Care, Support and Treatment of People with a Developmental Disability and Challenging Behaviours

Part I: Consensus Guidelines
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Jacques Pelletier
Editor
Foreword

More and more, families and caregivers are turning to community-based supports to care for adults with a developmental disability and challenging behaviours.

However, services and supports vary considerably throughout Ontario. Communities do not always feel that they have the proper resources to support and treat this group of people.

Recognizing the need for a comprehensive strategy to address the urgent needs of these individuals, the Legislative Assembly of Ontario in 2013 appointed a Select Committee on Developmental Services to make recommendations on improving the current situation. The committee made it very clear in its final report that a more robust network of developmental and mental health services and supports are crucial if people with complex needs are to have a good quality of life.”¹

Increasing care will only happen if communities can depend on a formal and effective system of services and supports. Responsibilities must be shared across all sectors, including health, justice, and education. We also need a regional and provincial system of resources, including budgetary and capital investments and an available, highly-skilled and trained workforce.

As a first step, we have developed a set of guidelines to help families, caregivers and agencies in the daily care, support and treatment of adults with both a developmental disability and challenging behaviours. The guidelines are based on what we heard during a year-long consultation process with people and organizations across Ontario. (Note: The recently proposed Dual Diagnosis Framework gives us the opportunity to work with our partners in the health sector to apply these guidelines. The Framework also complements these guidelines.)

By implementing these guidelines and developing pro-active training strategies in the second phase, Part II: Tools for the care, support and treatment of people with a developmental disability and challenging behaviours, we believe we can better support some of our most vulnerable people while contributing to the province’s goal of achieving inclusion for all Ontarians.

Jeffrey Hawkins
Guidelines Lead - CNSC-Ontario

Jacques Pelletier
Guidelines Project Director and Editor

Purpose

We developed these guidelines to:

• ensure that adults with a developmental disability who show challenging behaviours receive the supports, services, and when necessary, the treatments they need to live full lives in their communities

• represent essential elements that guide Ontario’s developmental services providers – families, caregivers and community agencies – when the people they support show challenging behaviours

• provide a foundation for best practices based on a general consensus agreed upon by the developmental services sector.

The guidelines are evidence based and:

• support Ontario’s goal to transform its system of developmental services into one that supports independence, inclusion and choice for all people with developmental disabilities in Ontario; ¹

• are closely aligned with the Dual Diagnosis Framework proposed jointly by the Ministry of Community and Social Services and the Ministry of Health and Long-Term Care.² The Framework defines systemic expectations with regards to community, social and health services. These guidelines capture the essence of good supports and treatment facilitation at the caregiving level. Both documents complement each other;

• complement the Behavioural Support Plan Reference Guide for Adult Developmental Services published by the Ministry of Community and Social Services. The Guide clarifies the requirements for managing challenging behaviour under the quality assurance measures and the policy directives. It can be used as an additional tool and resource for supporting persons with challenging behaviour.³

>Please note: The guidelines are recommendations for practice. They do not stipulate a standard of care or propose a single correct approach for delivering services or managing all clinical situations. Decisions regarding specific service development, caregiving and clinical approaches require individualized considerations that are the ultimate shared responsibility of individuals with a developmental disability, their families and close ones, service managers and professional health care providers.

These guidelines can change over time. Therefore, it is wise to always use sound judgement.

¹ Transforming Developmental Services in Ontario
Definitions

Dual Diagnosis
Dual diagnosis refers to people with a developmental disability who also have a mental health issue.

Developmental Disability
The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008 says that a person has a developmental disability if:

- the person has the prescribed significant limitations in cognitive functioning and adaptive functioning and those limitations:
  - (a) originated before the person reached 18 years of age;
  - (b) are likely to be life-long in nature; and
  - (c) affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity.⁵

Mental Health Issues
Mental health issues are defined as diagnosed mental illnesses or symptoms consistent with mental illness. A serious mental illness is defined as:

Disability - the reduced ability to perform basic living skills that interferes with or severely limits an individual’s capacity to function in one or more major life activities;

Duration - the recurring nature of mental illness means that there are likely to be intermittent episodes requiring acute care and periods of full recovery.

