

HORIZONS

ISSUE 1 • 2020

THIS ISSUE: INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

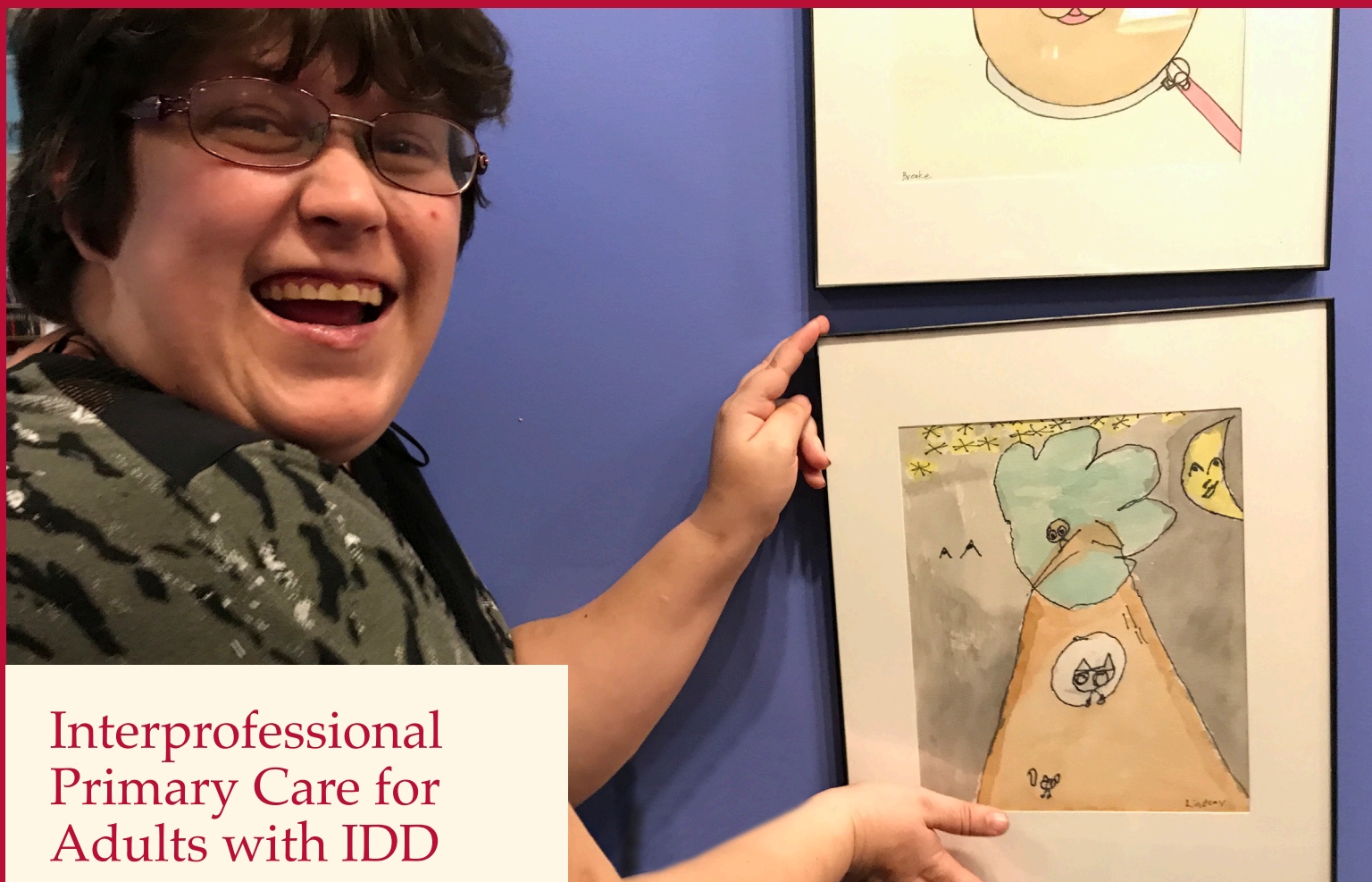


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Interprofessional Primary Care for Adults with IDD

By Dr. Nicole Bobbette, PhD, OT

Access to high-quality primary care has been identified as critical to improve the health of adults with intellectual and developmental disabilities (IDD) in Ontario.^{1,2} Adults with IDD experience high rates of physical and mental health conditions, often use health services more frequently than individuals without IDD, and continue to face barriers to care.² The 2018 *Canadian Consensus Guidelines on Primary Care for Adults with IDD* recommend interprofessional

primary care teams to increase access to a range of health services, and to offer comprehensive and co-ordinated primary care along the lifespan.³

Despite support for interprofessional primary care, there continues to be limited understanding of the key organizational attributes and processes that facilitate the provision of team-based care for adults with IDD.⁴ To address this gap, a multiple-case study examined the provision of interprofessional primary care in two team-based models in Ontario: family health teams (FHTs) and

community health centres (CHCs). Five interprofessional primary care teams participated in the study (three FHTs, two CHCs) and a range of patient, health provider and administrator perspectives were sought to improve our understanding of this approach. The following highlights important considerations for the provision of interprofessional primary care for adults with IDD in Ontario, and can be used to inform practice.

ORGANIZATIONAL ATTRIBUTES

Several organizational-level attributes were identified as important for the provision of interprofessional primary care for this population. Attributes included: the co-location of health providers and interprofessional services; having a shared medical record to support communication between health providers; having time and scheduling flexibility to adapt to patient needs; and having both supportive leadership and an organizational culture that focused on the care of vulnerable populations.

VALUING A TEAM APPROACH

Health providers consistently reported the value of having access to a team, particularly for patients with IDD who presented with high and/or complex health needs. A range of team members' expertise assisted in developing a comprehensive understanding of the patient, and in supporting advocacy efforts and system-navigation.

UNIQUE CONSIDERATIONS FOR CARE OF ADULTS WITH IDD

There was a consistent commitment to providing person-centred care across teams and professions. In addition, health providers identified that "a special sort of lens" was required to ensure high-quality, person-centred care for adults with IDD. A commitment to meeting a person where they are and taking a strengths-based approach was critical. As well, greater attention to engaging knowledgeable caregivers; getting creative with assessment and intervention strategies; and engaging care processes earlier on and more frequently than with patients without IDD were important to facilitate care. These processes build upon the foundational skillset of many health providers in primary care, and should be

employed to support the provision of appropriate and accessible interprofessional primary care that is consistent with recommendations outlined in the *Canadian Consensus Guidelines*.³

THE "GO-TO" PERSON

Both health providers and patients shared that it was very helpful to have an identified "go-to" person on the team. For patients and caregivers, this meant having someone they could reach to help them access needed health services. Having this connection to a team member (e.g., health provider, clinic clerk) made a difference in building patients' and caregivers' confidence and capacity to care for their health. For health providers, having someone on the team that could assist with system navigation

and connecting individuals with available resources across health, social, and developmental services sectors was highly valued. Nurse system navigators or community service workers often took on these roles for patients with IDD.

THE NEED FOR FURTHER ORGANIZATIONAL PROCESSES TO SUPPORT INTERPROFESSIONAL CARE

While the value of interprofessional primary care teams was recognized, results highlight that it was not always simple to engage a team, and that collaborative processes are still developing. In many practices, there was limited engagement of interprofessional services,

with physicians and nurses continuing to be the main health providers involved in the care of this population. There was also the recognition that a lot of collaboration between health providers occurred more informally "behind the scenes" versus in established and explicit collaborative care pathways (e.g., daily rounds/huddles, care conferences). Further work is needed to understand how interprofessional care is enacted in each team and to develop organizational processes that facilitate the provision of team-based care. More specifically, it will be important to determine what interprofessional services are needed to foster the health of adults with IDD, and to increase their access to targeted prevention and comprehensive care.

“*A collaborative-care model is absolutely going to have the best chance of providing the levels of, potentially, increased care that that population would need.*” (Family health team family physician #1.)

