

Responding to the Individualized Funding Environment

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Introduction to GLS

Great Lakes Society (GLS) is an integrated and coordinated network of sixteen (16) charitable agencies located across Ontario who deliver a range of specialized behavioural, clinical, health and medical services to children and adults with intellectual and developmental disabilities (IDD). GLS members are driven by evidence, outcomes and continuous improvement and they provide an important link for people with complex needs who require the support of Developmental Services (DS) and other sectors, having staff with specialized and clinical expertise. With a focus on understanding the specialized health and support needs of people with IDD, GLS members enable people to get the specialized support they need reducing barriers and creating more sustainable supports. The members of GLS provide clinical leadership and are committed to working collaboratively to transform health and social services to improve the quality of life and safeguard people with intellectual disabilities or autism presenting with complex needs, mental health conditions or behaviour that challenges; to ensure better outcomes by the development of high-quality person centered supports that promotes choice and control for people with IDD's.

Definition and Stats:

It is reported that intellectual and developmental disabilities (IDDs) affect 1-2% of the global population.¹ IDD is a lifelong condition that originates between birth and age 18 and it affects a person's ability to learn, communicate, retain information and undertake everyday activities. IDD refer to a broad range of developmental conditions associated with lifelong challenges in cognitive and/or adaptive functioning.^{2,3} According to Health Care Access Research and Developmental Disabilities (H-CARDD), Ontario reports prevalence rates as 0.78% or 66,684 individuals of the population having a developmental disability.⁴ Changes in diagnostic testing and criteria, population characteristics, and known risk factors leads to variability in prevalence rates of IDDs. Depending on the severity of the IDD, individuals require additional support and assistance from other people to carry out activities of daily living. Adults with IDD are recognized as a vulnerable population with complex needs due to higher prevalence of mental health conditions, physical health conditions, communication difficulties or challenging behaviours, and multi-morbidity as compared with the general population.^{5,6,7} It has been reported through literature that a significant proportion of people will require access to behaviour and mental health services. It is estimated that approximately 30%- 40% of the population with IDD has a co-occurring mental health need.⁸

¹ Maulik PK, Mascarenhas MN, Mathers CD, Dua T, Saxena S. Prevalence of intellectual disability: a meta-analysis of population-based studies. *Research in Developmental Disabilities*. 2011;32(2):419–36.

² McKenzie K, Milton M, Smith G, Ouellette-Kuntz H. Systematic review of the prevalence and incidence of intellectual disabilities: current trends and issues. *Current Developmental Disorders Reports*. 2016;3(2):104–15.

³ Daaleman TP. Special population: adults with intellectual and developmental disabilities. *Chronic Illness Care* 2018; 319–29.

⁴ Health Care Access Research and Developmental Disabilities (H-CARDD). 2013. Retrieved February 10, 2022. <<http://www.hcardd.ca>>.

⁵ Krahn GL, Fox MH. Health disparities of adults with intellectual disabilities: what do we know? What do we do? *Journal of Applied Research Intellect Disabilities*. 2014;27(5):431–46.

⁶ Anderson LL, Humphries K, McDermott S, Marks B, Sisarak J, Larson S. The state of the science of health and wellness for adults with intellectual and developmental disabilities. *Intellectual & Developmental Disabilities*. 2013;51(5):385–98.

⁷ Government of South Australia. (n.d.). SA Intellectual Disability Health Service Model of Care 2020. Retrieved February 27, 2022, from <http://www.cpsu.asn.au/upload/2020-Info-Updates/SA%20Intellectual%20Disability%20Health%20Service%20Draft%20MoC.pdf>

⁸ Fletcher, R. J. (2004). Information on dual diagnosis. Retrieved October 1, 2019 from <http://thenadd.org/resources/information-on-dual-diagnosis-2/>

Complexity of Needs:

Many people with IDD have difficulty accessing the right service at the right time to meet their needs. These barriers become more challenging when people have complex support needs. Complexity involves high levels of support needs across various life domains. These include physical, psychosocial, behavioural and social domains. The co-existence of multiple and complex needs impacts on the ability of generic services to effectively assess, identify and meet the range of needs. It is not the person with IDD that is complex but the system. People with IDD often get classified as complex because they challenge the service system's ability to respond to their support needs. People are often seen as complex because the service system is not structured, organized or resourced or otherwise able to respond to their needs.

Children and youth with more complex medical and mental health needs require intensive clinical supports prior to their transition and to follow them through adulthood. Adults in their 40s and 50s also experience the associated cognitive and health issues that the general population will usually experience at a later stage. Recently, we learned that adults with IDD disabilities between the ages of 18 and 64 are disproportionately represented among the top 5% high-cost health care users in Ontario.⁹ They experience higher rates than the general population of preventable diseases and conditions, as well as increased rates of psychiatric and substance-related and addiction disorders.¹⁰

People with IDD require a broad range of diverse community-based services to meet their needs. Support and service needs vary on the individual and their situational factors. Many people will require access to a variety of services and supports, this can include but is not limited to: support coordination across healthcare, human services, education, employment, income maintenance and other community-based supports. Additionally, some individuals with IDD will require assistance coordinating medical, therapeutic and behavioural health services.

Making the shift to community living rather than institutions benefits individuals with IDD by creating opportunities for individuals to become valued and contributing members of their communities, and improved quality of life, therefore making better use of taxpayers' dollars. It is essential to develop high-quality community-based services in order to ensure we as a system are respecting an individual's human rights and working towards achieving better outcomes: improved quality of life, better health and a contributing member of society. Research suggests that community-based supports and services are not necessarily more cost prohibitive than institutional care. Community-based care could be more costly however it is more cost effective given that it leads to better outcomes. Costs for individuals with IDD and complex needs and/or behavioural challenges are generally high, regardless of living environment.¹¹

⁹ Lunskey Y, de Oliveira C, Wilton D, Wodchis WP. *High cost users of health care among adults with developmental disabilities. Applied Health Research Question Series*. Toronto: Health System Performance Research Network and Health Care Access Research and Developmental Disabilities Program; 2017

¹⁰ Summary of Proceedings: 'Making the Invisible Visible'. H-CARDD Provincial Meeting, February 23, 2016.

¹¹ Mansell, Jim & Knapp, Martin & Beadle-Brown, Julie & Beecham, Jennifer. (2007). *Deinstitutionalisation and community living—outcomes and costs: report of a European Study*. Volume 2: Main Report.

Given that those with IDD will often have a multiplicity of needs, it is important that assessments are conducted in an integrated, planned and timely manner. A system that is reactive to risk and crisis will do little to build a resilient service. For persons with IDD who have behaviours that challenge and/or complex support needs, they require specialized clinical supports to live more inclusive lives. The complex and lifelong nature of IDD requires a special knowledge, a familiarity with the population and links with the system that supports them to be dealt with effectively. Based on the literature review conducted by SA Model of Care 2020, “there is no evidence for an ideal model of providing services to individuals with IDDs. Services work best when they are flexible and integrated, drawing together aspects of both mainstream and specialist services and highlighting interagency collaboration.”¹²

Both historically and in recent times, there has been a philosophical tug-of-war that can pit generic (mainstream) service supports against the expertise and specialized services that GLS members provide. This is unnecessary, as these services are truly complementary, not oppositional. As is the case for people who do not have an IDD, there are times when a person might require services from an individual or an organization with specialist knowledge. For people with IDD, there are situations where both individual need and systemic challenges create situations that cannot easily be overcome without specialized support. This is the gap that GLS members fill.

Role and Importance of Specialized Clinical Services:

Practitioners and professionals work with individuals with IDD to improve their health, wellness and capacity to participate in everyday life. Specialized clinical services facilitates collaboration and cooperation with other systems (health, justice, education, etc), they must be multidisciplinary and multidimensional in order to provide comprehensive diagnosis, assessment and clinical services to provide access, coordination and support through advice, assessment, interventions and treatments for those with complex support needs. Research has time and time again shown the need for the implementation of best practices when supporting individuals with IDD in order to create a responsive and effective system of support. Not implementing what we know to date results in an ineffective system that is unsatisfying to both professionals and individuals with IDD and their caregivers. The Ministry of Children, Community and Social Services, defines specialized resources to include: “services such as behavioural assessment and counselling services, speech and language therapy; specialized training for professionals who work with individuals who have a dual diagnosis (e.g., psychiatrists, psychologists, social workers and behaviour therapists); services that provide urgent support for individuals whose needs exceed the capacity of their caregivers; community outreach such as training, consultation and counselling for caregivers (e.g., agency staff, family, community health professionals); residential arrangements where individuals receive transitional or ongoing clinical supports from specialized professionals; research, professional development and training in best practice models of care, support and interventions.”¹³ GLS member agencies share an extensive inventory of specialized clinical services including psychiatry, psychology, nursing, family medicine, etc and allied health

¹² Government of South Australia. (n.d.). SA Intellectual Disability Health Service Model of Care 2020. Retrieved February 27, 2022, from <http://www.cpsu.asn.au/upload/2020-Info-Updates/SA%20Intellectual%20Disability%20Health%20Service%20Draft%20MoC.pdf>

¹³ Joint Policy Guideline for the Provision of Community Mental Health and Developmental Services for Adults with a Dual Diagnosis. Ontario Ministry of Children, Community and Social Services. (n.d.). Retrieved February 27, 2022, from https://www.mcscs.gov.on.ca/en/mcscs/publications/developmentalServices/joint_policy_guide/toc_joint_policy.aspx

therapies, occupational therapy, physiotherapists, social workers, behavioural therapists, etc. (see Appendix I), which provide an important link for people with complex needs who require the support of Developmental Services and other sectors enabling people to get the specialized support they need.

The report by the Ontario Ombudsman, *Nowhere to Turn* noted that gaps in specialized services leaves individuals and families with few choices, particularly when in crisis. “The violent, impulsive and destructive behaviour of some individuals with developmental disabilities can besiege their caregivers. Without sufficient specialized community supports and services, many resort to hospitals or the police for help.”¹⁴

DS providers have demonstrated time and again that when the right clinical resources are available and at the right time, individuals can be supported in their community and to live as independently as possible, while also preventing and/or limiting expensive and lengthy admissions to more institutional environments (hospitals or jails) or to inappropriate and unsafe housing. In the absence of specialized services, families and agencies experience significant stress and breakdown, and individuals experience suboptimal out-of-home placements where their complex needs are not addressed and their quality of life is severely limited. Several placement breakdowns could have been prevented had individuals received better community-based services and ongoing specialized services. Many could be discharged earlier if the right community supports are available and provided. Community-based services must include preventative and pro-active care that starts before problems manifest and we need to begin focusing on the individual’s needs and not the boundaries of the system.

Individualized Funding

As mentioned in the GLS document ‘Reimagining Specialized Developmental Services in Ontario’ one of the potential areas of conversation between the Ministry and GLS is that of Individualized Funding. Individualized funding is a term describing a process in which an individual identifies his or her 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 approach is designed to provide personalized and self-directed supports for people with an IDD, which places individuals at the center of decision-making around how and when they are supported. The United Nations identified Individualized Funding as one way in which empowerment might be achieved for persons with IDD’s.¹⁵ It is believed that inter-related benefits could include, freedom, flexibility and continuity of care/service/life, improved family life and social opportunities and enhanced self-image.¹⁶

- Contributes to self-direction, empowerment, independence and self-determination.
- Individuals with IDD can plan and select the supports and services that best suit their situation.
- Funding is portable

¹⁴ Ombudsman Report. Investigation into the Ministry of Community and Social Services’ response to situations of crisis involving adults with developmental disabilities. *Nowhere to Turn*. August 2016. p. 127 - 128

¹⁵ Fleming Pdraic, McGilloway, Sinead and Thomas, Steve. *Individualised Funding: A realist analysis to identify the causal factors that facilitate positive outcomes*. Switzerland, Disabilities 2021, Pg. 47.

¹⁶ *Ibid* pg. 51

Current Environment-How are Specialized Services Currently Being Delivered

Within the Developmental Service sector specialized services are primarily delivered through based funded transfer payment agency model. Specialized services include the following;

- Psychological and biopsychosocial assessments (cognitive functional expertise in trauma and mental health)
- Behavioural assessments and interventions
- Speech and Language Therapy
- Counselling services
- Urgent Response Support
- Case Management
- Specialized training for professionals who work with individuals who have a dual diagnosis (e.g., psychiatrists, psychologists, social workers and behaviour therapists)
- Community outreach
- Residential arrangements where individuals receive transitional or ongoing clinical supports from specialized professionals

These services are subject to rigorous quality assurance measures (QAM) ensuring the upmost quality and accountability. Provincial bodies such as GLS ensure a coordinated and consistent system of service delivery that is available and responsive. Having said this there is room for improvement within an Individualized Funding environment.

Reimagined Environment-How Might Specialized Services Be Delivered Moving Forward

During the COVID pandemic temporary measures were put in place to allow for the development and implementation behavioral support plans to be funded within the Passport program, as a result the question has been asked, whether or not this should/could be continued post pandemic? GLS believes the answer to this question is yes.

Like so many other community initiatives, implementation and a clear understanding of outcomes is paramount in order to achieve success.

Let's begin with the end in mind. GLS would support a system that delivers clinical services in a flexible fashion, providing a shift in power and responsibility from agencies/organizations to the person with an IDD or their representative, where the shift is requested and appropriate.

GLS identifies within their position paper ('Reimagining Specialized Developmental Services in Ontario', 2021), the important paradigm shift associated with Individualized Funding (IF). Further, GLS believes that if properly implemented, Individualized Funding within specialized services, can for many people, contribute to self-direction, empowerment, independence and self-determination.

The following is intended to encourage discussion and assist in forming policy regarding Individualized Funding within the delivery of specialized services in Ontario.

Key Considerations

Successful implementation of Individualized Funding is dependent upon a firm foundation based on research-based considerations. While not exhaustive, key considerations are as follows:

1. Choice:

While the realization of full citizenship is enhanced by increasing purchasing power and by the movement towards rights-based social policies and initiatives, not every individual will be comfortable with assuming the responsibility and stress associated with the decision-making processes of service planning and purchasing.¹⁷ With this in mind, it should be understood that for one person to self-direct the clinical services they require might be empowering, whilst for another, it may be seen as stressful. Maintaining transfer payment clinical services for individuals who request/require them would allow for increase choice, strong clinical options and sector stability.

2. Comprehensive legislative policy framework:

According to Stainton (2005); “Canadian disability policy and practice should progressively move away from the assumption that individuals with IDD’s are incapable of making choices, instead policy structures and instruments should progress towards supporting individuals with IDD to exercise rights and citizenship by supporting the articulation of choices and building the capacity to act on choices.”¹⁸

The Ministry of Children, Community and Social Services’ ‘Journey to Belonging’ reform plan lays out a clear vision, supporting principals and reform commitments that along with supporting policy will allow for the necessary supports. Supports that empower people, allowing them to live as independently as possible.

¹⁷ Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? *Social science & medicine*, 44(5), 681-692.

¹⁸ Stainton, T. (2005). Empowerment and the architecture of rights based social policy. *Journal of Intellectual Disabilities: JOID*, 9(4), 289-298.

3. **Personal Support Plans should determine the funding:**

The creation of personal support plans with clear indications of personal goals is at the heart of individualized planning not only because it helps to clarify individuals support needs, but it also monitors the effectiveness of services received and informs outcomes. The formal assessment process of need has been identified a key facilitative element of the individualized funding process.¹⁹

4. **Accountability, Quality and Safeguards:**

Individualized Funding seeks, among other things, to give people more choice and control over their social care and support services to enable them to lead more independent and fulfilling lives. Within this pursuit, **accountability** plays an important and complementary role. Ogden suggests that empowerment and accountability are 'reciprocal interdependencies'.²⁰

In a similar fashion, systemic **quality** better enables the individual with an IDD to pursue an inclusive life, one where the person is empowered to make choices and live as independently as possible, without concern that the 'not for profit' or 'for profit' provider is providing quality services.

Safeguards need to be fully incorporated into adult supports so that services focus on the person rather than the process.²¹

5. **Rural, Remote and Specialized considerations:**

Rural and remote areas may experience a lack of alternatives within the community. This is often referred to as a 'thin market'.²² This occurs when there are very few providers of a service in a local area resulting in constraints of choice and control. This is particularly common in rural and remote areas where vast distances between participants and providers or in areas where specialized services are not available. Ensuring a strong inventory of services providers is fundamental to allowing for choice.

In addition to the barriers faced by rural and remote areas, we also need to recognize that there are limited specialized service providers and community resources that are able to support French Speaking individuals. We need to ensure that services are available and accessible to Francophones across the Province of Ontario.

In addition to the 'thin market' barrier, there is also the cost barrier. Many families in rural and remote jurisdictions have reported additional costs making it next to impossible to secure clinical services in rural and remote areas.²³

¹⁹ Fleming Padraic, McGilloway, Sinead and Thomas, Steve. Individualised Funding: A realist analysis to identify the causal factors that facilitate positive outcomes. Switzerland, Disabilities 2021, pg. 53.

²⁰ Ogden, S., Glaister, K.W., & Marginson, D. (2006). Empowerment and Accountability: Evidence from the UK Privatized Water Industry. *Journal of Management Studies*.

²¹ Carr, Sarah (2013). *Enabling risk, ensuring safety: Self-directed support and personal budgets*. London

²² Malbon, Eleanor, Carey, Gemma, Meltzer, Ariella. *Personalisation Schemes in Social Care*.

²³ Dew Angela, Bulkeley Kim, Veitch, Craig, Bundy Anita, Lincoln, Michelle, Brentnall Jennie, Gallego, Gisselle, Griffiths, Anita. *Carer and service providers' experiences of individual funding models for children with a disability in rural and remote areas*. Australia, Health and Social Care, 2013.

6. Need for upskilling and training:

People with IDD's should be supported in their decision making through the provision of capacity-building programs (including information and education) and the presence of appropriate safeguards to manage risk and promote safety. As people with IDD's increasingly act as employers they must be supported to acquire/develop the necessary skills. Recent evidence suggests that people availing themselves of individualized funding are in fact capable of acquiring the necessary skills.²⁴

In situations where individuals with IDD's are supported by another person, the need for upskilling and training is equally important. The role of managing a personal budget on someone's behalf is a difficult and demanding task that also requires specialized training.²⁵

7. Marketization and entrepreneurship:

Transitioning to a fee for service environment will require transfer payment agencies to adjust their services accordingly. Choice for the person seeking services is to a large degree dependent on a robust market that provides multiple service providers.²⁶

Conclusion

In conclusion, GLS supports a thoughtful integration of Individualized Funding model for Clinical services in Ontario. This model, in order to be successful must ensure the following:

- Choices for individuals
- Policy framework
- Personal Support plans
- Accountability, Quality and Safeguards
- Rural, Remote and Specialized considerations
- Upskilling and Training, and
- Marketing and entrepreneurship

²⁴ Fleming Pdraic, McGilloway, Sinead and Thomas, Steve. Individualized Funding: A realist analysis to identify the causal factors that facilitate positive outcomes. Switzerland, Disabilities 2021, Pg. 48.

²⁵ Turnpenny, Agnes, Rand, Stacey, Whelton, Beckie, Beadle-Brown, Julie, Babaian, Jacinta. Family carers managing personal budgets for adults with learning disabilities or autism. Wiley, September 2020.

²⁶ Malbon, Eleanor, Carey, Gemma, Meltzer, Ariella. Personalisation schemes in social care.

Appendix I – GLS Members Clinical Supports Provided

Specialized Provider	Audiology	Behaviour Therapy	Comm. Disorder Asst.	Developmental Therapist	Dietician	Kinesiology	Dental services	Medicine – Dev. Paeds.	Medicine – Family Med.	Medicine Genetics	Medicine Neurology	Medicine - Psychiatry	Massage Therapy	Nursing (NP)	Nursing (RN)	Occupational Therapy	Pharmacy	Physiotherapy	Psychology	Psychometry	Seating Technician	Social Work	Speech Language Path
Access Community Services		✓			✓							✓					✓		✓			✓	
Bethesda		✓	✓					✓							✓	✓			✓	✓		✓	✓
Brantwood						✓							✓		✓	✓					✓		
Canopy		✓	✓																			✓	
Central West Specialized Developmental Services		✓	✓		✓				✓			✓			✓	✓		✓	✓	✓			✓
Cochrane Temiskaming Resource Centre		✓	✓	✓	✓				✓				✓		✓	✓		✓	✓	✓		✓	✓
Community Living Huronia		✓													✓								
Developmental Services of Leeds and Grenville		✓	✓						✓	✓		✓				✓			✓	✓		✓	
HANDS TheFamilyHealthNetwork.ca		✓	✓	✓											✓				✓	✓		✓	✓
Ongwanada		✓			✓				✓			✓			✓	✓	✓	✓	✓		✓	✓	
OPTIONS Northwest		✓													✓	✓			✓		✓	✓	✓
Pathways to Independence		✓							✓		✓	✓			✓	✓	✓	✓	✓		✓	✓	
Regional Supports Associates		✓	✓									✓			✓	✓			✓	✓			✓
Sunbeam Residential Developmental Centre		✓			✓		✓		✓			✓	✓		✓	✓	✓	✓			✓	✓	✓
Surrey Place Centre	✓	✓	✓	✓	✓			✓	✓			✓		✓	✓	✓	✓	✓	✓	✓		✓	✓
Valor & Solutions		✓	✓									✓		✓	✓	✓	✓		✓			✓	✓