

Now is the Time

Key Principles and Core Elements to Bring About Effective Individualized Funding Mechanisms

The dawn of a new day in Ontario – A time to build together

Individualized Funding Coalition for Ontario, 2022 - By Judith McGill

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The dawn of a new day in Ontario
A time to build together



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The Individualized Funding Coalition for Ontario welcomes others to draw from the extensive synthesis of information, research, collective knowledge, and experiences through this paper. When crediting the Individualized Funding Coalition for Ontario please include the website address where possible. We would appreciate receiving an email letting us know how you were able to draw from or use the information and/or how you found it helpful. Email address: info@individualizedfunding.ca

Now is the Time has been written within the context of a full and meaningful life for people living with disabilities in their neighbourhoods and communities. Much of the paper is based on insights and experiences of people, families, and allies in the Province of Ontario.

Important Note: The Individualized Funding Coalition for Ontario believes that the information in this paper applies well to seniors - older citizens - for whom the opportunity and option to have individualized funding for home and community supports, to live their best life at home, is critically important.

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Foreword

A Message of Appreciation and Optimism

The Individualized Funding Coalition for Ontario (IFCO) would like to thank all who participated at various gatherings and working groups hosted by IFCO over the decades. This includes being part of round tables, focus groups, learning events, planning sessions, Straight Talk days, Coffee & Conversations, and Have Your Say gatherings. It also includes the strategic efforts of various IFCO Ad Hoc Working Groups.

Additionally, we would like to say a separate thank you to the incredible leaders who authored and co-created previous works with and for IFCO.

To people, families, and allies who shared vital information and experiences at meetings and gatherings over the years – we extend our appreciation. To those who attended the Straight Talk days, your input, drawn from the summary reports that came out of the two days, is included in this paper and with IFCO’s strategic planning goals.

More recently, for the people, families and allies who invited us to speak at your meetings and/or who joined IFCO on Zoom during the pandemic -- a special thank you for your participation and contribution during such challenging times. Those opportunities whether to learn, ask questions or share your knowledge and experiences have kept us grounded as leaders and volunteers with IFCO. They have also provided affirmation for the values and principles of the ‘Coalition’.

This paper, called *Now is the Time, Key Principles and Core Elements to Bring About Effective Individualized Funding Mechanisms in Ontario* is a compilation of information and insights that have stood the test of time. It is information that has been re-affirmed by many people, families, allies, and stakeholders over the last 18 months, and by recent international research and writings.

The paper was made possible because of the long-standing hard work and generous contribution by people and families who we see as leaders. It has been enhanced by the commitments of many: independent facilitators, agency service providing partners, and provincial groups who have stood beside the ‘coalition’, worked in collaboration, and provided resources and/or in-kind support for the work.

Many thanks to these allies for their efforts to honour what many people, along with their families or trusted others have expressed needing and wanting. Simply put: an everyday, ordinary life that they can self-direct.

Finally, we would like to thank our writer, Judith McGill for the excellent work she did synthesizing the rich array of information available to create this ‘KEYSTONE’ paper for the Individualized Funding Coalition for Ontario.

The ‘KEYSTONE’ in masonry is the wedge-shaped piece at the top of an arch that locks the other pieces in place. A KEYSTONE can also be described as something on which the rest of a system or structure depends for support.

IFCO believes that the KEYSTONE principles and core beliefs in this paper are essential. They are central to holding and supporting the aim of individualized funding and the realization of successful models and approaches. These KEYSTONE principles are what everything else relies on for optimal functioning – in other words, for working well.

We invite people living with disabilities, their trusted others, families, allies, partners, researchers, and government to read and share this material. We hope that it will serve to enhance and enrich: conversations, creativity and imagination, future planning and systems design going forward.

Respectfully,

Leadership Team, 2022

Individualized Funding Coalition for Ontario

1 Key Principles and Shared Beliefs

The Individualized Funding Coalition for Ontario has mobilized people, families, allies and supportive organizations for close to three decades. Our purpose: to learn from one another and articulate a clear vision for individualized funding in Ontario.

Individualized Funding is not a new concept; it has been in place in Canada . . . and in other parts of the world for more than 30 years. Individualized Funding 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.” (Dozar, M., Gallant, D., Hannah, J., Hurd, E., Newberry, J., Pike, K., & Salisbury, B., 2011, p. 8)

These principles and shared beliefs have been consistent and shared by people and families over many years as they strive to envision a better tomorrow, today. This report is a synthesis of many of the writings produced by the Individualized Funding Coalition for Ontario as well as some national and international research reports on the subjects of: individualized funding and unencumbered supports like independent facilitation and planning, and more.

For necessary change to take place, people, along with their family and/or trusted others, must be clear about what they hope to achieve through choosing individualized funding as an option. Most importantly, they need to be able to share their vision of a better future and how they intend to get there using individualized funding.

Now is the time to bring about effective individualized funding mechanisms in Ontario. To achieve this the Individualized Funding Coalition for Ontario believes there are key principles and shared beliefs that lead to people having meaningful support to contribute to their communities, and living an everyday, ordinary life full of purpose.



