

2021

Reimagining Specialized Developmental Services in Ontario

SUBMITTED TO: MCCSS
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Executive Summary

Introduction to GLS

GLS is an association of sixteen (16) 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. Developmental Services (DS) sector clinicians are skilled in developing and adapting strategies when working with a range of functional abilities and disabilities. GLS members are experienced in providing the appropriate specialized assessments and interventions this group of individuals require and are able to integrate the behavioural and biopsychosocial approaches necessary to support success in community.

The Importance of GLS' Specialized Services

GLS member agencies provide an important link for people with complex needs who require the support of Developmental Services and other sectors, having staff with specialized and clinical expertise. With a focus on understanding the specialized health and support needs of people with developmental disabilities, GLS members enable people to get the specialized support they need reducing barriers and creating more sustainable supports. GLS members:

- Provide Specialized Services, driven by evidence, outcomes and continuous improvement;
- Provide the link between Developmental Services and the Health Sector;
- (Eight (8) members) Are responsible for the Community Networks of Specialized Care (CNSC);
- Educate; and
- Respond to extraordinary community needs

GLS members have established a network of agencies that support each other through the exchange of resources based in evidence, outcomes and continuous improvement. This synergism has resulted in agencies that are proactive and responsive to people's changing needs throughout their lives.

Reimagining Specialized Services across Ontario

In the context of "Journey to Belonging," and in partnership with MCCSS, GLS would welcome the opportunity to broaden the conversation, inviting others to reimagine how Specialized Services across Ontario can best support people with developmental disabilities who have complex and multiple needs.

Potential areas of conversation could include:

- Supplementing face-to-face supports with digital technology;
- Creating a comprehensive, sustainable 'Just-In Time, Just-Enough' service model;
- Formalized provincial collaboration of Specialized Services;
- Building the capacity of the DS, Health and Other Sectors; and
- Responding to the individualized funding environment.

Thank you for the opportunity to share our passion for the support of people.

Introduction to GLS

GLS is an association of sixteen agencies located across Ontario. Members deliver a range of specialized behavioural, clinical, health and medical services to children, youth and adults with intellectual and developmental disabilities (the people). The members of GLS collectively provide services and supports to people who have multiple and complex needs that are often unable to be met in other community agencies. Current members include:

- Access Community Services, Port Hope
- Bethesda, Thorold
- Brantwood Community Services, Brantford
- Central West Specialized Developmental Services (CWSDS), Oakville
- Cochrane Temiskaming Resource Centre (CTRC), Timmins
- CLH Developmental Support Services, Midland
- Developmental Services Leeds and Grenville, Brockville
- Hands – The Family Help Network, North Bay
- Ongwanada Resource Centre, Kingston
- Options Northwest, Thunder Bay
- Pathways to Independence, Belleville
- Regional Support Associates (RSA), Woodstock
- Sunbeam Community and Developmental Services, Kitchener
- Surrey Place, Toronto
- Canopy Support Services, Peterborough
- Valor & Solutions, Ottawa

At this time, GLS does not represent all providers of multiple and complex supports; however, opportunities to expand membership are being explored, as is the potential to create a repository of agencies providing similar supports, and an inventory of the services they provide.

GLS members define the unique supports they provide as ‘Specialized Services’ – services that go beyond those offered in the more mainstream Developmental Services sector. These services are of a higher intensity for those with greater challenges or more complex needs and are often offered by regulated health professionals who also specialize in Intellectual Disability (ID), including nurses, occupational and physio therapists, social workers, behavioural therapists, psychologists and psychiatrists.

DS sector clinicians are skilled in developing and adapting strategies when working with a range of functional abilities and disabilities. They are also experienced providing the appropriate specialized assessments and interventions this group of individuals requires and are able to integrate the behavioural and biopsychosocial approaches necessary to support success in the community. Members also provide DSO eligibility assessments, specialized respite support, and assistance to people who have become involved in the legal / judicial system.

The Importance of GLS' Specialized Services

GLS members provide Specialized Services driven by evidence, outcomes and continuous improvement.

The importance of specialized services existed before COVID-19, and it has in no way diminished – rather it has increased as the fall out and long term repercussions of COVID-19 began to be identified. In Ontario and Canada, the number of practitioners with this specialized expertise is relatively rare. Having these supports available is a strength of Ontario's community service system. Because the demand for this expertise far exceeds current availability, the members of GLS are creating strategies to make their knowledge, skills and expertise as accessible as possible. The emphasis on a sustainable and knowledgeable workforce extends to the GLS workforce.

Both historically and in recent times, there has been a philosophical tug-of-war that can pit generic developmental 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 a developmental disability, there are times when a person might require services from an individual or an organization with specialist knowledge. For people with developmental disabilities, 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.

The need for specialized behavioural therapy and psychological services is paramount. A clinician in this area who also specializes in developmental disability has expertise that enables the following types of services to be made available:

- Psychological and biopsychosocial assessments and counselling (cognitive functional expertise in trauma and mental health);
- Behavioural assessments and interventions;
- Development of behavioural support plans and overall support strategies;
- Crisis management;
- Comprehensive understanding and expertise in the management and complexity of ID across the lifespan of the individual;
- Grief and relationship counselling specific to individuals with developmental disabilities;
- Children's developmental assessments;
- Attachment work / counselling play therapy;
- Sensory assessments skills system;
- Emotion regulation programs; and
- Occupational and physio therapy, social work, nursing, etc.

GLS Members Provide the Link between Developmental Services and the Health Sector

As is evident in the examples cited above, the role of Specialized Services in DS and other sectors is critical. However, this role is not only important at a time of crisis. GLS members have provided that important link between Developmental Services and other sectors for many years, in many situations. They consistently prove their ability to adeptly navigate and enhance the supports of daily living offered in the Developmental Services sector and non-specialist supports offered in other sectors.

Having staff with clinical expertise and an understanding of the DS sector and individuals with developmental disabilities provides more generic health providers with access to specialized expertise on the unique features of this particular cohort of society. GLS members are often called upon to consult with, assist, support and educate health care providers on providing appropriate health services for people with developmental disabilities. Without this expertise, acute and complex health care conditions may not be identified or adequately addressed.

With their focus on understanding the specialized health and support needs of people with developmental disabilities, and their connections to both sectors on both a local and provincial level, GLS enables people to get the specialized support they need, with the help required to navigate the complexities of service systems. The broader health sector also benefits significantly from this relationship, as GLS competently builds capacity within the health system to adequately address the additional health needs experienced by people with a developmental disability.

GLS members are responsible for all eight (8) Community Networks of Specialized Care (CNSC), providing an invaluable link in supports for people.

GLS Members (8) are Responsible for the Community Networks of Specialized Care (CNSC)

As GLS members deliver a range of specialized behavioural, clinical, health and medical services to children, youth and adults with intellectual and developmental disabilities, they also work closely with those entities in the developmental services sector that coordinate access and connections to services, and are responsible for the Community Networks of Specialized Care (CNSC). The mandate of the CNSC clearly indicates their role in coordinating the supports a person with complex needs requires, including supports within the health care and justice sectors. As stated above, the specialized skills and expertise needed to provide the required support to those individuals is not available within the health system. The CNSC finds the expertise and specialized supports a person needs within the DS sector, from the members of GLS. The relationship between the two groups can be clearly articulated as a relationship of coordination and delivery – the CNSC coordinates the most complex support and, in doing so, they reach out to the organizations best able to deliver that support – members of GLS.

GLS Members Educate

In addition to providing specialized clinical treatment, the experts within GLS member organizations also provide education to all staff in the DS, health and other sectors, in order to build their capacity to respond appropriately, to improve outcomes and to increase the quality of care provided to supported individuals across the care continuum. For example, a dietician / nutritionist with specialized skills for the DS population can provide diet and nutrition guidance contextualized for people with developmental disabilities, such as advice specific to dysphagia, enteral feeding, swallowing assessments, etc.

GLS Members respond to extraordinary community needs

During the initial response to, and subsequent waves of COVID-19, the members of GLS experienced a significant increase in requests for assistance. These requests continue unabated, and are expected to rise in the upcoming months and years. Requests for service include:

- Individuals who were already affiliated with services increased their requests for assistance as they staved off loneliness, anxiety, boredom and the repercussions linked to a loss of routine and having minimal social contact. Mental health concerns are a growing issue.
- Families / caregivers who support people in their family home requested supportive counselling and behavioural strategies, in order to keep their family out of crisis.
- Developmental Service agencies reached out for counselling support for individuals in service and when they were unable to respond to the increase in challenging behaviour and mental health issues that emerged. GLS members responded by offering increased behavioural, psychiatric and nursing supports.
- When there was a marked gap in the health sector's ability to provide COVID-19 tests safely and effectively to people with developmental disabilities, assistance was provided by GLS members to overcome communication challenges and to help people who did not fully comprehend what was to occur. Nursing supports related to COVID-19 hospitalizations were also requested.
- Requests for specialized respite and crisis residential services increased significantly. As these much-needed services needed to be temporarily suspended, GLS members responded by providing the expertise needed to enable people to remain in their homes, safely.
- Many DS agencies were unaccustomed to the more comprehensive health, safety and sanitization protocols that became necessary. They were supported by GLS members, who offered their expertise on infection control, donning /doffing PPE, training for staff teams, and coping strategies for people with developmental disabilities who were required to wear PPE. For many people with complex and multiple needs, wearing and being around people with PPE was particularly traumatic as it was a new sensory requirement, it deviated from set routine, and it invoked stress and anxiety.

Despite this unprecedented demand for service, GLS members have focused their resources on responding to most immediate and acute need. Flexible and innovative strategies were quickly developed to meet the increased demand for service. Because of their close relationship with one another, GLS members were able to maximize and share internal resources, while also leveraging pre-existing partnerships and relationships with Public Health and the broader health sector.

For further information on GLS contributions within the COVID – 19 pandemic please see Appendix A.

Reimagining Specialized Services across Ontario

GLS invites the MCCSS to work with us to create a provincial system that is fully aligned with the “Journey to Belonging,” where the right specialized supports are available at the right time, and just enough support is offered to complement and leverage community-based services. There is no competition, nor is there a philosophical chasm. Specialized Services are a necessary part of supports to people with developmental disabilities, at the times when they are needed.

The members of GLS have debriefed on their recent experiences, identifying opportunities and challenges that arose as a result of COVID-19, and how GLS aligns with “Journey to Belonging.” At this time, these conversations are still internal to GLS. With the support of the MCCSS, GLS would welcome the opportunity to broaden these conversations, inviting others from across the province in to reimagine how Specialized Services across Ontario can best support people with developmental disabilities who have complex and multiple needs. Looking ahead, there are tremendous opportunities to develop innovative service offerings. Potential areas of focus are listed below:

Supplementing Face-to-Face Supports with Digital Technology

Now that the initial technology learning curve has been addressed, and the needed technology is now more readily available, opportunities exist to continue to use digital technology in situations where it is clinically appropriate. Technology has enabled some obstacles and barriers related to geography, travel, scheduling, privacy, and security to be addressed. The timing is right to further explore when, and when not, to use videoconferencing technology in the delivery of Specialized Services. For example, leveraging the use of virtual services may be particularly important for large and rural catchment areas; however, many people do not have access to technology and the support they require cannot be offered through a virtual platform.

People with similar needs may be provided with group support, even if they live in different parts of the province.

As exciting and tempting it is to see technology as the answer to many of the accessibility issues facing people, GLS members have already identified significant limitations. As mentioned earlier, it was estimated that over 25% of people could not be provided support using this technology, for a wide variety of reasons. It is envisioned that more comprehensive guidelines for the use of technology in specialized / clinical services would better inform the degree to which specialized supports, interventions and programs can be made available electronically. This will also require more secure videoconferencing platforms in order to maintain or improve the confidence in privacy, confidentiality and consent, and to meet Ontario’s privacy legislation.

Creating a Comprehensive, Sustainable Just In Time, Just Enough Service Model

In certain circumstances, people with developmental disabilities who have complex and multiple needs require the assistance from people and organizations located across the province. Without the right supports at the right time, it becomes more difficult to be successful, decreasing quality of life. GLS members can meet the specialized support needs by offering provincial coordination and delivery of supports – both virtually and face-to-face - that enables people to receive the right amount of support, at the time when it is needed.

The benefits of online support – reaching further, faster, is indisputable. Although some specialized supports can be done virtually, others need to be offered face-to-face. For example, face-to-face sessions often include tactile and / or concrete items being used. This is not as easily achieved with a virtual connection. In a future service delivery model, both types of services would be maximized, to ensure the right type of support is available, at the right time. An opportunity exists to strengthen the blended delivery model further and increase the capacity to provide comprehensive specialized supports.

Formalized Provincial Collaboration of Specialized Services

To date, GLS members have collaborated in an impromptu, situation-specific manner. Now, GLS is well positioned to formalize this collaborative role and offer some specialized services without being limited to geographic boundaries. GLS has explored the concept of a provincial mobile response team in the past but believes the time for this service is now. Having completed the inventory of skills that are available with the GLS member agencies, it is apparent that there is an opportunity to truly capitalize on this experience and provide individualized approaches. With provincial coordination, an understanding of the needs of the person, and knowledge of where specialists exist who can best provide this support, a mobile response may now be possible.

Building the Capacity of the DS, Health and Other Sectors

The Specialized Services provided by the members of GLS are critical for the success of adults with complex and multiple support needs. However, this expertise, and how it benefits children, youth and adults with developmental disabilities, is not well understood. An important lesson learned is that other sectors are not fully aware of the unique needs of people with developmental disabilities – and the DS sector as a whole – relegating the work of the sector to an afterthought. It has also been shown that community-based occupational and physio therapy, social work, nursing, nutrition, behaviour and psychology services lack the in-depth knowledge and expertise required to effectively work with individuals with a developmental disability and the associated challenges and complexities. GLS can build capacity of the workforce with initiatives focused on formally identifying ID as a speciality, and then taking steps to heighten awareness and understanding of this specialty, ultimately building capacity in the DS, health and other sectors.

Due to the clinical expertise and experience embedded in the service models of many GLS member organizations, several GLS members have emerged as regional "IPAC Champions" for MCCSS funded agencies throughout the COVID-19 pandemic. Having an in-depth understanding of MCCSS funded congregate living settings and the unique needs and vulnerabilities of persons served in our sector has

allowed our IPAC subject matter experts to serve an essential and effective function in supporting all MCCSS funded agencies with IPAC practices and pandemic protocols, managing outbreaks and even effectively operationalizing innovative, leading edge vaccination efforts for our persons served and essential caregivers. Our members have long-established connections with Health Care and Public Health, and have been recognized through the provincial IPAC Champion initiative as a critical resource for the Developmental Services sector. The continuation and expansion of our role as IPAC Champions and key liaisons with healthcare, Public Health and the new Ontario Health Team (OHT) model will be critical to ensuring a proactive, collaborative environment supporting the health, safety and well-being of persons served in our sector.

Responding to the Individualized Funding Environment

GLS recognizes the important paradigm shift that occurs in a direct, or individualized funding system, and sees potential to work with people, families and service providers outside of the funded service model. A comprehensive costing of this level of service is welcomed. While the full range of opportunities fee-for-service presents are still being explored, GLS' membership are exploring ways to make supports more accessible, available, and responsive. Potential concepts include fee-for-service training and certification, offering additional supports that are not currently available, and creating resources that may be of assistance to a range of audiences. Innovative respite and crisis services may also be possible through this model. GLS would welcome the opportunity to work with the MCCSS to explore this potential further.

Conclusion

By putting people first, GLS member agencies have, for many years, provided specialized behavioural, clinical, health and medical supports based on peoples unique needs and circumstances. We welcome the opportunity to work with MCCSS ensuring that people with developmental disabilities are empowered to live wonderful lives.

For additional information, please contact:

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Appendix A: COVID–19 Overview

During the initial stages of the COVID–19 pandemic, members of GLS responded to the requests for support in innovative, and person-directed ways. Digital delivery of services was made available using videoconferencing, when possible and appropriate. Resources were developed and shared across the sector, COVID-19 guidelines and protocols were interpreted, adapted and disseminated, and all efforts were made to ensure the expertise that exists amongst the members was capitalized on across the province.

Best practice and innovative approaches were a focus throughout COVID-19, as GLS focused on building capacity within the DS sector - and other sectors such as health - to be able to continue to respond to the unique needs of people with a developmental disability and complex needs. Examples of capacity building include:

- Working alongside health professionals to expand their knowledge of the special considerations of people with developmental disabilities;
- Working closely with the mental health sector to provide assessments of individuals in emergency / crisis situations, such as suicidal ideation; and
- Providing assistance and guidance to Public Health officials, hospitals, COVID-19 testing centres, and representatives of the health sector as they struggled to understand and adapt policies and practices to the DS sector.

Now, as COVID-19 is in its fourth wave, members of GLS have reflected on their work, aligned it with the strategic direction of MCCSS, and are encouraged by the strong alignment between their approach and the approach being put forth by the Ministry, with the focus on:

- Strengths and person-directed services;
- Earlier intervention;
- A skilled workforce;
- Utilization of technology; and
- Implementing best practices and collaboration across agencies and sectors.