“ I think there’s a lot more we need to know about collaborative care that we don’t. I mean, I think we all have talked about how wonderful it is for such a long time now, but the examples of it are, in my own experience, few and far between, and it’s not as easy as it sounds.” (Family health team family physician #2.) ”

A LACK OF CLARITY ON SERVICES AND SUPPORTS

Concerningly, many patients with IDD and their caregivers did not know what supports were available, and more explicit communication around how interprofessional primary care teams work, and what they offer, would also be helpful. Ensuring that available services are explicitly discussed is an important step in building patient capacity to access needed services. It cannot be assumed that patients with IDD and caregivers a) know the services available, and b) understand the potential contributions and value of these interprofessional health services to their health. Engaging and educating caregivers alongside patients with IDD is a critical part of this process as caregivers often assist in advocating for, and facilitating access to, health services.⁵

NEXT STEPS

Interprofessional primary care teams have tremendous potential to support patients with IDD along the lifespan; however, it cannot be assumed that high-quality, accessible and appropriate interprofessional care will happen without attention. This study identified important considerations for care that can be implemented at the organization and provider levels. Particular attention needs to be focused on developing organizational processes to engage in an interprofessional approach.

Finally, ensuring that patients and caregivers understand the services available to them, and how these services can help them achieve their goals and improve their health, is critical to optimizing the value of interprofessional primary care.

Dr. Nicole Bobbette is an occupational therapist and postdoctoral fellow at the Azrieli Adult Neurodevelopmental Centre at Toronto’s Centre for Addiction and Mental Health. She recently completed her PhD in Rehabilitation Science at Queen’s University and continues to be an active member of the Queen’s Department of Family Medicine’s Intellectual and Developmental Disabilities Research Program.

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Pathway to Diagnosis:

How to Help Adults with a Suspected IDD

By Dr. Meg Gemmill

As a family doctor with enhanced skills training in primary care of adults with intellectual and developmental disabilities (IDD), one of the most common questions my colleagues ask me is how to get supports and services in place for someone who is suspected to have an IDD, but who has never received a formal diagnosis.

In a recent survey of primary care providers in the Kingston area, 79.3 per cent surveyed were caring for one to six people who they suspected may have a

diagnosis of IDD but who had never received a formal diagnosis (unpublished data). Yet the process for helping these patients is not always clear. Thirty-nine per cent of primary care providers surveyed did not know the appropriate steps to help their patients obtain a formal diagnosis.

Primary care providers can observe aspects of the clinical encounter that could indicate a patient might have an IDD, such as slow response time, repeat visits for the same issue, difficulty following instructions, frequently missed follow-up appointments, and concrete or literal thinking. Although other conditions

can cause these restrictions, such as learning disabilities, acquired brain injury, chronic mental illness, autism spectrum disorder, and mild cognitive impairment, noting these features in a clinical encounter may help a primary care provider identify patients who might benefit from additional support.

Supports for adults with developmental disabilities in Ontario are allocated through Developmental Services Ontario (DSO). Examples of supports the DSO provides include case management, advocacy, person-centred planning, recreation and employment opportunities, and respite care. Many of these services are delivered by agencies of the DSO, such as the Ongwanada Resource Centre, Community Living Kingston and District, and Christian Horizons in Kingston. To be eligible for these services, a person must be 18 years of age, must live in Ontario, and must have an intellectual or developmental disability. To prove they have an IDD, a person must have had a psycho-educational assessment, which includes an assessment of both cognitive and adaptive function.

Adults with IDD often have had a psycho-educational assessment in childhood, usually through school. If this assessment is not currently in the primary care provider's chart, sometimes the patient, a previous physician, or even the patient's former school has a copy of these records. It can be worth trying to track them down because getting a new assessment can be difficult and expensive. Unfortunately, the school system only keeps the records for five years, so caregivers of children who do receive psycho-educational assessments through the school should be strongly encouraged to keep a copy of these assessments, and to provide a copy to the child's primary care provider so it can become a part of their medical record.

If there are no previous psycho-educational reports, a new psycho-educational assessment will need to be completed to be eligible for services through DSO. Psycho-educational assessments are completed by a clinical psychologist, and to pay privately for this service costs in the range of \$1,000 to \$3,000. The Queen's Psychology Clinic is able to perform psycho-educational assessments for clients on a sliding scale based on the family's combined income. There is usually a wait to access this assessment.

If a person is still unable to get a psycho-educational assessment to confirm the diagnosis of IDD, they should get in touch with DSO directly to see what options are available to them. If their primary care provider works in a team that includes a community services worker, this person might also be able to contact DSO directly on their behalf. DSO might be able to provide funding for a psycho-educational assessment in exceptional circumstances, but this requires strong advocacy on the person's behalf.

A primary care provider who strongly suspects a diagnosis of IDD and can articulate good evidence of this should advocate to DSO on behalf of their patient to help support their application. An example of good evidence would be known involvement with a DSO agency in the past. It is also important to note that once a person qualifies for supports through DSO, they automatically qualify for funding from the Ontario Disability Support Program (ODSP).

Primary care providers can play an important role in both identifying and advocating for patients who might have an IDD, and who might benefit from support from Developmental Services Ontario.

In a recent survey of primary care providers in the Kingston area, 79.3 per cent surveyed were caring for one to six people who they suspected may have a diagnosis of IDD.

Dr. Meg Gemmill, MD, CCFP, is the program director of the Enhanced Skills and Intellectual and Developmental Disabilities programs at Queen's Department of Family Medicine.

With help from Maria Sherwood, Community Services Worker at the Queen's Family Health Team, Queen's Department of Family Medicine.

For further information, please refer to:

[Developmental Services Ontario](#)

[Queen's University Psychology Clinic](#)

[Screening for Developmental Disability](#) — from the *Implanting Health Checks for Adults with Developmental Disabilities: A Toolkit for Primary Care Providers*, from the Health Care Access Research and Developmental Disabilities (HCARDD) Research Group

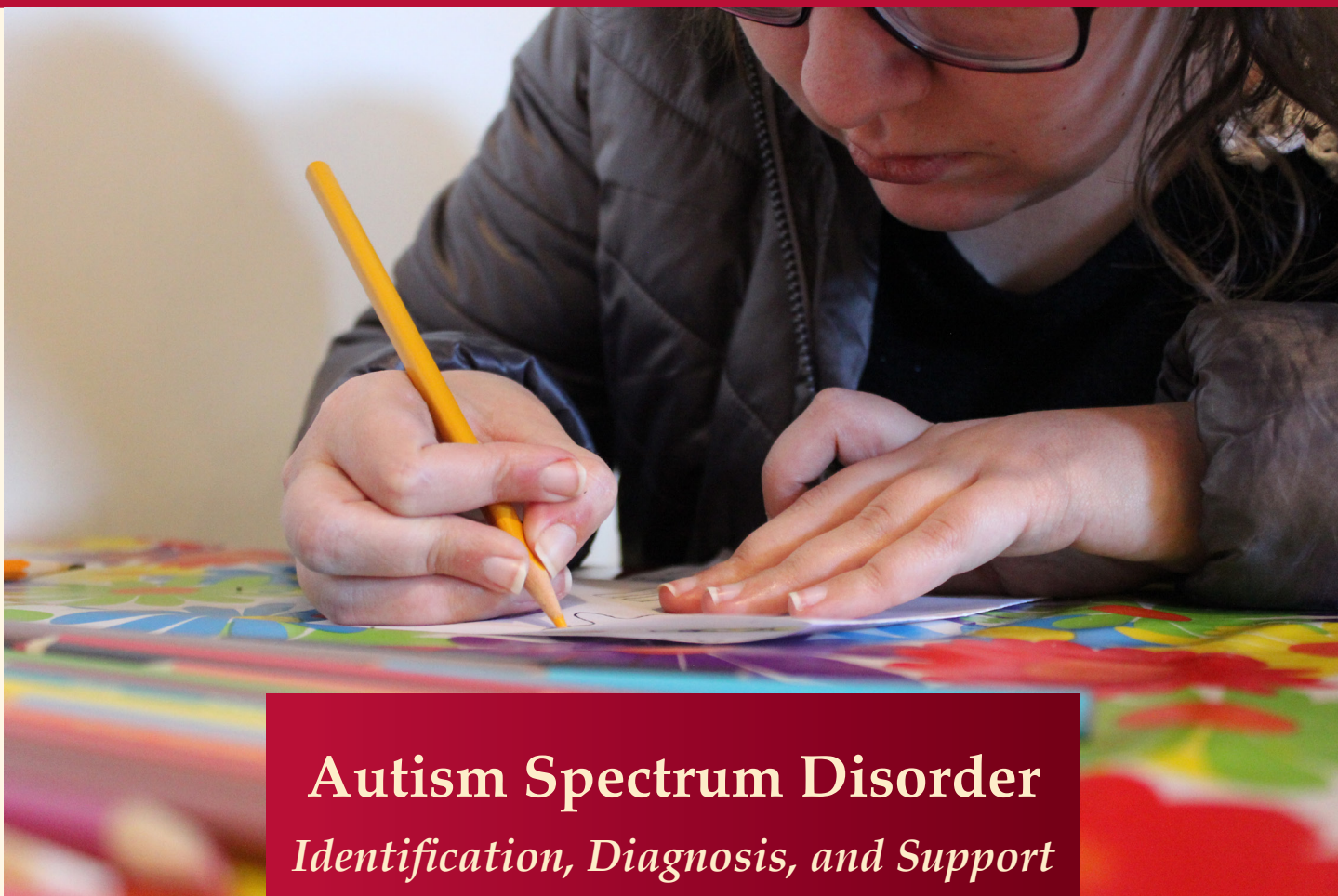


Photo courtesy H'art Centre

Autism Spectrum Disorder

Identification, Diagnosis, and Support

By Samuel Kim, Erika Hilderley, and Dr. Tess Clifford

At the Psychology Clinic at Queen's, a significant proportion of our work in the last number of years has involved the assessment and diagnosis of autism spectrum disorder (ASD). We have learned that the heterogeneity across people who meet the diagnostic criteria for ASD often makes it challenging for caregivers and health-care professionals to reliably identify whether behaviour meets the threshold for diagnosis. We believe this highlights a service gap in the publicly funded health and mental health services in our community. In this article, we hope to share our experiences and desire to build the capacity of allied professionals in the identification, diagnosis, and support of people with ASD in our community.

Autism spectrum disorder is a neurodevelopmental disorder with a broad range of impairments in social-communication skills, and patterns of repetitive behaviours, restricted interests, and sensitivity to sensory experiences and small changes in the environment. Currently, one in 66 children in Canada are diagnosed with ASD.¹ It is thought that the prevalence of the diagnosis has continued to increase over the last decades as a result of an improved ability to detect ASD, as well as a broadening of the diagnostic criteria.²

The Canadian Pediatric Society recently released three position statements related to the care of youth with ASD, including standards of diagnostic assessment. These standards highlight the roles of multiple health-care providers in the assessment and diagnosis of ASD, and identify appropriate tools that can support primary care providers in completing these assessments³.

Unfortunately, the historical notion that only “experts” in ASD should diagnose the disorder appears to have inhibited those in primary care from exploring this diagnosis. In addition, the myth that ASDs are rare permeates general practice. Our hope is to dispel these myths.

Our belief is that primary care providers have the knowledge, understanding, and ability to provide service to individuals with ASD, including diagnosis. Whether that be through the use of standardized questionnaires, behavioural observations, or clinical interviews, primary care providers have the resources and knowledge to be competent in conceptualizing ASD.

With that said, we are aware that some cases are very clear, while others are not that straight forward. There is an emerging body of research examining the degree to which people mask or camouflage symptoms of ASD,

in particular girls and women with typical intellectual development.⁴ In our experience, it is common that people with ASD are able to engage in brief conversation with health-care providers; however, when these conversations extend longer than simple pleasantries, or require a need to expand on topics, we see that social communication impairments become more evident. In addition, some caregivers have their own struggles with communication, making it challenging to rely on informant reports alone.

Further, while symptom onset occurs in the early developmental period, impairments may not be identified until expectations exceed the individual's skill set. We find that learned strategies (e.g., inhibiting repetitive movements, forcing oneself to make eye contact) can often mask symptoms.

On top of this, we commonly see individuals present with a variety of other diagnoses before ASD is ultimately confirmed.⁵ Most often, these include attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), anxiety disorders or symptoms, and sensory sensitivities. In more complex cases, individuals may have been diagnosed with depression, bipolar disorder, or personality disorders (e.g., borderline, schizoid, avoidant), most of which appear to be treatment-resistant.

What we have recognized is that these previous diagnoses can bias our clinical judgement (i.e., diagnostic overshadowing), and tend to necessitate spending more time to tease apart the cause of the impairments. We have learned that first impressions or heuristics can be ill-informed, and we encourage others not to rule out ASD without an assessment. We now rely heavily on collateral information (e.g., report cards, informant questionnaires, observations, medical documentation) to determine whether further assessment is warranted.

With all that said, we can see that many cases may not require a comprehensive assessment in order to make a diagnosis, and there will be some that are beyond a primary care provider's capacity, given breadth of knowledge and time constraints. These cases may benefit from being directed to appropriate allied health professionals, community services, and specialists. An example of this can be found in the case study on the next page.

Once a diagnosis has been confirmed, it can be hard to know the next steps needed in order to support clients and caregivers attempting to access services, particularly in the current landscape of uncertainty related to services for people with ASD. Based on our experience, caregivers and clients are often distressed, having struggled with longstanding adaptive, social, and behavioural concerns and their associated costs. We have found that families benefit from education related to sources of financial support (e.g., disability tax credit), local support groups

(e.g., Autism Ontario) and developmentally appropriate school supports, and interventions associated with the diagnosis of ASD⁶. As such, we feel a need to be strong advocates for our clients as care providers. For us specifically, this has meant offering outreach education for professionals and caregivers, and liaising between services and service providers.

Our hope with this article is to empower primary care providers to overcome the myths associated with the diagnosis of ASD, and to share our personal experiences. One of the most compelling observations in our work has been the therapeutic value of communicating this diagnosis. By framing the individual's experiences through the lens of ASD, we see improved relationships amongst family members and with service providers, in turn, assisting everyone in accessing and implementing appropriate supports. In taking the approach of talking about ASD as a mismatch between the person's brain (or skills) and the expectations of the environment, we can all work together with families to find supports that help to match the environment to our clients' skills. Ultimately, the result is compassionate, collaborative, client-centred care.

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Case Study

Franny is a 13-year-old girl who has been struggling to regularly attend school for the last two years. Her mother reported that Franny seems to have no motivation to go to school, or leave the house in general.

When you ask her what she does when not at school, Franny shrugs, looks down and seems unengaged. Her mother describes that she typically sleeps during the days she's not at school, and then reports that Franny stays up very late reading a specific series of graphic novels. Franny interrupts her mother, snapping at her, "That's not true, mother!" When you ask her for her perspective, she doesn't respond, and eventually her mother describes that she and Franny are frequently disagreeing about the facts and at times she feels frightened that Franny will physically hurt her when she is very distressed. Franny scoffs at this, saying "I would not!"

In a review of Franny's chart, there is documentation of a consult with a psychiatrist in the last year after her older brother called police, reporting that she had cornered her mother in the bathroom and would not let her leave. It appears as though the situation centred around Franny's reaction to her mother's plans to go out for the evening, something that is noted to happen very rarely in their home. The psychiatrist diagnosed ADHD and suggested family therapy and parent coaching related to behaviour management.

There are also notes from Franny's early childhood highlighting that her developmental milestones were generally on time, she was often "shy" during clinic visits, and her mother reported frequent tantrums and picky eating in the preschool and early school years. It is also noted that Franny was described as very bright and precocious, and she has also been diagnosed with a learning disability affecting writing.

You invite Franny to return for a future appointment, and she indicates she will if her mother can come with her. You also ask for the school to provide some information about their observations of Franny at school. Franny and her mother return three weeks later with a note from her teacher indicating Franny has attended about half of the school days so far this year. In turn, the teacher is not confident in her assessment of Franny's academics. She notes Franny is bright, though does not share her ideas with the class, and appears very anxious about having to speak in front of others. It is highlighted that Franny does not really fit in socially. Though she does have one peer she will pair up with for group work, she spends recess alone reading her graphic novels. The teacher notes that Franny seems easily distracted by noises, such as other students chatting during work periods, and often chooses to work in the hall with headphones on. She notes that Franny reports having headaches, often asking to leave the class, especially when the French teacher arrives.



Samuel Kim, M.Sc., graduate student; Erika Hilderley, M.A., M.Ed., C. Psych. Assoc. (supervised practice), psychological associate; Tess Clifford, Ph.D., C. Psych., psychologist and director, The Psychology Clinic at Queen's.

The Psychology Clinic at Queen's is a training clinic for graduate students in clinical psychology. Students are trained under the supervision of registered psychologists. Since 2005, we have provided a wide range of psychological assessment and intervention services to the Kingston community on a sliding-scale fee-for-service basis. For more information, please visit our [website](#).



Ongwanada

Supports and Services for Individuals with IDD and Complex Needs

Gail, a person supported by Ongwanada, enjoys the health benefits of spending time in the hydrotherapy pool with an occupational therapy/physiotherapy staff member. Photo courtesy Ongwanada.

Article submitted by Ongwanada

A member of the Kingston community since 1948, Ongwanada has been working in developmental services since 1967. A non-profit, accredited organization, Ongwanada supports people with developmental disabilities (DD), with a special focus on those with complex needs, and their families, so they can lead full lives, effectively supported in their communities.

Programs and services are delivered at three main sites in Kingston, more than 20 community residences between Napanee and Gananoque, and other homes across the region. In addition to residential options, some of Ongwanada's other services include planning and case management, clinical services, respite, community behavioural services, adult protective services, and community participation supports.

SUPPORT AND SERVICES FOR INDIVIDUALS WITH COMPLEX NEEDS

As a regional provider of specialized and clinical services, Ongwanada has a multidisciplinary team of

clinicians with expertise in DD supporting individuals with complex medical and behavioural needs. This team provides psychological and behavioural services, nursing, nutrition counselling, social work, and occupational/physical therapy, all with expertise in DD. Ongwanada also operates a pharmacy and radiology department that is open to the public for X-Ray and ECGs.

For individuals who require assessment and/or treatment for severe behavioural challenges, Ongwanada operates the Southeastern Regional Transitional Treatment Home, a four-bed home for individuals over the age of 18 with a developmental disability and mental health needs and/or challenging behaviour. Treatment periods range from six to 24 months. Ongwanada also has another home designed specifically for those with complex needs that offers three individualized suites and provides short-term stabilization/treatment.

For individuals with complex medical needs, Ongwanada operates homes with nursing staff working as part of the interprofessional team to ensure individuals' physical and emotional well-being.

In its efforts to support individuals with DD, including those with complex needs, both behaviourally and medically, Ongwanada is assisted through a partnership with Queen's Family Health Team (QFHT). Physicians from the QFHT work in conjunction with the Ongwanada team to provide care to the individuals in the majority of Ongwanada's community residences in the Kingston and Gananoque areas. A formal partnership is also established with a local physician/health team in the Napanee area. A key part of the care team, physicians work closely with Ongwanada's clinicians. This consistency in care and physician expertise, compassion, and support is vital to Ongwanada's ability to support individuals with complex needs.

As lead agency for the region's Community Network of Specialized Care, Ongwanada also has a team comprising a complex support co-ordinator, health care facilitator, and dual diagnosis justice case manager who work closely with individuals, families, and agencies across the South East region to assist in the co-ordination of services and supports across a variety of sectors including justice, health, mental health, addictions, education, housing, and developmental services.

The complex support co-ordinator provides cross-sector co-ordination for case resolution to facilitate access to required services and supports including specialized services, and serves as liaison among different sector partners.

The health care facilitator provides support to primary health care providers and non-developmental service agencies working with people with complex and multiple needs, and supports developmental service agencies to better address individuals' health care needs. This facilitator also assists with linkages to health services and identification of gaps that require augmenting to meet individuals' specific needs.

The dual diagnosis justice case manager works collaboratively with other court-support workers and discharge planners to support court diversion of people with DD. The case manager supports collaborative

contacts with community services such as developmental and mental health services for diversion planning; and with mental health court-support workers, and local correctional and custody facilities, for appropriate discharge planning.

Individuals eligible to access the services of the complex support co-ordinator and health care facilitator must meet the High Support and Complex Need criteria established by the Ministry of Children, Community and Social Services, which is based on a person's support needs and their behavioural and medical scores from Developmental Services Ontario's support intensity scale assessment. To access the services of the justice case manager, an individual must have, or be suspected to have, a developmental disability and have criminal charges.

EDUCATION, RESEARCH, AND KEEPING PACE WITH CHANGES TO THE SECTOR

In an effort to meet the ever-changing needs of the individuals it supports, and to keep abreast of changes within the sector, Ongwanada maintains a number of regional, provincial, and cross-sector connections.

One of several strong community partnerships is with Queen's University, to collaborate internationally in research that enhances the understanding of individuals with DD and improves their quality of life. The Queen's Genomics Lab at Ongwanada (Q-GLO) is a research facility

whose primary focus is on mental health-related conditions including autism spectrum disorders, DD, and neuropsychiatric disorders. Services the lab provides include sample biobanking, genotyping, statistical analysis, bioinformatics, and various clinical and psychological assessments. Ongwanada also contributes to other research initiatives in DD, including projects with Health Care Access Research and Developmental Disabilities (H-CARDD), which was developed to address disparities in health status and health care access that individuals with DD face in Ontario.

Ongwanada is also the lead agency for the Kingston Internship Consortium (KIC), designed to prepare

“*Ongwanada is also the lead agency for the Kingston Internship Consortium (KIC), designed to prepare psychology interns to practise as clinical psychologists.*”

psychology interns to practise as clinical psychologists. This Canadian Psychological Association-accredited internship provides a breadth of training experiences with a diverse disability-focused population. The interns work with individuals with physical, emotional, cognitive, social and/or occupational impairments that may have occurred as a result of processes related to development, illness, trauma, or injury. Recognizing that disabilities present different challenges to individuals at different stages of their development, the internship exposes interns to a lifespan perspective.

To accomplish its goals, the KIC unites the resources of [Ongwanada](#), [Queen's University](#), [Providence Care Hospital](#), and [KidsInclusive](#), with each organization providing a unique perspective on the role and skills required of psychologists in the identification of function and disability, the promotion of maximum participation, and the minimization of limitations.

Additionally, Ongwanada has teaching agreements with a number of postsecondary institutions, including Queen's and St. Lawrence College, to ensure future graduates from programs such as medicine, nursing, occupational/physical therapy, and behavioural psychology have knowledge and experience in developmental services.

Outside of educational partnerships, the organization also has a strong regional and provincial presence as a lead to many initiatives in the developmental service sector. More recently, with the changing landscape of health care across the province, Ongwanada is contributing to the development of Ontario health teams to ensure awareness of people with DD and their specific health care needs.

ACCESSING ONGWANADA'S SERVICES

To make a referral for Ongwanada's services, including specialized clinical services and the Community Network of Specialized Care, contact Developmental Services Ontario at (613) 544-8939. To make a referral for a child, contact Ongwanada's intake at 613-548-4417, Ext. 3311.

Ongwanada Clinical and Specialized Services at a Glance

Number of individuals
referred for clinical services in
the last year:

366

Number of clinical services
provided
in the last year:

1,761

Number of individuals
referred to Community
Network of Specialized Care
(CNSC):

99

Number of individuals
currently in service with CNSC:

74



Photo courtesy H'art Centre

Finding Social Inclusion through Inclusive Employment

By Dr. Rosemary Lysaght, PhD

If asked why they work, most people can respond fairly effortlessly. The top responses typically relate to three main things — the monetary benefits of earning a wage to support oneself or one's family, the intrinsic value associated with doing something you enjoy, and the social connections and friendships associated with work. Dig a little deeper, and many can identify benefits such as mental stimulation, the sense of personal identity, and social contribution that come from work involvement. And, yes, some would give it all up and live a life of leisure if they could.

There is abundant research showing that people with intellectual and developmental disabilities (IDD) value the same things in employment that average working people do, and as a vulnerable population, some of the benefits associated with paid work are even more important for this diverse group.

Employment is a key social determinant of health, and has clear links to other social determinants through its contributions to financial well-being, skill

development, and social capital. Thus, it is no surprise that international studies have identified a number of physical and mental health benefits associated with paid employment in people with IDD. Integrated employment has been reported to contribute to increases in self esteem, personal empowerment, independent living, self-advocacy skills, and quality of life¹. In addition to the personal gains, there are a number of community benefits associated with employing people with IDD, such as improved workplace climate and the building of diverse and inclusive communities.

CHALLENGES TO GAINING EMPLOYMENT FOR PEOPLE WITH IDD

Despite the fact that the majority of people with IDD indicate they want to work, employment rates for this population are remarkably low, estimated at anywhere from 32 to 46 per cent². There are a number of factors responsible for the dismal job numbers, and low unemployment rates in the community are surprisingly not the main culprit.

One challenge arises from a lack of focused education and vocational preparation programs to provide the necessary skill development, job matching, and job modification support needed to secure a strong match between an aspiring worker's abilities and an employment opportunity. Another barrier becomes the legal requirement for employers to compensate workers at standard market wages, even if their work falls below competitive levels. This is particularly an issue in the case of severe disability, where even a willing employer may not have sufficiently deep pockets to employ a worker with low productivity in a competitive economy.