Respecting the inherent dignity of each person

We believe in the inherent dignity and worthiness of each person, their family and their trusted others and respect their capacity to make worthwhile contributions to one another and the broader community regardless of age, gender, ability, impairment, and social status.

We align with the fundamental beliefs adapted from a 2006 report by the Citizens Against Restraints Leadership as outlined below:

We believe that offering services and supports at the lowest level of formality and as naturally as possible, is essential to meaningful change. This belief implies, among other things, that those with the closest knowledge of a difficult challenge need to be involved in the creative problem-solving process. (pp. 8-9)

We believe that as much as possible, when supporting people that typical resources (i.e., family, friends, neighbours, work, school, faith communities, etc.) and typical approaches (i.e., effective teaching strategies, positive role modeling, high expectations, positive physical and social environments, etc.) are used to their greatest advantage. (pp. 8-9)

We believe that we must strive to reduce unnecessary bureaucracy, formalization and complexity within the supports and services offered to people and their families as much as possible. (pp. 8-9)

Close, freely given relationships are key to people living an everyday ordinary life as full citizens.

We believe that close relationships are the single most meaningful safeguard in a person's life. These freely given relationships need to be intentionally developed and sustained over time.

In 2021, significant research about individualized funding was published called, *Individualised Funding: A Realist Analysis to Identify the Causal Factors That Facilitate Positive Outcomes*. This research was built upon previous work comparing many studies published internationally on individualized funding.



Fleming, P., McGilloway, S., and Thomas, S. (2021) report that “overly complex and cumbersome bureaucracy” decreased the likelihood of positive outcomes, and “the presence (or possibility) of a strong network of support that utilised collaborative decision making between the funding recipient and funders/support agencies,” considerably improved hoped for outcomes (p. 56).

In preceding research, the following was noted: “Historically, the types of supports available to people with a disability were based on medical needs only. More recently, however, the importance of social care needs, such as keeping active and socializing, has been recognized.” (Fleming, P., McGilloway, S., Hernon, M., Furlong, M., O’Doherty, S., Keogh, F., & Stainton, T., 2019, p. 2)

With that in mind, that is the importance of social connections and actively participating, it should be noted that the Individualized Funding Coalition for Ontario (IFCO) strongly aligns with the following Core Beliefs of the Ontario Independent Facilitation Network (OIFN) as stated on their website:

We believe in the rights of all people to set the pace and direction of change in their lives so that they will be included in their neighbourhoods and communities and have the same freedoms and responsibilities of any other citizen, as upheld by the United Nations Convention on the Rights of People Living with Disabilities, Article 19. (OIFN, 2022, What We Believe, para.1)

We believe that natural neighbourhood connections and community resources are the first resort for people to learn and contribute in meaningful ways and become known and valued as contributors. People having strong and ongoing relationships based on mutuality and trust is fundamental to genuine inclusion and belonging. (OIFN, 2022, What We Believe section, para. 4)

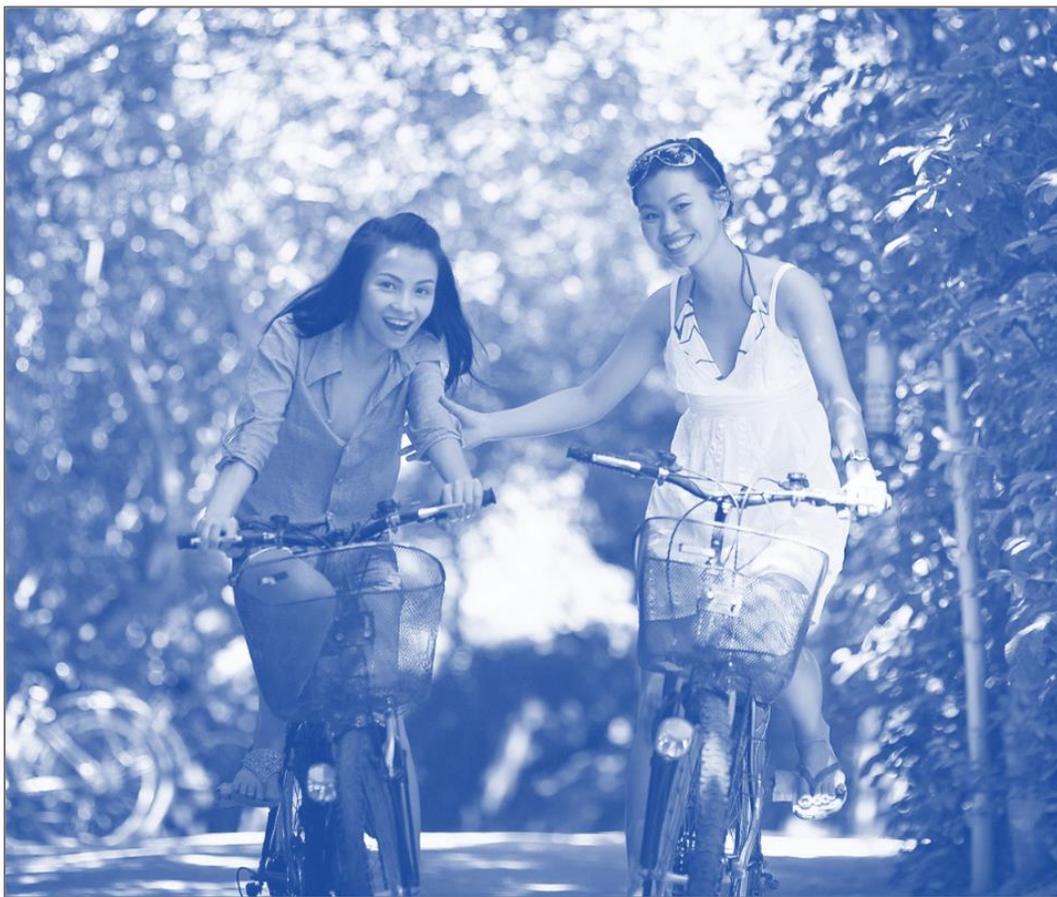
Fleming et al. (2021) reports that by “building upon existing informal and formal relationships (to include extended family members, such as aunts, uncles, cousins, friends, and members of the wider community) through a process of co-produced goals and plans”, people and families were more likely to experience community inclusion and a wider network of support. (p. 56)

Even more important is the finding by Fleming et al. (2019) regarding how invaluable support networks are for people and families experiencing success. “Strong, trusting and collaborative relationships in their support network . . . facilitates processes such as information sourcing, staff recruitment, network building and support with administrative and management tasks”. (p. 2)

This 2019 research, called *Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review*, found that with well-designed models people with disabilities experienced: “greater flexibility in their lives, improved self-image and self-belief; more value for money; community integration; freedom to choose ‘who supports you’; ‘social opportunities’; and needs-led support”. (Fleming et al., 2019, p. 2)

More recently, a 2022 report by Eddie Bartnik and Ralph Broad called *Power and Connection: The International Development of Local Area Coordination* has identified that:

Now more than ever, it is time to look at how, together with local people, communities and services, we can build the conditions for people to stay strong, safe, connected and valued as active, contributing citizens and to re-balance our limited resources towards a greater focus on individual, family and community, capacity building and mutual support. (p. 14)



Control and autonomy over day-to-day life and decisions

Along with the Ontario Independent Facilitation Network (OIFN), the Individualized Funding Coalition for Ontario believes in and wants to ensure that people have meaningful and appropriate “support for decision-making and that each person has the capacity to express their will and their preferences in some way and can be involved in directing their life and taking charge of key decisions with the support of others”. (OIFN, 2022, What We Believe section, para.3)

IFCO believes there is a direct correlation between people with disabilities living everyday ordinary lives as a part of their community and having control over their funding for support.

Individualized funding is “an umbrella term for disability supports funded on an individual basis that aims to facilitate self-direction, empowerment, independence and self-determination.” (Fleming et al., 2019, p. 5)

The 2019 research - a mixed-method systematic review - confirmed that the most important outcome of support funding for people, was having control and autonomy over day-to-day life and decisions. This desire for control and choice was aimed at creating a productive and interconnected life where the person is assisted to be a valued member of their community. This is in line with the IFCO Accord.

Our Accord - Individualized Funding Coalition for Ontario

The Individualized Funding Coalition for Ontario supports the self-determination of persons with disabilities.

We believe in all people having control over decisions concerning where they live, with whom they live, with whom they associate, and how they spend their lives.

In order to achieve this, we recognize that Ontario must develop a system of funding whereby the person requiring assistance, supported as appropriate by family and/or significant others, has access to and control over the funds allocated for [their] supports. (Individualized Funding Coalition for Ontario, 2022, home page, upper right corner)

People need access to unencumbered/independent facilitation and planning supports

We believe that facilitation and planning support, as a solid option for people, must be free of conflicts of interest. In other words, it would be unencumbered with no ties to and independent of other systems supports and services. This means ‘facilitation and planning’ that is separate from: the determination of eligibility, access mechanisms, assessment processes, and funding determination. It also means being separate from direct service provision.

A key principle is that people would have access to independent facilitation and planning supports where the person, in the context of their family and/or their trusted others, is supported to imagine better. They determine the pace and direction of change alongside others.

Facilitation and Planning support is proven to be an essential aspect of self-determination. People are much more likely to maximize their use of individualized funding when given support with relationship and network building, shifting the power dynamics in their life, strengthening their willingness to become known by others and have a voice in their life and in key decisions.



One of the key strategies identified in improving outcomes in the research report, was that the person and their family and/or loved ones were able to access intermediary services which supports them in terms of planning and managing how money is used. (Fleming et al., 2019, p. 2)

In other words, where people had meaningful outcomes, mechanisms were made available to support the person to make the most use of the funding by assisting with things like setting out their vision and clarifying their next steps.

Whether facilitation and planning supports are identified as ‘intermediary services’, Local Area Coordination or Independent Facilitation, there are several common outcomes described in all three international research reports that are derived from these essential supports including:

- Living a rich and fulfilling life, supportive natural relationships, citizenship, contribution, and family resilience
- More welcoming, inclusive, supportive, and better resourced communities
- Transformed service systems and more effective use of resources, where services have a stronger partnership with and connection to local people and communities and complement and support, rather than replace, informal and community solutions (Bartnik, E., Broad, R., 2022, p 15)

It is now, absolutely clear that effectively designed and delivered facilitation and planning supports (like Local Area Coordination) provide a long-term evidence base that moves from the crisis-service model to one that supports sustainable individual, family and community resilience, mutual support and strong value for money.

(Bartnik, E., Broad, R., 2022, p 18)



2 Fundamental Premises of Individualized Funding

Adequate investments: enough funding for people to live a full and meaningful life

Individualized funding programs must be adequately invested in so that people and families have enough funding to support individuals to live a full and meaningful life included in their neighbourhood and community. For this to be possible individualized funding models would ensure:

- that people, their families and/or loved ones have significant control over the funding so that it can be used to enhance the person's life and strengthen the person's sense of voice and autonomy.
- that funding is reliable and can be counted on to sustain the person's lifestyle once they reach adulthood.
- that the funding is accessible to all citizens who are interested in making use of individualized funding.

Recognition and protection of citizenship rights, including appropriate supports for decision making

For individualized funding models to be a viable choice they must acknowledge people's rights as citizens and protect these rights by presuming legal capacity and respecting the need for accommodation/s, including the following:

- Recognizing the inherent right and necessity for people to have appropriate support for making key decisions and choices in their life.
- Recognizing people's fundamental right to self-determination and to live life of their own choosing with the support of others as stated below:

People First of Canada believes that all people, regardless of disability, have legal capacity. People have the right to make their own decisions and choices. The decisions and choices made by a person with an intellectual disability need to be honoured in terms of legal capacity and the authority to act. If a person has a support network or decision-making team, this needs to be honoured in terms of legal capacity and the authority to act on behalf of the person. (People First of Canada, 2022, Legal capacity section, para.1)

3 Core Elements of a Desirable Individualized Funding Model

Directed at assisting the person to build a more meaningful life in their community with valued social roles and opportunities for contributing



A viable and equitable choice

- For individualized funding to be a viable choice, it needs to have the same provisions that other services and supports have.

Accessible to all

- It must be available to all people who have a developmental disability regardless of the level of their disability, age, cultural and/or sexual identity and socio-economic status.
- It must be available to people whose families do not speak English as their first language and who for whatever reason may need support with managing the funding.

Written and communicated in plain language

- All the written material and social media associated with individualized funding needs to be in plain language.
- Adequate resources need to be developed to accommodate those with who use languages other than English and French and who use sign language.

Willing to recognize the natural authority of the family

- The natural authority and commitment of families must not only be recognized by government but also protected.

Adequately and equitably funded

- People and families need to have adequate funding to carry out meaningful life goals.
- Need for widening the areas that are eligible for individualized funding and disability supports including: home support, employment support, attendant services, skill development, supports for learning and literacy opportunities, and relationship building.

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- Funding allocations need to be principle-driven and equitable. Equity means that people have what they need, and they have identified what that is and why.
 - An effective, independent appeal mechanism must be made available so that people and families can challenge funding allocations and prioritization.

Portable

- Individualized funding needs to be portable so that if and when a person moves within the province, their money follows them and can be administered seamlessly in the new location.
- The principle of portability also ensures that if a person is not satisfied with a service or any aspect of their support, they can enter into a respectful process and then freely transfer their individualized funding allocation to another transfer payment agency and purchase alternative services and supports.

Willing to recognize the legal capacity of the person receiving the funds and provide accommodation to the person for supported decision-making

- There needs to be a presumption of legal capacity built into the eligibility and implementation of individualized funding.
- Meaningful accommodation needs to be provided to offer support for decision making in such a way as to address the person's specific needs.
- Funding mechanisms must ensure that there is no requirement for seeking substitute decision-making status on behalf of the person to be eligible.

Reliable and sustainable over time

- Once individualized funding is granted to an individual it needs to be guaranteed over time as needed (unless accountability measures that are fully understood with opportunity to correct things are not adhered to or funding is drastically reduced for all services and supports across the province not only for those utilizing individualized funding).
- There needs to be a system of accountability that is based on values, self-determination, citizenship, inclusion, and empowerment.
- Individualized funding to include cost of living increases on an annual basis.
- Funding allocations would be adjusted on a regular basis when there are significant changes in a person's circumstances and needs so that the person is not placed at further risk.

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- Formal processes would be in place for responding to changing needs, thus ensuring funds are adjusted to meet those new challenges (e.g., as people age, health conditions for person or their family, change in living situations, etc.).
 - Funding allocations would be designed to permit the system to respond “just in time” to a person’s needs rather than focussing on expensive “just in case” approaches.

Flexible

- Use of the funding needs to have maximum flexibility to adjust to variations in need and short-term crisis situations to remain relevant and responsive to the person and their family and/or loved ones. For example, fiscally sharing as a best practice has been one strategy to achieve this.
- Expenditures need to be flexible enough to assist with building the resilience and capacity of the person, their family and/or loved ones.

Easy to understand and simple to self-manage

- The requirements of self-managing the funding is straightforward and easy to implement.
- Simplicity implies that it does not require undue paperwork and reporting requirements that are unnecessary and burdensome for people and families.
- User friendly policies and supports are in place to manage reporting complexities and audit controls.

Access to low-cost administrative support when desired

When families purchase administrative and accounting supports from transfer payment agencies, these supports are best when transparent and low cost. People and families would receive:

- Support to maintain/track their budget by providing simple to use tracking sheets and regular reports on finances.
- Adequate support to maintain financial records and receipts.
- Assistance with preparing any reports required by government.
- Clear, consistent and well-established lines of accountability.

Offer people and families concrete supports with support worker requirements

- People and families need assistance with recruitment, hiring/contracting and retention of support workers (support worker titles vary depending on funds).

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- Supporting people and families to follow provincial and federal legislation for employment and self-employment.

Offer people and families concrete supports for independent facilitation and planning

- Expand provision of these supports across the lifecycle, from childhood to adulthood so that the person and family can create an everyday ordinary life and manage key life transitions in a sustainable and flexible manner.
- People and families need access to dependable, consistent and ongoing independent facilitation and planning support (to maximize the resources available and facilitate worthwhile outcomes.
- Ensure that independent facilitation remains unencumbered. These supports need to be free of conflicts of interest and separate from direct service provision and/or eligibility and funding determination.

People and families receive quarterly installments of funding in advance

- People and families could receive quarterly installments of funding to secure proper cash flow, timely payments and ensure support worker retention as well as equitable access to funds (with the reconciling of expenses at the end of the quarter).

Accountability measures are reasonable, and specific to a person's needs

- Reasonable accountability measures for individualized funding (beyond eligibility for purchases made) need to be in place for people, families/trusted others, and service providing agencies.
- Accountability measures need to be tied to concrete statements of goals and would be designed to take the person's changing needs into account.

Critical awareness of the need for separating out key functions in the system

- Ensuring that housing and supports are separated.
- Ensuring that advocacy, independent facilitation and planning, and system's access, assessment, and allocation of individualized funding, and direct services operate as separate functions.
- Separating functions enables people to build their own community networks and have more power and choice.

4 Pressures and Challenges that Get in the Way of People and Families Creating Everyday Ordinary Lives in Their Communities



Limitations of the Passport (direct funding) program

Over the past eight years, when persons with developmental disabilities reach 18 years of age, and are determined eligible for adult services, they are automatically given a yearly allocation of \$5000 from the Passport program. This allocation is given on a ‘one size fits all’ basis without any consideration of the person’s individual support needs.

The Passport program is limited in terms of supporting people to build a life in their neighbourhood and community, and addressing the overall needs of an individual. It is focussed solely on community participation support and does not address the need for support funding so that people can customize and create a home of their choosing.

While within the program there is an additional provision for people to receive Passport funding beyond the \$5000 minimum, it is generally reserved for a select number of adults who are determined to be in serious crisis or put at risk of becoming homeless.

Recipients of the funding can spend up to a maximum of \$2,500 for person directed planning and facilitation support. While this may be helpful, for youth leaving school who are in a full-time paid day program, the funding offers very little accompaniment support for transitioning into an everyday, ordinary life as an adult.

Significant financial pressures and lack of equity in the system

The current reimbursement structure of the Passport program creates significant financial pressures for families due to the delayed and intermittent pay back schedule. Families with limited financial means experience undue stress and hardship when having to carry the costs themselves in order to retain community support workers, without knowing in advance when they will be reimbursed.

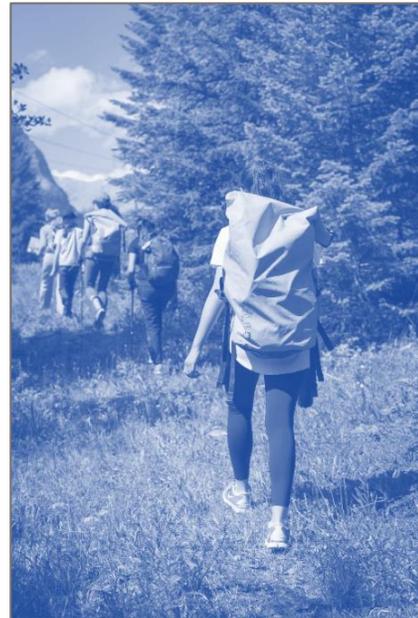
The increasing expectation for agencies in the developmental disability sector to recoup the costs of day supports through a fee for service model

Over the last decade, transfer payment agencies have been increasingly expected by the Ministry of Children, Community and Social Services (MCCSS) to create a menu of day services based on a fee for service model. This means that the person and their family must pay a fee to get the support.

These agency day supports typically have a top-down approach versus a bottom-up model where the person (with the support of their family/and or trusted others) decides how to create a meaningful life. Supports that are designed to meet the individuals needs and interests on a one-to-one basis, are not typically available. Creating and sustaining individualized adult roles in the community is not the focus.

There is across the board a lack of decent choice of supports and services available. For the most part in Ontario, transfer payment agencies can offer fee for service options and can charge what they like for their day time supports. As well, several private and 'for-profit' service providers have emerged on the scene and contribute to the prohibitive costs of fee-for-service day programs. Two concerns regarding these private operators: they are operating without any governmental oversight and accountability, and the emphasis is on growing congregate day programs. This is different than transfer payment agencies who are accountable to government, and where a number are moving to support people on an individual basis with inclusion. The differences between government funded transfer payment agencies and private operators are increasing. More and more private operators see an opportunity for people to spend their Passport funding in these day programs that exist without oversight, and that tend to be selective about who can attend.

The shift to people and families having to pay for day supports and services, has placed significant economic pressures on families.



People and families, outside traditional support systems, must pay for day supports with their limited community participation funding and subsidize the rest of the costs with their own private funds. This is possible for only those families with the financial means to do so.

For most families, the onus of having to continuously pay for adult services and supports with limited support funding, seriously impacts their capacity to save and/or retain savings for their own retirement. Due to the real threat of not having enough money for retirement as they age, families are much more insistent on trying to access services like congregate group homes and paid day services. This keeps people on long waiting lists for paid services and in crisis. More notably, when families engage in long range forecasting of the costs related to provision of care for their family member when they are no longer alive, the costs seem insurmountable.

Pressure on people and families to get started right away spending their individualized funding

There is pressure on people and families to get started spending their Passport funding right away once it is received. Without being given adequate support to imagine better and work through next steps within the context of a broader vision for building a meaningful life in neighbourhood and community, families are choosing congregated day support options as a short-term solution (even though it may not be their first choice). These options can sometime result in some level of inertia setting in, especially when families need to be working and/or are aging and tired. Without adequate independent facilitation and planning support for creating individualized options, and without adequate support funding, people and families can feel they have no viable choices for working toward their vision of the future.

Lack of resources to engage independent facilitation and planning

There is a serious lack of resources to engage independent/unencumbered facilitation and planning supports that assist people, their families and/or trusted others to customize supports and explore next steps. Furthermore, over the past four years, there has been a steep decline in the availability of trained and experienced independent facilitators and planners across the province. There are families who would like to see these supports made available to children and families in the early years, well before leaving high school and continue throughout the person's life.

Most of the independent facilitation supports in the province are available only as a fee for service option that forces people and families to choose to spend their meager funding on facilitation over individualized accompaniment support.

People and families find themselves having to rely on the good will of key decision makers in transfer payment agencies. When these key personnel leave their positions, people and families must keep negotiating their needs and broker new agreements with relatively new agency representatives. This constant renegotiating is exhausting for families. Many families identify the essential role of independent facilitation support in helping to broker these complex situations with the person and family.

Government investments continue to be put into bureaucracy and traditional, congregated services

Rather than investing in providing adequate and meaningful individualized funding and the necessary infrastructure to support people and families to maximize this funding, government investments continue to be put into bureaucracy and traditional services. While most people and families are limited to \$5000 per year of Passport funding, new money is invested into central access and navigation supports. These bureaucratic investments, aimed primarily at family education and navigation support, continue to take priority while ‘hands on’ supports that make a tangible difference in outcomes, like independent facilitation, are not forthcoming.



Investments need to be made in those families who are willing to meet their family members needs through managing individualized funding supports. There is significant research available to indicate that individualized funding arrangements make it possible for people to set broader more individualized goals and create a richer network of support for themselves over time.

Continuous prioritization of youth leaving child welfare and other congregate housing services

The Ministry of Children, Community and Social Services (MCCSS) focusses much of their new investments in housing on high priority transition aged youth and others who are leaving child welfare and other congregate housing services. This focus excludes those whose needs are complex and difficult to meet by families in the community without adequate funding and supports.

The exclusion of persons living with their parents, creates an uneven playing field and leads to unwarranted crisis situations arising within families.

There is a widening gap between people and families who need affordable, individualized home options and support funding and those already in congregated housing services including child welfare services.

Need for partnering with government to work at making individualized home options more affordable and sustainable

Many families across Ontario want to ensure that they can create sustainable individualized home options for their family members that are affordable using individualized funding.

Families need creative and reliable ways to partner with all levels of government in this process. For individualized home options to be affordable there must be broader individualized funding allocations that take into account and separate out the housing support costs. Families need innovative pathways for partnering with government so that their contributions are more impactful, and the accountabilities are not overly bureaucratized.



For families without substantial financial means and savings, partnering with government to create an individualized home option is out of their reach. These families have few choices other than putting their family member on a lengthy wait list for fully funded congregate housing options. Creative partnerships need to consider ways to work with people and families who are committed to creating individualized housing options (e.g., portable rent subsidies, renovation loans, secondary suites, forgivable down payments on mortgages....).

People and families are given limited power and control over funding and decision-making

When people and their families and/or trusted others are allocated individualized funding and it is brokered by a traditional Transfer Payment Agency, they are often given an individualized service and not an individualized support arrangement where decisions are made by the person together with family and allies.

People and families who are using individualized funding, need maximum flexibility to innovate and respond to individual situations as they arise. The lack of flexibility and options for responding to changing circumstances and crisis situations leave families without enough autonomy to make and carry out the necessary decisions.

It is critical that people, their families and/or trusted others are acknowledged, respected and trusted as key decision makers. Current implementation guidelines and individualized funding accountability practices indicate to families that they are not to be trusted with managing and maximizing the funds. This creates an overall environment of distrust and suspicion.

People and families experience a lack of security and peace of mind



People and families experience a lack of security and peace of mind in choosing this model, because it is difficult to determine whether individualized funding is a viable and sustainable option over time. For individualized funding to be a viable choice it needs to have the same provisions that other adult services and supports have.

People and families have no assurances that this model is sustainable over time and therefore cannot afford to make the necessary investments and commitments to make it work.

People and families want autonomy and control - but they do not want to be unsupported, they do not want to be alone (they want to be with some like-minded families), and they do not want service to be the only option when they are gone. They want and need assistance and support to build resilient succession into the next generation (circles, networks, etc.)

People and families experience a crisis in recruiting and retaining good community support workers

Due to not being given enough individualized funding, people and families find themselves unable to compete with the decent rates of pay offered by transfer payment agencies, school boards and long-term care homes. This puts people at a considerable disadvantage in securing capable and experienced community support workers.

The individualized funding movement has been led primarily over the years by families who are now aging

Individualized funding models require ongoing advocacy from people and families so that policy staff within the Ministries can continue to evaluate the model's usefulness and effectiveness.

The individualized funding movement has been led primarily over the years by families who are now aging and unable to contribute as they once did. Families who are just now becoming aware of the need for making this a viable option, acknowledge the level of experience and dedication of senior parents and are overwhelmed by the task of keeping the individualized funding model accountable to people and families in the future.

Lack of real support for the rights of people and legal capacity

Across our country and the province of Ontario, people living with disabilities are leading the way with their messaging for their right to make choices and live with the same responsibilities and opportunities as all citizens. People are saying they want rights protected, “to live where we choose, and to have enough supports to live independently, to have enough income to live with dignity, and to be involved in the community.” (People First of Canada, 2022, United Nations Convention on the Rights of Persons with Disabilities section, para.1)

We all “make decisions or enter into agreements . . . based on our legal capacity as a person and a citizen. Most people are assumed to be competent, but this is not always true for people with intellectual disabilities.” (People First of Canada, 2022, Legal capacity section, para.2). People living with intellectual/developmental disabilities, and others, in Ontario face laws that are out-of-date. This has affected the way supports are provided. People First of Canada (2022) states clearly that: “Disability should never be used as a benchmark for competence.” (Legal capacity section, para.2)

Final Thoughts

The Individualized Funding Coalition for Ontario (IFCO) has always drawn information broadly from people, families, allies, consultants, researchers, and others with first hand experience and knowledge of existing individualized funding programs and best practices provincially, nationally, and internationally. The *Now is the Time* paper is a synthesis of all the above, while outlining principles and elements for achieving effective individualized funding programs.

IFCO has also always used ‘individualized funding’ as an umbrella term for all individualized, self-directed funding models and approaches, as seen with this paper. Other terms used for individualized funding approaches can include the following: direct funding, self-managed, self-directed care, family managed, individualized or personalized budgets, etc.

The Passport program – a direct funding program for adults with a developmental/ intellectual disability - was highlighted as an example in this paper. This was done in part because people and families with Passport funding had come together with IFCO a few times, (as did allies, independent facilitators, and service providing partners), sharing their first-hand knowledge. We also found there were lessons to be learned. One in particular, that was reinforced by people and families, that small amounts of inadequate funding do not lead to a full life of contribution and participation.

Information shared directly with IFCO regarding other individualized funding programs that exist in Ontario also described various issues (e.g., wait lists, the need for adequate funding, eligibility criteria that present barriers, and the lack of supports for: facilitation, support workers, and decision-making, etc.).

If we are to see people leading the way in their quest for an everyday ordinary life of inclusion, opportunity, choice and control, then families, trusted others, allies, service providers and government have a responsibility to get behind them.

Individualized funding approaches that recognize basic rights with supports for decision-making, along with good principles, and adequate funding to live a good life - all together are keystone pieces that will make a significant difference moving forward.

What’s next? Collectively and collaboratively, all of us, individuals, families and allies, have a great deal of strategic work ahead. We leave you with an invitation for collective action . . . Now is the Time.

Individualized Funding Coalition for Ontario

Bibliography

References

- Bartnik, E., Broad, R. (2022). *Power and Connection: The International Development of Local Area Coordination*. The Centre for Welfare Reform.
<https://citizen-network.org/library/power-and-connection.html>
- CAR Leadership. (2006). *Citizens Against Restraint: Belief Statement and Position Paper*. Citizens Against Restraints.
- Dozar, M., Gallant, D., Hannah, J., Hurd, E., Newberry, J., Pike, K., & Salisbury, B. (2011). *Individualized Funding: A Framework for Effective Implementation*. National Individualized Funding (IF) Discussion Group.
https://individualizedfunding.files.wordpress.com/2014/07/individualized_funding_framework_english1.pdf
- Fleming, P., McGilloway, S., Hernon, M., Furlong, M., O'Doherty, S., Keogh, F., & Stainton, T. (2019). *Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review*. *Campbell Systematic Reviews*, 3.
<https://onlinelibrary.wiley.com/doi/epdf/10.4073/csr.2019.3>
- Fleming, P., McGilloway, S., & Thomas, S. (2021). *Individualised Funding: A Realist Analysis to Identify the Causal Factors That Facilitate Positive Outcomes*. *Disabilities*, 1, 47-57. <https://doi.org/10.3390/disabilities1010004>
- Individualized Funding Coalition for Ontario. (2022). *Our Accord*.
<https://individualizedfunding.ca/>
- Ontario Independent Facilitation Network. (2022). *OIFN's Core Beliefs*.
<https://www.oifn.ca/what-we-believe/>
- People First of Canada. (2022). *PFC Priority-Legal Capacity*
<https://www.peoplefirstofcanada.ca/priorities/legal-capacity/>
- People First of Canada. (2022). *United Nations Convention on the Rights of Persons with Disabilities*. <https://www.peoplefirstofcanada.ca/priorities/united-nations-convention/>

Resources

- Broad, R., (2015). *People, Places, and Possibilities: Progress on Local Area Coordination in England and Wales*. The Centre for Welfare Reform.

-
- Community Living Ontario. (2021). *Building a Full Life + a Home of One's Own in the Community*. Community Living Ontario.
- Dingwall, C., Kemp, K., Fowke, B., (2006). *Creating a Good Life in Community: A Person-Directed Planning Guide*. Individualized Funding Coalition for Ontario
- Foley, K., Attrill, S., McAllister S., & Brebner, C. (2021). *Impact of transition to an individualised funding model on allied health support of participation opportunities*. *Disability and Rehabilitation*, 43(21), 3021-3030.
<https://doi.org/10.1080/09638288.2020.1725157>
- Individualized Funding Coalition for Ontario. (2007). *Transformation of Services: Expanding the Possibilities for Citizenship, A Signature Paper*. Individualized Funding Coalition for Ontario
- Lord, J., Kemp, K., Dingwall, C., & Hutchison, P. (2006). *Moving Toward Citizenship: A Study of Individualized Funding in Ontario*. Individualized Funding Coalition for Ontario.
- Lord, J., & Hutchison, P. (2008). *Individualized Funding in Ontario: Report of a Provincial Study*. *Journal on Developmental Disabilities*, 14 (2), 44-53.
- Lord, J., & Hutchison, P. (2003). *Individualized Support and Funding: Building Blocks for Capacity Building and Inclusion*. *Disability and Society*, 18(1), 71-86.
- McGill, J. (2010). *Direct Funding and Accountability: What is of Prime Importance? Report from the Ad Hoc Working Group of the Individualized Funding Coalition for Ontario*. Individualized Funding Coalition for Ontario.
- McGill, J. (2012). *Report on the Direction of Independent Facilitation and Person Directed Planning in Ontario*. Individualized Funding Coalition for Ontario.
- Ontario Independent Facilitation Network. (2018). *Core Elements of Independent Facilitation; Scope of the Work*. OIFN. <https://www.oifn.ca/wp-content/uploads/2018/07/OIFN-Core-Elements-of-Independent-Facilitation-June-2018-FINAL.pdf>
- Ontario Round Table on Individualized Funding. (2000). *Linking Individualized Supports and Direct Funding, Making Money Work for People; A Pathway to Self Determination and Community Involvement for People with Disabilities*.
- Stainton, T., & Salisbury, B. (2005). *Individualized Funding*. Presentation at policy forum, More Choice and Control for People with Disabilities, Funding Approaches. Ministry of Children, Community and Social Services.

Appendix

Individualized Funding Programs and Approaches in Ontario

When the Individualized Funding Coalition for Ontario was established in 1994, there were two types of individualized funding programs available in Ontario. The first one, the Special Services at Home (SSAH) program provided funding for children with disabilities and adults with developmental disabilities, and was funded by the Ministry of Children, Community and Social Services. It continues to exist today but only supporting children with disabilities and their families. The second, Direct Funding (for self-managed attendant services) began as a pilot in 1994 and was funded by the Ministry of Health for people living with a physical disability. In 1998 it became a full program and continues today.

Since then, there have been a few other individualized funding programs created and funded by both Ministries. The names and criteria for these programs are not always the same, but they have these common features: individuals have control and decision-making power with their funding, and for children, their family has the control.

You can learn more about the individualized funding programs and approaches that currently exist in Ontario through links to each of the government programs from the Individualized Funding Coalition for Ontario website at this link:

<https://individualizedfunding.ca/whats-in-ontario/>

Published by the Individualized Funding Coalition for Ontario.

This paper is a synthesis of many of the writings produced by the Individualized Funding Coalition for Ontario as well as some provincial, national and international research reports and information, and direct input from people, families and others. It is about individualized funding, independent facilitation and planning, individualized mechanisms and structures for people including the recognition of rights, support for decision-making, social networks and more. All this leading to an effective individualized approach for living an everyday, ordinary life of inclusion and social connections.

The principles, core elements and approaches described in this paper apply to all people living with vulnerabilities at every stage of life from young children and families looking for community inclusion, to youth and adults living their own unique lives, to elders and seniors who want to stay in their homes, neighbourhoods and communities.