These have been consistent messages from the members of GLS for many years.

Examples of the GLS response to COVID-19 in the DS sector include:

- Providing digital supports, like videoconferencing technology, to provide aspects of specialized supports to people who would otherwise receive in-person assistance. This technology made it possible to provide critical services during a particularly taxing period of time, and enabled people to have access to support in a timely manner. It is important to note that videoconferencing could not be used in all situations - based on estimates from the members over the past six (6) months, more than 25% of supports could not be offered virtually due to the specialized circumstances and people's clinical needs.
- Creating virtual support groups for families and people with developmental disabilities, including online day services, as a way to assist with building new routines and structures, and keeping people active and engaged. One (1) agency, for example, ran six (6) support groups starting in April 2020, serving approximately thirty (30) people who would have otherwise received limited support.
- Developing DS sector specific policies and procedures to enable organizations to contextualize and operationalize guidelines developed by Public Health.
- Updating guidelines and best practices to be able to provide both in-person and virtual supports. These guidelines will evolve into policies and procedures that can guide interactions with specialized and clinical services moving forward. It also resulted in an increased capacity to schedule videoconference meetings.
- Sharing and making available the expertise of the GLS organization to other members, so they could collaborate to ensure people received the best support possible, regardless of where the expertise was located in the province. For example, a speech-language practitioner from one (1) of the GLS member agencies developed 'plain language' social stories and education explaining the pandemic. Thirty (30) kits were provided to people who needed them most, and an electronic version was then posted on the agency website and shared across the province by the GLS members.
- Supporting direct service providers who were working with isolated people, by offering behavioural services education opportunities.
- Providing virtual training on Courtroom Roles to assist people with developmental disabilities involved in the justice system during COVID-19.
- Responding wherever possible to requests to support adult DS group homes that were experiencing staffing shortages due to quarantine and self-isolation requirements. As the DS sector was not considered "essential" at the outset of the pandemic, and thus, not eligible for emergency childcare, significant staffing capacity reductions occurred.
- Increasing the confidence of community agency staff who had not used PPE in a manner and to the extent that was required to respond to COVID-19. Training sessions with GLS nursing staff were offered to overcome this lack of experience, lack of confidence, stress and some confusion.
- Leveraging in-house procurement expertise / resources to acquire necessary supplies in an environment where PPE was limited.
- Responding to partner DS agencies when they received requests for crisis support from families of children, youth and adults with a developmental disability.

Examples of ways GLS increased the capacity of other sectors include:

- Providing assistance and guidance to Public Health officials, hospitals, COVID-19 testing centres and representatives of the health sector as they struggled to understand and adapt policies and practices to the DS sector.
- Many GLS members had their registered staff do the COVID-19 swabbing of persons-served, then sent the swabs off to Public Health for lab processing. This was beneficial for the individuals we served as the swabs were done by staff who were familiar to / trusted by our clients, and who had the in-depth knowledge of the individuals' clinical, physical, emotional and behavioural needs in order to reduce the stress and anxiety of this intrusive procedure. It also avoided having to transport clients to public testing sites, and avoided testing delays where a mobile testing unit may have been available in the community.
- GLS members were able to work with the LHIN, Public Health and local OHT to carry out one-time COVID-19 surveillance testing of congregate living front line (asymptomatic) staff this Fall.
- Because members of GLS have registered staff, and because of long-standing relationships with healthcare entities, GLS members were able to conduct staff surveillance testing without a significant draw on healthcare resources.
- Increasing specialized nursing intervention and offering specialized nursing services to meet the increased phlebotomy service demand.
- Working closely with the mental health sector to provide assessments of individuals in emergency / crisis situations, such as suicidal ideation.
- Linking and providing guidance to the mental health sector when after-hours calls to a distress line increased.
- When requested, offering advice and expertise to other sectors that support people with developmental disabilities who have complex and multiple needs.

These are all examples of initiatives taken in response to COVID-19; they were only possible because of our previous work together and relationships with other sectors. These practices are reflected in “Journey to Belonging” in both the Guiding Principles and the Key Commitments. GLS welcomes conversation that addresses how we might collaborate to shift to a more sustainable system that includes Specialized Services post-pandemic.