Diagnosis - includes schizophrenia, mood disorders, anxiety, depression, organic brain disorders, paranoid psychosis or other psychoses, severe personality disorder, concurrent mental health and substance abuse disorder and dual diagnosis.

People with a dual diagnosis can be functionally and medically complex. Individuals may:

- have serious sensory modulation issues and communication disorders
- exhibit challenging behaviours⁶ (self-injury and/or aggression toward others or their environment).

Based on the 2013 Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario⁷, there are approximately 66,000 Ontarians, aged 18-64, with a developmental disability. Close to half of these adults have a coexisting mental illness, a condition also referred to as dual diagnosis.

An excellent resource that complements these guidelines is the publication for families and caregivers entitled Dual Diagnosis: An Information Guide, by Yona Lunsky and Johnathan Weis published by CAMH.

Definitions

⁵ The SIPDDA definition is comparable in most aspects to the health system definition of Intellectual Developmental Disorder as published in the Diagnostic and Statistical Manual of Mental Disorders-V (DSM-V):

“Intellectual Disability (Intellectual Developmental Disorder)” is characterized by impairments of general mental abilities that impact adaptive functioning in three domains, or areas. These domains determine how well an individual copes with everyday tasks:

- The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.
- The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
- The practical domain centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks.”

⁶ “Challenging behaviour” is defined in Ontario Regulation 299/10 as “behaviour that is aggressive or injurious to self or to others or that causes property damage or both and that limits the ability of the person with a developmental disability to participate in daily life activities and in the community or to learn new skills or that is any combination of them”. (MCSS Policy Directives for Service Agencies).

Challenging Behaviour
Ontario Regulation 299/10 defines challenging behaviour as:

“behaviour that is aggressive or injurious to self or to others or that causes property damage or both and that limits the ability of the person with a developmental disability to participate in daily life activities and in the community or to learn new skills or that is any combination of them.” (See also Policy Directives for Service Agencies – Ministry of Community and Social Services.)

Professor Eric Emerson has defined challenging behaviour as:

“Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.”

Challenging behaviour can occur:

- because a person feels bad, depressed, angry, frustrated, alone, isolated, or at times because a person is hurting or doesn’t feel well physically.
- because a person is uncomfortable with ambient noise, light, textures and needs some form of “break” or “escape”; or perhaps because a person’s basic needs such as sexual or security needs are not met.
- because a person needs attention, whether positive or negative.
- due to conditions such as epilepsy, trauma, as well as specific syndromes, or mental disorders.
- due to pain or discomfort caused by physical conditions such as dental problems, ear infections, ingrown toenails, constipation: physical health, as a rule of thumb, should be constantly monitored and addressed.

Challenging behaviour can also be a way to communicate distress of some kind to caregivers. Challenging behaviours are not inherent. They happen for a reason.

Two of the most common challenging behaviours shown at times by persons with developmental disabilities are aggression and self-injury. Other behaviours that can be of concern involve any kind of sexually inappropriate behaviour.

Community Living Ajax Pickering and Whitby use the following “Challenging Behaviour Continuum” diagram. It shows the different types and levels of challenging behaviours that these guidelines cover, as well as the agency’s service philosophy with regards to such needs.

Most people with a developmental disability and challenging behaviours are supported by their families and community-based agencies. Lack of access to clinical resources, varied approaches, and not enough cross-sector fluidity are ongoing problems between health services and social/community services.

Families, developmental services agencies, and their health-sector partners are gradually making progress in meeting the needs of this group of individuals.

Providing supports to people with extreme challenging behaviours, especially aggression is the biggest challenge. Some people experience breakdowns in their care or residential setting and end up being hospitalized in forensic units or incarcerated in detention centers. Individuals with a developmental disability and challenging behaviours seldom belong in such facilities but can at times stay in them for long periods of time. As well some patients with developmental disabilities and challenging behavior are hospitalized in acute care hospitals while no longer needing acute services, but are waiting to be discharged to a setting more appropriate to their needs.

Some agencies in the developmental services sector have the resources and experience to support these individuals. They need to continue help developing more generic community-based competencies to offer long-term care and supports to this group. These guidelines will fall short of their ultimate objective unless there is a concerted, non-ideological, cross-sector effort to address this issue.

The late William Gardner contributed through his writing and publications to the field of intellectual disabilities to better understand and treat challenging behaviours. He has over 140 publications and most of them related to mental health issues in persons with IDD. Dr. Gardner has contributed to the NADD literature through the NADD Bulletin, writing book chapters for the NADD Press, and authoring or co-authoring NADD Press books such as:

- Behavioral Supports: A Multimodal Functional Approach
- Practice Guidelines for Diagnosis, Treatment & Supports
- Treatment of Aggression in ID

http://thenadd.org

### Philosophy

As one of many service providers in the community for adults with developmental and/or intellectual disabilities, Community Living Ajax Pickering and Whitby provides different service models based upon an individual’s need. The level of support is guided by the supported individual’s choice and their care plan requirements. We strive to collaborate resources when needs change beyond our scope of services, we will assist individuals in planning and moving to the next level of care, either within our Association or the broader community. Our service is delivered by staff who will promote a professional, honest approach and ensure that the integrity of the process is upheld by being accountable for all facets of our services.

### CHALLENGING BEHAVIOUR CONTINUUM

#### AGGRESSION

**Not Directed at Persons**
- Throwing objects
- Destroying property
- Stealing
- Ripped off clothes
- Spreading of feces
- Oppositional behaviour

**Directed at Persons**
- Hitting
- Head butting
- Hair pulling
- Screaming
- Verbal abuse

#### SELF INJURY BEHAVIOUR

**Not Directed at Persons**
- Head banging
- Hand biting
- Excessive scratching
- Picking of the skin

**Directed at Persons**
- Kicking
- Spitting
- Biting
- Scratching

#### INAPPROPRIATE SEXUALIZED BEHAVIOUR

**Not Directed at Persons**
- Touching a non-consenting partner or children in a sexual way
- Engaging in sexualized behaviours that involve self-injury

**Directed at Persons**
- Gropping
- Exposing oneself
- Masturbating in public
Guideline 1: Principles

All services for adults with a development disability who show challenging behaviours should be based on the following principles:

- the right to be fully included in their community where they can foster their physical, social, emotional, intellectual and spiritual development
- the right to receive supports tailored to their needs, goals, preferences, and culture
- the right to receive the appropriate treatment when they need it from their community health and social services agencies
- the right to have their needs addressed if they are involved with forensics/justice
- the right of youth with a developmental disability who show challenging behaviours (as well as their families) to receive the support they need to transition into the adult services system

- the recognition that older adults need supports as they age
- the recognition that people should be given an opportunity to make informed decisions about their lives and the supports and treatments they receive.

Most of these principles also appear in the Dual Diagnosis Framework proposal.

General supports as well as specialized and/or clinical services should:

- respect and promote the uniqueness and diversity of people and their families
- help remove the stigma and discrimination that negatively impact mental health and social outcomes
- help individuals develop strengths and resilience so they can grow in their sense of safety, self-worth, and personal fulfillment

- focus on independence, employment, meaningful activities and recreational opportunities that establish positive social roles and help develop relationships within the community
- contain plans to fading restrictions imposed at times on individuals through ongoing monitoring
- work towards continuous improvement and change by building on evidence-based practices, life experiences, and research.
Guideline 2: Supporting People in Exercising their Rights

This guideline encourages families and developmental services agencies to help adults with a developmental disability exercise their rights in all areas of their lives, particularly when they interact with health, justice and social services.

The Canadian Charter of Rights and Freedoms and the Ontario Human Rights Code apply to all Ontarians. It can be challenging for people with a developmental disability to understand and exercise their rights. Therefore, we need to support them appropriately.

Many adults with a developmental disability can and do interact with services within their communities throughout their lives. They need to be able to exercise their individual rights within any of these services (e.g. developmental, health, educational and rehabilitative). People with challenging behaviours may have greater difficulty in protecting their rights when trying to access additional supports.

Families, caregivers and developmental service agencies who support adults with challenging behaviours should be familiar with the following legislation:

- