability related support needs.
- **Funding** – is based on a person-directed plan developed by the individual; involves direct payment to the individual (or their designated supporter); is subject to transparent ceilings and guidelines.
- **Planning** – is directed by the individual; planning functions are separate from eligibility, service delivery and funding functions.
- **Supports for Implementation** – a support structure is necessary; it may be informal (Support Circle) or formal (Microboard); supports are distinct from funding, eligibility and assessment processes.
- **Quality and evaluation** – quality standards, safeguards and ongoing evaluation are in place.
- **Accountability** – individuals are accountable; procedures are simple and flexible.

Individualized Funding has been shown to achieve higher levels of satisfaction and enhanced inclusion for people with disabilities.

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1. United Nations, "Convention on the Rights of Persons with Disabilities" http://www.un.org/disabilities/convention/conventionfull.shtml

Plain Language Summary

This paper was written to help families, government and people with disabilities understand what Individualized Funding is, and what we need to do to make it work.

In March, 2010, Canada signed a paper called the *Convention on the Rights of Persons with Disabilities*. Signing the paper means that government agrees with what was said in the paper about people with disabilities. The paper says that people with disabilities:

- Are worthy of respect (when someone is 'worthy' that means they deserve the same respect as any other person).
- Should have the freedom to make choices.
- Have the right to independence.

Sometimes people with disabilities need other people to help them so that they can live the way they choose to live. It is important that the government gives people with disabilities enough money to live as others do in their community. We think the government is responsible for:

- Letting Canadians know that people with disabilities are worthy of respect, have the freedom to make choices and should have the right to independence.
- Guiding Canadians to support people with disabilities through Individualized Funding.
- Teaching and training the groups that get money to help people with disabilities about Individualized Funding.
- Make rules that make Individualized Funding possible.

Individualized Funding is a good way for the government to give people with disabilities money. Right now the government gives money to groups that work with people with disabilities, and the groups decide what kind of help they will give to people with disabilities. When we use Individualized Funding, people decide what kind of help they want and need, and then use the money they are given to hire people or groups to help them. Individualized Funding is already being used in British Columbia, Alberta, Manitoba, Ontario, New Brunswick and Prince Edward Island.

Individualized Funding works when the person with a disability:

- Decides for themselves what they need to live their best life.
- Works with people they choose to help them.
- Writes down a plan about how the money will be used (with help if they need it).
- Gives the plan to the government who then gives the money to the person with the disability.

Individualized Funding works best when:

- People with disabilities know how to apply for the money.
- People with disabilities can get the money no matter where they live.
- The money is used to help the person with disabilities.
- The rules are fair.
- The rules make sense.
- The rules can be changed if they need to be changed.
- The amount of money a person gets depends on their plan.
- A person can ask for the amount of money to be changed if something changes in their life.
- The cost of support is included in the plan.
- People do not have to apply again if they move.
- There is a good plan that is written down.
- The plan includes the names of the people who are helping and what they are doing to help.
- People with disabilities can hire people they know, or a professional to help them.
- The groups that provide the money do not decide how to spend it—that decision is made by the person and the people they choose to help them.
- Family, friends and groups that the person works with are seen as very important.
- The person who is getting Individualized Funding decides if the plan is working for them.
- There are ways to find out if there are problems with the plan and a way to fix problems.
- People who receive Individualized Funding keep track and can prove where the money is spent—with help if help is needed.

People using Individualized Funding may need help to make it work the best way for them. Sometimes people with disabilities need help to:

- Find the right staff people.
- Help with the money and the reports to government.
- Put a group together to help them make a plan.
- Find someone to help with all the parts of Individualized Funding (coordinate).

People who are using Individualized Funding tell us:

- Individualized Funding does not cost any more money than what the government spends now—sometimes it costs less.
- People with disabilities and their families are better able to control what goes on in their lives—they are able to choose the help they want.
- They are more in charge of their homes and community lives.

Individualized Funding helps people with disabilities and their families to take charge of their own lives. In order for Individualized Funding to work, the groups that help people with disabilities need to change too. Individualized Funding needs to happen in a way that will make sure Individualized Funding is available even as people's needs change. It is important that people who get Individualized Funding keep track of the money that is being spent. It is important that the amount of money people get can be used for help they want, even if they are spending it on things that were not funded before. Individualized Funding is an important way for people with disabilities to have choice.

1.0 Introduction

In December 2006, the United Nations (UN) General Assembly adopted the *Convention on the Rights of Persons with Disabilities*. Canada ratified this Convention in March 2010, after securing the agreement of all provinces and territories. By adopting this important Convention, Canada acknowledges the importance of "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons."

These rights must be honoured if people with disabilities are to be fully included and valued as citizens in the relationships and opportunities that are central to community life. However, many people with disabilities and their families who support them often require a variety of personal supports or other services to help ensure their full citizenship and inclusion. These supports and services must be funded and provided at a level and in a manner that upholds individual rights.

Individualized Funding (IF) represents a significant tool through which to advance the goals and values of the UN Convention, and the needs and aspirations of Canadians with disabilities.

IF is a mechanism that people with disabilities (and their families) can use to exert increased control over the variety of supports and services they require to live inclusive lives in their communities. IF is not a new concept; it has been in place in Canada (albeit in a limited manner) and in other parts of the world for more than 30 years. IF is a mechanism that is highly valued by people with disabilities and families, and is associated with higher levels of autonomy, independence and social participation.

Despite its demonstrated value, IF has not been fully embraced within mainstream disability policy frameworks in Canada. It remains a model that is not well understood by policy makers, service providers, and people with disabilities and families. To further complicate the issue, current funding mechanisms that are referred to as IF are often not comprehensive and fail to meet known standards for successful implementation.

This document has been created by the *National Individualized Funding Discussion Group*, a group of family members, professionals and academics who have come together to foster the further understanding, development and implementation of Individualized Funding in Canada for persons with disabilities and their families. This Framework is meant to outline the key elements required for the successful development and implementation of IF.
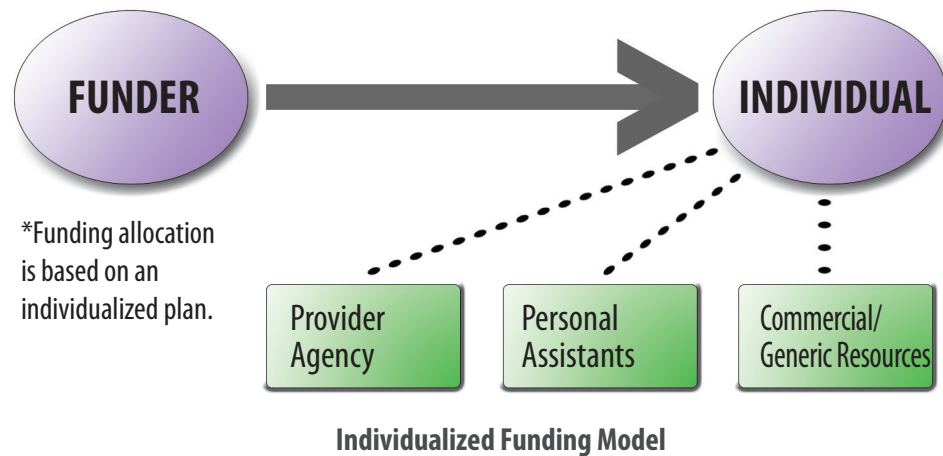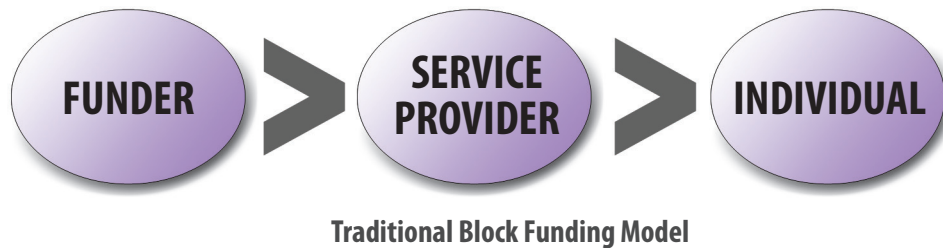
The Discussion Group hopes this document will be a useful resource for:

- All levels of government wishing to pursue policy development and implementation of individualized funding;
- Service providers and community organizations interested in IF policies and practices, and;
- Individuals and families interested in individualized funding as an option.

Individualized Funding's use starts with the reality of day-to-day lives; it recognizes that funding, services, and supports should not define the individual's needs, but should respond to, and be built around them. Further, IF recognizes that these needs must be identified by the individual, not by the professionals around them. No single element of this framework is sufficient to bring about change. Only when full consideration is given to all the necessary design and delivery elements will IF fully enable individual/family control, and lead to significant improvement to people's lives.

There are several definitions of Individualized Funding. Most generally, it describes a payment mechanism in which an individual identifies their needs and presents an outline of the needs, including how the needs can be met in the community (a plan) to a funding body (typically government). This is the only funding model that ensures that all requested funding goes directly to the end user. It is a demand-side funding mechanism, which enables individuals to have significant control over the public funds that are allocated for their disability-related support needs. Policy frameworks that enable Individualized Funding are currently in place in many locations around the world. British Columbia, Alberta, Manitoba, Ontario, New Brunswick and Prince Edward Island have established IF policies and practices.

The diagrams below outline the differences between traditional block funding for services and Individualized Funding. With block funded services, government (as the funder) has a direct contractual relationship with service providers, which deliver services to people on the basis of a defined program. Individualized Funding changes the relationship with the person receiving the services. Through IF, government has a direct contractual relationship with individuals who choose the services (and service providers) they want and need.

FUNDER > **SERVICE PROVIDER** > **INDIVIDUAL**

Traditional Block Funding Model

FUNDER ➜ **INDIVIDUAL**

*Funding allocation is based on an individualized plan.

| Provider Agency | Personal Assistants | Commercial/ Generic Resources |

Individualized Funding Model

2.0 Core Principles of Individualized Funding

- Self-determination is necessary for full participation and inclusion in society. All individuals have capacity for self-determination.
- Quality of life is enhanced when people with a disability are in control of needed supports and services.
- Supports are person-directed, comprehensive, flexible, responsive and reflective of what a person envisions for their life.
- The role of family, friends, and support networks in providing support to the individual is recognized and given legitimate status.

The following framework elements have been demonstrated to be essential to successful implementation based on evidence and learning from a number of jurisdictions (both nationally and internationally) in which individualized funding was used as a key mechanism to achieve increased personal control, enhanced individual outcomes, and as a catalyst for larger systems change. These elements are foundational to effective

implementation. Therefore it is imperative that the core principals of IF remain the same across provinces and territories. It is, however, acknowledged that jurisdictions will differ in practice and delivery.

2.1 Eligibility

Disability is the consequence of people's attitudes and the way society is organized (the 'social' model), not the inevitable result of the individual's impairment (the 'medical' model). Unfortunately, rules that currently govern access to personal supports are based on the medical model, which creates problems for Canadians with disabilities. Eligibility criteria often keep people out of the system rather than ensure that they receive the goods and services they need. Accordingly, eligibility for individualized funding must strive to be based on these criteria:

- Fairness and transparency;
- The disability-related support needs individuals have that impede their ability to pursue their citizenship goals;
- Universally available to all eligible individuals;
- People with disabilities play a central role in articulating their needs, and;
- Eligibility should not be contingent on any real or perceived notion that a person is unable to administer the funding.

2.2 Funding

- Funding is designed to meet the individual's specific disability-related support needs, as well as personal goals for a good life in the community.
- Funding is determined based on a person-directed plan, in which the needs, goals and circumstances are identified by the individual themselves, not by professionals.
- Funding is provided as a direct payment to the individual with a disability. If the individual and/or their network so chooses, the payment may go to another person or organization who would administer the funding on behalf of the individual with a disability.
- Funding is based on an individualized budget.
- Individuals can choose any reasonable options within general policy and funding parameters.
- Funding may be subject to 'ceilings' as determined by each jurisdiction.
- Established ceilings reflect reasonable costs required to meet identified needs and goals in a number of life areas.
- Ability exists to negotiate beyond established maximums, if required funding level falls outside the established ceiling.
- Funding ceilings and guidelines are transparent.

- Individuals have the ability to reallocate funds within the approved budget and accumulate funds (to an identified limit).
- Funding for necessary administration and/or management purposes are contained in each personal budget.
- Funding is portable within and across jurisdictions.
- Individuals have the ability to renegotiate funding as their circumstances change.

2.3 Planning

Planning provides the foundation for each person to identify their strengths, interests and goals, including the supports required to achieve the life they envision. A good plan reflects the individual's needs and goals, and has flexibility to allow for changing needs and circumstances. When the individual is in charge of the planning process, they are able to define what a 'good life' means, and how it should be achieved. Planning also helps to identify the key roles that individuals, families and personal networks, communities, governments and service providers can play in developing or providing opportunities for a good life in the community.

To be effective, personal planning must:

- Be directed by the person;
- Be separate from the eligibility, service delivery and funding functions;
- At the discretion of the individual, be facilitated by an external neutral party who is knowledgeable about the options and supports available to the individual they are supporting, and who is able to guide the process. This external party might be asked to help in the development of plans and budgets, to provide information, or to assist people to find, purchase or create supports required to help build relationships, and;
- Be available to the individual as needed over time.

To carry out successful planning, the individual must have access to the needed supports to direct their plan, such as brokerage or facilitation services.

2.4 Supports for Implementation

- Individualized Funding requires a support structure to ensure its effective implementation.
- Supports may include: assisting the individual to recruit, screen and hire their staff; assistance with financial management and reporting procedures; and assistance with financial accountability requirements.
- Supports available for the administration of funding are separate from the funder and service system.

- Support as provided by family, friends and support networks is recognized as essential to helping guide the individual through the process.
- Support networks can come in different forms and may be informal (e.g., Support Circles) or formal (e.g., Microboards).
- Facilitation support (if required) is available to help guide and plan with the individual and ensure the individual's decisions are followed through on.
- Personal supports are distinct from the roles of the funding agency and the people involved in the assessment and eligibility process.
- Choice as to administrative, financial and management supports and procedures are vested with the individual (or their support network).
- Some individuals will choose to hire their own support staff; they may also choose to handle the administration of their plan on their own.
- Other individuals may choose to receive this support through brokerage or coordination services.

In an IF approach, government has a responsibility to:

- Promote self-determination, community capacity and inclusion through policies which support these principles;
- Provide education and training to support the concept and implementation of IF at the bureaucratic, service provider and agency levels, and;
- Create strong policies and legislation that support and recognize principles of IF and that allow for evaluation, learning, flexibility, adaptability and change.

Planning must be ongoing, at the family, community and government levels in order to manage the challenges which can arise.

2.5 Quality and Evaluation

- Success is self-measured (i.e. is the individual living the life that they desire?).
- Ongoing evaluation (at a systems level) is in place in order to guide implementation.
- Clear quality standards of services are in place.
- Safeguards exist to protect the individual and their rights.
- An appeal mechanism is in place to address individual disagreement with funding or support arrangements.
- Issues that arise (at a policy and/or delivery level) are monitored, attended to and reviewed on a continual basis.

2.6 Accountability

- Individuals receiving IF funding are accountable (with support if required) for the

funding they receive and the manner in which funds are spent.
- Effective accountability procedures are simple and flexible.
- Lines of accountability are clear, consistent and well established.
- User friendly policies and supports are in place to manage reporting complexities and audit controls.
- User-friendly financial accounting and accountability procedures are in place.
- Support (to the individual and/or their support network) for adhering to accounting expectations are available.

3.0 Conclusion

The adoption of an Individualized Funding (IF) approach has been demonstrated to achieve significant benefits, including:

- Significantly higher levels of satisfaction on the part of people who use services and supports;
- Greater participation and control by individuals with a disability and their families as to the type and extent of supports and services;
- Enhanced inclusion of people within their homes and communities, and;
- Cost neutrality (in many cases there are documented cost savings).

IF enables individuals and families to take a more proactive role in their lives and represents a way for people to have a greater say over the decisions that affect their daily lives. To be effective, IF must operate within the context of a broader system of change and systemic support. IF must be implemented in a manner which ensures sustainability on all levels. Finally, a balance between accountability, flexibility and choice must exist for the individual, so that they can live the best life possible.

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Recommended Resources:

The Centre for Inclusion and Citizenship at the University of British Columbia has created a comprehensive Literature Review on Individualized Funding. You can find the review at:

http://cic.arts.ubc.ca/research-knowledge-exchange/individualized-funding-literature-reviews.html

Glossary of Terms:

Brokerage: is a system function and process in which advice, information and technical assistance is made available to individuals who request support to identify and access needed community services and supports and negotiate for and use individualized funding.

Circles/Networks of Support: A group of people who meet together on a regular basis to help an individual accomplish their personal goals in life. The circle acts as a community around that person (the 'focus person') who, for one reason or another, is unable to achieve what they want in life on their own and chooses to ask others for help. The focus person is in charge, both in deciding who to invite to be in the circle, and also in the direction that

the circle's energy is employed, although a facilitator is normally chosen from within the circle to take care of the work required to keep it running.

Independent Planning Support/Facilitation: Facilitates a person-directed planning process in an independent capacity, without conflicts, with people who have a disability along with their family, friends and others – their support network. This leads to participation and contribution in a full and rich community life.

Microboards: Formed by a small group of committed family and friends joined together with a person with challenges to create a non-profit society. Together this small group of people address the person's planning and support needs in an empowering and customized fashion.

Person-Directed Planning: A person-directed plan tells us about the focus person, future dreams, supports needed to be successful and action steps to move towards those dreams. The focus person directs and owns the plan. Person-directed planning upholds the following principles: person-directed, ongoing, individual rights, diversity, relationships, inclusion.

Supported Decision Making: Some individuals with disabilities may rely on the advice and assistance of others when making decisions. They may call upon their support network - that is, their parents, other family members or friends - to help them understand their choices. The members of the support network can provide information, ideas and advice that help vulnerable persons to make their own decisions. This is what supported decision making means: vulnerable persons making their own decisions, with support and advice from family and friends, if desired.