Other barriers include the ODSP "trap" — where workers and families hesitate to work due to the perception that reductions in employment support payments based on earned wages is unfair, or will leave them vulnerable should employment become irregular or unsustainable. Some families have concerns about the safety of their disabled family member travelling to and working independently in community workplaces. Finally, stigma can reduce the likelihood that a person with IDD will be considered for a job opportunity.

GETTING PEOPLE TO WORK

A number of approaches to improved work participation for people with IDD have been attempted internationally. "Supported employment" is the most well-evidenced means for achieving integrated employment for people with mental health disabilities, and the model has been increasingly applied to populations with IDD over the past 40 years³.

This approach is based on the individual placement and support (IPS) model, and targets regular jobs at comparable pay and job benefits to those of other workers doing the same job receive. Key features of this approach are individualized job matching, on-the-job support while mastering job demands, and ongoing supportive follow-up for the duration of the job. This model allows for career progression as skills develop or interest in a particular job wanes.

Other strategies have been used to augment the IPS model, including the concept of job carving, which involves customizing a community job by identifying tasks a person with IDD can successfully perform, and matching those to an employer for whom those tasks create value. For example, an employer could identify several low-level, productivity-reducing tasks across a range of highly paid jobs — such as replenishing supplies for production workers or removing waste products from work areas — and create a job for a worker with IDD who has skills in rapid response, transporting goods, and attention to detail.

Another solution is to assertively create jobs for people who are hard to employ, either through development of social enterprises or through microenterprise approaches. The social enterprise approach is based on community-development principles, and creates small to mid-sized businesses that operate in the regular marketplace and hire high proportions of people with employment barriers. The model includes worker supports, flexible employment conditions, and opportunity for worker voice, and can include a mix of people with disabilities and those without. The inclusive nature of such businesses can be achieved either through building a diverse workforce within the business or through creating jobs that involve direct public contact, as in cafés or delivery services. Contemporary social enterprises that operate in accordance with prevailing labour laws also match wages and work benefits.

Microenterprise is essentially self-employment, but small-scale co-operatives formed by a group of persons with IDD are also considered within the microenterprise framework. Various small-business development grants can support startup of such small businesses, though earnings, since they are not typically wage-based, can be low.

Finally, policy-based decisions can greatly impact employment outcomes for people with IDD. The productivity challenge associated with some people with IDD has been addressed in two ways. Many governments, including Ontario, have implemented employer wage subsidies, most of which provide a financial bonus to employers for a three- to six-month period while a new worker learns the job and integrates into the workplace.

The other solution is to create a provision for paying the worker with IDD at a rate proportional to work output. Productivity-based, sub-minimum wage (SMW) pay systems have been implemented in Australia⁴ and Israel, with the effect of increasing inclusive employment for workers with IDD.

Although sometimes controversial, productivity-based wages can in fact create higher levels of income than other employment options due to the high regular wages paid in these countries and the opportunity for the assessed wage to increase over time through annual re-assessments. For example, a new worker on a SMW program in Australia would receive a minimum of six weeks of supported job integration at the outset, and then his work rate would be rated by an external assessor. If he was appraised as working at 50 per cent of the rate of an average worker in that position, he would receive half the usual wage paid. So if the usual wage for the job is \$16 per hour, he would receive \$8 per hour. A year later, if his work rate increases, say to 75 per cent, his wage would jump to \$12 per hour.

“
*There is abundant research showing
 that people with intellectual and
 developmental disabilities (IDD) value
 the same things in employment that
 average working people do.*”

In addition, most social assistance programs, including ODSP, have implemented measures to reduce the disability benefit trap and ensure that workers with disabilities can retain full benefits while earning up to a certain ceiling, and to lose only a portion of wages earned above that ceiling. Until the start of 2020, ODSP recipients could retain the first \$200 of monthly earned income without affecting their benefit amount, and would then lose 50 per cent of the remaining amount (childcare and disability-related expenses excluded)⁵.

IS PAID WORK FOR EVERYONE?

One of the central tenets of inclusion is the notion of choice. As in the general population, people with IDD have a right to choose the type of work they do, to choose what form of work (e.g. individual placement, social enterprise, or self-employment) is a fit for them, and to choose whether they want to work at all. The decision may be complicated by the availability of supports to find and keep work, job opportunities that exist in the local community, and transportation options. Many people with IDD prefer to engage in volunteer work roles, or a combination of paid and unpaid work. As a form of contribution, volunteer work holds many of the same benefits as paid employment, although it lacks the instrumental and symbolic benefits of paid work.

Overall, it seems that the responsibility of government and communities is to create conditions where all can exercise their right to social contribution and, in doing so, to create a vibrant and inclusive society. Despite good evidence as to how to get there, it will take a concerted effort to meet these goals.

Dr. Rosemary Lysaght, PhD, is a professor and associate director of the Queen's School of Rehabilitation Therapy. She is an occupational therapist, and holds graduate degrees in rehabilitation, and educational research and evaluation. She has worked as an occupational therapist in Canada and the U.S., and has led research and evaluation studies in North America and internationally. Her research focuses on policy and practice in the area of work integration for people with disabilities and other employment barriers.

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Photo by Karen Dolan

H'art Centre

Inclusive Arts for All Abilities

Article submitted by H'art Centre

More than two decades ago, H'art Centre understood people with developmental disabilities (DD) in our community had much to offer, and the arts could be a valuable vehicle for them to do just that. Starting out as a small organization in a storefront studio, the centre has grown into a thriving downtown arts hub, and its dream to bring "accessible arts to all abilities" has become a reality.

H'art Centre is an award-winning registered not-for-profit, charitable community arts hub that provides artists with disabilities and those facing barriers with opportunities to create, study, and produce works in the arts and to collaborate with qualified, trained community artists. The centre nurtures a vibrant, exciting, and supportive culture that encourages artists, staff members, volunteers, and audiences to reach beyond limiting beliefs and expectations. The goal is to value and recognize artists individually for their abilities, and to share this understanding with the world.

Since its founding, H'art has created five programs (H'art Studio, THE BOX, Able Artists, the H'art Accessible Arts Program, and MixAbilities) and countless projects to fill gaps, to address barriers, and to encourage everyone to get involved in the arts.

H'ART STUDIO

Launched in 1998, H'art Studio was the centre's first, and remains its core, program. It provides adults with DD with artistic skill-building and creation-based workshops led by trained, professional local artists and arts educators. More than 150 local artists and 1,000 volunteers and post-secondary field placement students have joined the mix. Through exhibits, community art projects, an illustrated children's book series, performances, and other activities, studio artists have shared their abilities with more than 20,000 audience members.

H'art Studio's next major work is a docu-dance called *Small Things*, a story told through dance, spoken word, original music, and video projections.

It features performances or contributions from more than 50 H'artists and guest artists. Working with talented choreographers throughout the season, this unique work marries documentary and dance as the stories of parents' experiences of raising a child with DD are told through film, intertwined with live dance featuring their adult children onstage. The two art forms twist and turn, and sometimes collide as these families explore the small joys they have found together. Originally scheduled to be performed as part of the 2020 [Isabel Bader Centre for the Performing Arts'](#) Human Rights Arts Festival, which was cancelled due to COVID-19, *Small Things* is now tentatively scheduled to be performed in April 2021.

ABLE ARTISTS

Able Artists is an ongoing series of talks, performances, and workshops that bring professional Canadian artists with disabilities and leaders in the inclusive arts movement to Kingston to share their work and insights, and to advance accessible arts for artists and audiences. Over its nine years, the series has presented dozens of artists, and many of the featured arts groups have included artists with intellectual disabilities, including Ottawa's Propeller Dance, Montreal's Les Productions des Pieds des Mains, and Ottawa's Tamir Neshama Choir. Able Artists has inspired more than 2,200 audience members at workshops, lectures, film screenings, and performances at multiple locations in Kingston.

THE BOX

When the group experienced difficulty finding accessible venues appropriate for the Able Artists performers, they decided to create their own. THE BOX, a 3,500-square-foot accessible and versatile performing arts space, was completed in 2012 with support from more than 40 private donors, and immediately received the 2012 City of Kingston Access Award.

THE BOX is more than a space; it invites a diverse and inclusive population to develop, produce, and present their endeavours to the public. It supports partnerships, co-productions, and the sharing of expertise. At the venue, H'art has facilitated activities for a wide variety of organizations, including Queen's University, the City of Kingston, Theatre Kingston, Addiction and Mental Health Services KFLA, and the Down Syndrome Association of Kingston, among many others.

H'ART ACCESSIBLE ARTS PROGRAM

The H'art Accessible Arts Program (HAAP) works to bring meaningful arts-based programming to the community. In 2019, a roster of trained HAAP artists and supportive volunteers led weekend arts workshops for more than 800 seniors living in long-term care residences.

Launched in 2017 to respond to the trend of adults with DD entering long-term care facilities when they age out of group homes, their caregivers die, or their parents are too elderly to care for them at home, the program is an opportunity for H'art to share expertise, build awareness of the value of arts to people with disabilities, foster connections with long-term care staff, and train a new pool of inclusive artists.

MIXABILITIES INCLUSIVE ARTS TRAINING PROGRAM

While preparing to deliver the H'art Accessible Arts Program, H'art recognized the need to ramp up inclusive arts training for Kingston's artists in general, and in 2018, it created the MixAbilities Inclusive Arts Training Program.

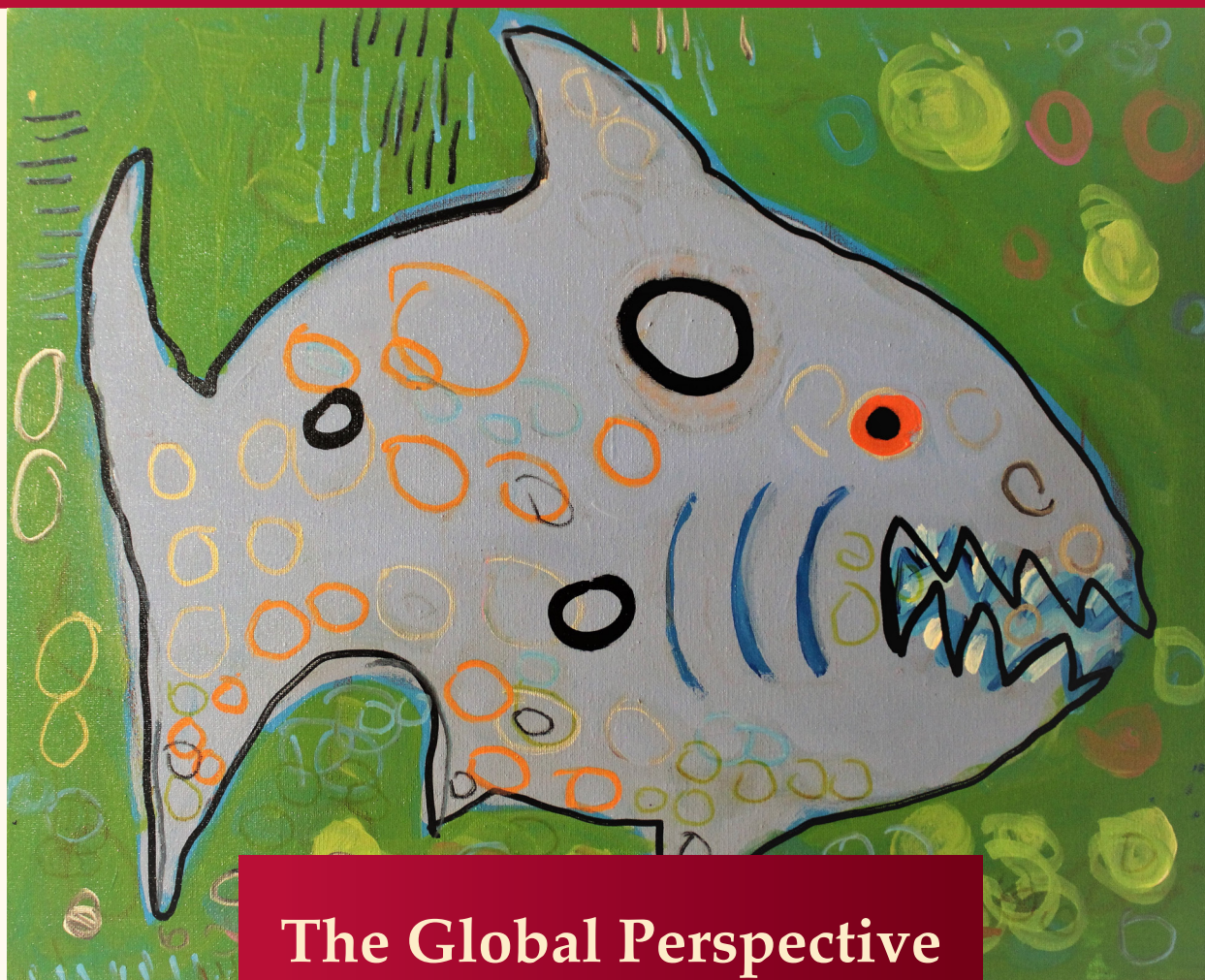
The program is designed to help local artists/educators learn to:

- increase their awareness and understanding of H'art Centre's vision and mission;
- effectively and empathetically support participants with disabilities or who are D/deaf as they progress in the arts;
- develop skills and confidence as inclusive artists/educators, and;
- increase their knowledge and understanding of the value of arts to people who are D/deaf and those with disabilities.

After the program's pilot phase, MixAbilities received the City of Kingston 2018 Celebrating Accessibility Award in the category of Education. H'art is now working to expand the program to meet the needs of the wider arts community, with hope of seeing national development.

H'art Centre continues to deliver programs and share its expertise so more communities can learn best practices, and recognize and remove barriers to participation in community arts programming, events, festivals, and services.

For more information about H'art Centre, visit hartcentre.ca



Painting courtesy H'art Centre

The Global Perspective

Common Issues, Shared Goals

By Dr. Heather Aldersey

Around the world, people with intellectual and developmental disabilities (IDD) and their families face a range of challenges. I have the great privilege to partner with people with IDD and their families in a number of countries to promote their full and equal enjoyment of human rights and fundamental freedoms through participatory action research.

Although each country presents unique opportunities and challenges for people with IDD, globally, people with IDD face a number of common issues, many of which focus on living meaningful lives in the community. This can relate to access to meaningful employment; health (promotion, prevention, and treatment); education in the least restrictive environments (with a preference for full inclusion in regular schools); appropriate housing; having meaningful friendships and leisure activities; and enjoyment of sexual and reproductive rights. Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is particularly

important for people with IDD around the world. This article recognizes the equal right of all persons with disabilities to live in the community, with choices equal to others.

In many low- or middle-income contexts, people with IDD and their families face even more significant challenges, due to higher levels of poverty, limited government supports and services, and limited access to specialized personnel and services, including diagnostic and referral pathways. People with IDD face stigma and discrimination everywhere in the world, but this may be particularly acutely felt in contexts where IDD is associated with evil spirits, parental transgressions, and witchcraft.

There are many great local non-governmental organizations (NGOs) and disabled persons organizations (DPOs) on the ground that are taking action and advocating to improve community inclusion and human rights for people with IDD. Additionally, self-advocacy organizations, family self-help groups, and peer support organizations

are creating opportunities for people with IDD and family members of people with IDD to connect, share support and resources, and present a united local voice in advocacy efforts. There are also a number of international organizations that work in many communities around the world for the same purpose. Here is a selection of some of my favourite organizations working to promote the full and equal enjoyment of human rights and fundamental freedoms for persons with IDD and their families globally.

DISABILITY RIGHTS FUND

This fund provides grants to self-advocates with IDD (and other DPOs) around the world to support improved equity.

DOWN SYNDROME INTERNATIONAL

This UK-based organization strives to improve quality of life for people with Down syndrome, promoting their right to be included on a full and equal basis with others.

INCLUSION INTERNATIONAL

This network of people with IDD and their families advocates for the human rights of people with IDD worldwide. It represents more than 200 member federations in 115 countries throughout five regions including the Middle East and North Africa, Europe, Africa, the Americas, and Asia Pacific.

INTERNATIONAL ASSOCIATION FOR THE SCIENTIFIC STUDY OF INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (IASSIDD)

This organization is the first and only worldwide group dedicated to the scientific study of intellectual disability. It is an international, interdisciplinary, and scientific non-governmental organization that promotes worldwide research and exchange of information on intellectual and developmental disabilities.

LILIANE FOUNDATION

The Liliane Foundation supports children with disabilities around the world. I have seen it highly active and making a true difference in the lives of children with IDD and their families in every country in which I work. The foundation focuses on promoting child development, enabling environments, and community-based rehabilitation.

Dr. Heather Aldersey is an associate professor (Queen's National Scholar) at the Queen's School of Rehabilitation Therapy. She holds a Canada Research Chair (Tier 2) in disability-inclusive development and is the scientific director of the International Centre for the Advancement of Community Based Rehabilitation.



In many low- or middle-income contexts, people with IDD and their families face even more significant challenges, due to higher levels of poverty, limited government supports and services, and limited access to specialized personnel and services.





Intentional Communities

Centralized, Supportive Housing that Meets Individual Needs

Photos courtesy Reena

By Bryan Keshen, CEO, Reena

Developmental disabilities (DD) represent one of many sub-categories of disabilities experienced by a wide range of the Canadian population. According to the National Survey on Disabilities, 13.7 per cent of the Canadian population has a disability. Of this group, four per cent are estimated to have a DD. In Ontario alone, this translates into 81,000 individuals aged 15 and older.

While many people with DD are able to live independently, additional supports are often needed to guarantee a good quality of life. Due to their unique impact, developmental disabilities are complex and can require specialized living situations that incorporate ongoing supports, as needed, often in the form of supportive housing.

Currently, the need for supportive housing for individuals with DD in Ontario outnumbers the supply significantly. Wait lists are long.

In 2013, the “wait list” (“service registry” is current provincial government terminology for what many in the broader community refer to and experience as the “wait list” for housing) indicated that 12,000 adults with DD in Ontario were waiting for residential services. By 2017, that number had climbed to 15,700.

Long wait lists do not only affect the lives of those with DD but also the lives of direct families and caregivers. Many people with DD currently live at home with their parents or other relatives who function as their primary caregiver.

THE INTRODUCTION OF INTENTIONAL COMMUNITIES

The concept of intentional communities has been used for quite some time to house individuals with DD in countries such as the U.S., Israel, and the Netherlands. Made up of groups of people living together on the basis of common values, the idea is that a centralized approach concentrates resources and ensures a more seamless experience of care for each individual.



In Ontario, a group of service providers under the umbrella of the Intentional Communities Consortium has developed this interpretation of community-based supported living to reduce wait lists, and to provide more tailored integrated supports to individuals with DD. One example is the [Reena Community Residence](#) (RCR) in Vaughn, Ontario.

Opened in 2012, the RCR is an *intentional community* — a creative response to community needs — housing 83 individuals with DD. It was established by Reena, a non-profit organization that promotes dignity, individuality, independence, personal growth, and community inclusion for people with DD within a framework of Jewish culture and values.

The philosophy behind the RCR care model is to support a wide range of individuals, based on their unique needs. For instance, residents may be living alone with minimal supports or they may be part of a complex care model where several service-delivery agencies are involved.

The residence is home to many individuals with a dual diagnosis (55.8 per cent of residents). Of all residents, almost 69 per cent identify as having a DD. In addition, approximately 22.1 per cent have been diagnosed with autism spectrum disorder, and approximately 12 per cent have a physical disability. More specific diagnoses vary considerably, including acquired brain injury, cerebral

palsy, anxiety disorders, schizophrenia, and bipolar disorder.

The RCR provides a unique opportunity to address two particular problems that people with DD face in Ontario: 1) the lack of affordable supportive housing specifically designed for individuals with DD; and 2) the need to integrate supports that are often provided through a range of different agencies.

The intent is to provide an independent and meaningful life connected to families, friends, and neighbours. Like independent living, individuals have their own apartment unit, and similar to a group home, 24-hour supervision is available as needed.

The four-storey apartment building offers residential living, respite, and day programs in one location. With 60 apartments, offered in one-, two-, and three-bedroom units, its unique blend of residential and day programs makes it a busy place, both day and evening. View a virtual tour of the residence [here](#).

Beyond providing a home and supports, this integrated program builds a community where people can live, work, and play. Tenants are asked to commit to a social vision that emphasizes the importance of living and sharing life together. Residents, who range in age from their 20s to mid-80s, are encouraged to look out for their neighbours and can expect the same help from others.

This residence personifies inclusion, not only as one of Reena's core values, but also as a core practice. It serves adults and seniors with a range of special needs such as developmental, physical, and/or mental health.

When they arrive, each tenant is facing a major life transition, such as moving out of their childhood home for the first time; downsizing from the family home; finding an independent, supportive home after years of searching; and developing personal independence in their new home.

Research shows the RCR model is particularly effective for individuals wishing to transition from another housing type that is not meeting their desired levels of support or independence needs. For instance, the model has shown to be suitable for individuals transitioning from living with parents as caregivers, as they can achieve independence (through having their own apartment), coupled with access to a diverse set of ongoing support services.

SUPPORT INTEGRATION

At the RCR, Reena partnered with March of Dimes Canada, Circle of Care, and the Central Local Health Integration Network (LHIN) (Home and Community Care) to deliver a range of services to some residents. The RCR currently offers two different complex-care

models: one involving the March of Dimes, and the other involving a mix of care providers, as needed. These complex-care models aim to leverage joint funding from the Ministry of Children, Community and Social Services (MCCSS) and the Central Local Health Integration Network (LHIN), to reflect a collaborative model created by an advisory group of parents, and to offer a person-centred approach to service delivery.

THE CROSS-SECTOR COMPLEX MODEL

The cross-sector complex model was developed in response to rising concern among families, caregivers, and members of health and social services communities that the current approach for supporting adults under 40 with medical complexities and DD is insufficient.

It offers a highly individualized approach to care that integrates services from health and developmental service providers into a single, co-ordinated, person-centred package. It is a promising approach to service for adults with medical complexities and DD, whose needs are not being met in traditional models of care (e.g. home or traditional group home settings).

One of the model's most promising contributions is that individuals develop friendships and lasting relationships with peers in a natural social environment — with people who are not family members and not staff.



*I don't feel like a caregiver nurse ...
[We] play chess ...
[Go for] walks and ice cream. For the first time in many years, we are treating them and acting like sons and mom and dad.
(Parent)*

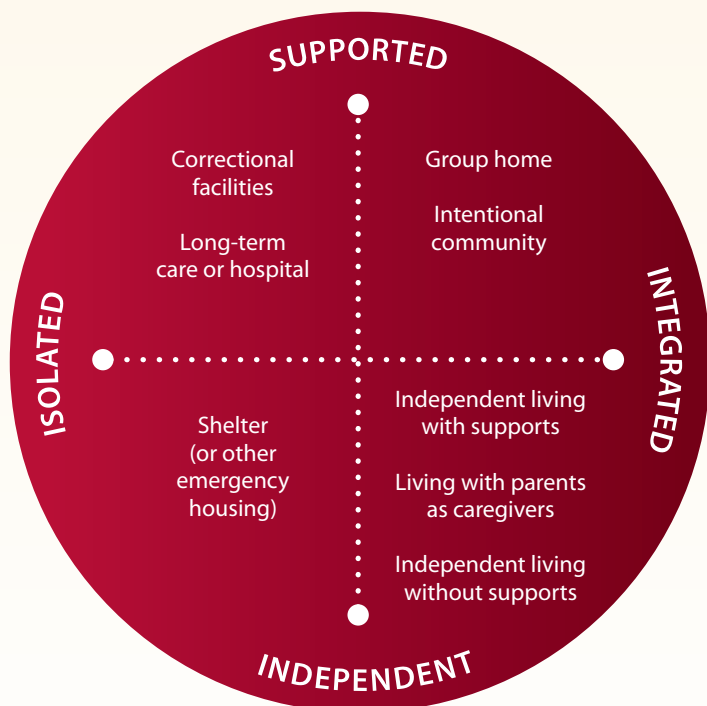
From a health perspective, the model enables access to appropriate health care and developmental services that would be limited in the family home. It increases the capacity to secure appropriate care that has the potential to decrease worsening of symptoms and unnecessary complications in a vulnerable population that may be cognitively challenged to communicate the decline of their own health.

For the health system, the model provides a safe and medically appropriate alternative that could alleviate strain on long-term care homes and reduce the number of individuals occupying beds in hospitals that are deemed alternate levels of care.

SITUATING THE INTENTIONAL COMMUNITY MODEL

Reena recently conducted a study to understand how intentional communities such as the RCR differ from other forms of supported housing for individuals with DD.

Four distinct categories of housing types were identified on two separate continuums: Supported — Independent and Isolated — Integrated.



Community integration is seen as a key ingredient for providing a meaningful life to individuals with DD, and was the philosophy that formed the basis of many of the supportive housing models that exist today.

The intentional community model falls within the “supported-integrated” quadrant.

INTENTIONAL COMMUNITIES IN THE KINGSTON AREA

Starting in December 2019, a series of meetings brought together members from a wide range of local organizations to learn about the intentional community concepts. These organizations included Ongwanada, Community Living Kingston, Christian Horizons Kingston, Queen’s School of Medicine, the City of Kingston, Developmental Services Ontario — South East Region, family practice clinics, and religious organizations.

In January 2020, Bryan Keshen, co-chair of the Intentional Communities Consortium and CEO of Reena, and Fred Winegust of Reena shared first-hand knowledge, experience, business value metrics, and improved health outcomes to the local participants. The discussion focused on the intentional community model Reena has deployed in Vaughan.

Reena’s hope is that Kingston groups, who work in this space, will come together in a community-wide, cross-organizational effort to bring a version of the intentional community model to Kingston.

This joint effort would not only benefit the 350+ individuals with DD in Kingston, but would begin to tackle the wait list for affordable accommodation with integrated supports, in a group home or supported independent living arrangement in Kingston.

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Physician LEADership Transition of Care Co-ordination Programs to New Ontario Health Teams

*QMed LEAD team: Ishita Aggarwal, Milena Bullen, Dr. Liz Grier, Marielle Paule Balanaser, and Sara Sarbar.
(Absent: Alexandra Donaldson)*

By Dr. Liz Grier, Sara Sarbar, Ishita Aggarwal, Marielle Paule Balanaser, Milena Bullen, and Alexandra Donaldson

Physician leadership is understood to be an integral part of health-system management, and in recent years there has been particular system focus on delivery of integrated care for special patient populations. However, health care also goes through periods of change and transformation, and through these transitions physicians and other health-care leaders must be able to adapt and evolve the programs and care initiatives they lead.

Dr. Liz Grier from the Queen's Department of Family Medicine's Intellectual and Developmental Disabilities (IDD) program is fortunate to work with a group of medical students from the QMed LEAD program on a project that captures the crux of this type of health-care transition. The focus is taking a Health Links care co-ordination program, which was adapted and implemented specifically for adults with

IDD, and aligning its key components and evaluation insights to inform the integrated care and system navigation programming of the new Ontario health teams (OHTs).

QMED LEAD STUDENTS MEET QUEEN'S FM IDD PROGRAM

The QMedD LEAD program, an elective available to Queen's medical students, includes seminars and independent learning modules on the intersection between physician leadership and health systems science, as well as a volunteer consulting engagement with a local organization in the community. The curriculum elaborates on the CANMEDS leadership role and includes knowledge of health-care structures and processes, health-care policy and economics, health information technology, quality improvement and value-based care⁽¹⁾.

In introducing themselves to Dr. Grier, a group of five Queen's medical students shared the range of interests that brought them to pursue the QMed LEAD program, including health advocacy, quality improvement, and policy change. In fact, some of the students had previous experience working in government and liked the opportunity to view the health system from a different angle. The students also were attracted to the program's volunteer consultation engagement, which provides exposure to frontline providers and the opportunity to give back to the Kingston community.

The students met with Dr. Grier in January and toured Ongwanada, the local developmental service agency, where they were able to see firsthand some of the multidisciplinary care programs and realize the importance of advocacy and careful system design for this vulnerable population.

Dr. Grier also explained to the students the SE-LHIN Health Links care co-ordination program for adults with IDD. This program involves an adapted template for the provincially standardized care plan form, and includes special considerations around sensory overload, communication challenges, unique issues around consent and capacity, and capturing the individual with IDD's voice in exploring patient-centred health-care goals. Of note, the majority of adults with IDD with high-cost health-care needs have concurrent mental health issues and this — as well as the mental health and well-being of their families — is a particular focus of the program.

The Health Links initiative, which is Ministry of Health and Long-Term Care-based, is “cross-sectoral by design” in that participating patients were recruited from Ministry of Children, Community and Social Services developmental service crisis tables. Implementation results showed that this approach was successful in bridging these sectors, engaging patients and their caregivers, and providing useful interventions aimed at strengthening community-based primary care ⁽²⁾. Results analysis also showed that patients recruited had characteristics in keeping with provincial data on high-cost use and adults with IDD, including challenging behaviour associated with caregiver burnout, transition to group home care, and high rates of both physical and mental health conditions ⁽³⁾.

QMED LEAD CONSULTATION — PROJECT QUESTION AND METHODOLOGY

After these introductory meetings, the students then launched into their consultation engagement, which is to take the lessons learned from implementation of adapted and specialized care co-ordination for adults with IDD and align these with the goals of OHTs, thus facilitating seamless transition to this new model of care.

The students conducted a thorough literature review including Health Links Ontario guidelines, review of the IDD Health Links implementation and evaluation, as well as provincial data on high-cost health-care use for this population. They then reviewed key transition and implementation documents for OHTs, including integrated care guidelines, OHT recommendations from the Ministry of Health, and shared frameworks from OHTs currently in full application status. Key alignment areas were identified and further explored through interviews with experts in the field of IDD. The outcome will be a brief written communication piece scheduled for completion in May 2020.

PROJECT HIGHLIGHTS TO DATE

The consultation work is going well, and several areas deserve initial highlighting. The students have captured a model of the pillars of integrated care by Goodwin et al. based on the “Three A's” of “Alignment, Agility, and Attitude” ⁽⁴⁾. These have translated well to the IDD Health Links experience.

The need to **align** was identified through finding a common language to define complexity as it exists across different providers, in this case involving both social service and health-care professionals. **Agility** was evidenced in this program by the nimbleness of the “cross-sectoral by design” approach, resulting in proactive identification of care integration issues, rather than encountering them as a barrier down the road and attributing a lack of success to “siloe care.” The important **attitude** for an integrated care program was nicely captured by the inclusion of champions in the field, including local family physicians with training in developmental medicine, senior case managers from developmental service agencies, and leadership from the Kingston Health Link.

Another model the students have explored is the continuum of care co-ordination across “front stage and back stage” activities involving both health-care providers and the managers who oversee them ⁽⁴⁾. The students will utilize a best practice care pathway diagram and overlay the IDD, cross-sectoral lens, thus creating an effective graphic mapping of how integrated care should flow for this special population.

Finally, a critical piece of this alignment work is to explore the Quadruple Aim of OHTs: improved patient, family, and caregiver experience; patient and population health outcomes; value and efficiency; and provider experience ⁽⁵⁾.

In terms of patient experience, adults with IDD and their caregivers not only have one but often multiple multidisciplinary teams they are simultaneously navigating. Effective care co-ordination serves to ease this burden and improve patient satisfaction. In terms of

improving health outcomes and efficiency, measurable benefit would come from OHTs focusing on adults with IDD as an identifiable target population. A significant portion of adults with IDD — up to 20 per cent — are known to experience persistent high-cost use and also have poor health-care outcomes — high rates of 30-day readmission, alternate level of care (ALC) and long-term care admission, as well as premature mortality ⁽⁴⁾. Thus, focusing on adults with IDD for care co-ordination programs would serve to improve economic value of the system while simultaneously increasing patient and caregiver quality of life indicators.

Health-care and social-service providers often feel overwhelmed and isolated in caring for complex patients, however, the relationships and collaborations facilitated through co-ordinated care conferences can counter this and result in rewarding provider experiences.

STAKEHOLDERS AND DISSEMINATION

A significant and varied number of stakeholders serve to benefit from the creation of this communication piece, including patients and caregivers who may join OHT advisory boards as self-advocates, developmental service agencies, (many of whom have signed on as collaborating organizations for existing OHTs), as well as health-care professionals (both primary care and specialists) who care for adults with IDD. The document will be shared with the Kingston, Frontenac and Lennox and Addington OHT planning committee and distributed across Ontario through several avenues, including the Health Care Access in Developmental Disabilities (HCARD) newsletter, the Community Networks of Specialized Care, and the provincial network of managers for developmental service agencies (e.g. Ongwanada, Reena, Community Living Ontario, etc.).

The QMed LEAD project will be of great utility to physicians and other leaders providing co-ordinated care for IDD patients through the transition to OHTs. It will also provide a rich educational experience for this group of QMed LEAD students about how to sustain program continuity while also evolving through changing health-care paradigms. As physicians, we need to discover how to be adaptable to provide care and advocate for our most vulnerable patients, even in changing landscapes.

For more information about this project, please contact Dr. Liz Grier at iddprogram@dfm.queensu.ca.

Article provided by Dr. Liz Grier, Senior Advisor, IDD, Queen's Department of Family Medicine, and QMed LEAD students Sara Sarbar, Ishita Aggarwal, Marielle Paule Balanaser, Milena Bullen, and Alexandra Donaldson.

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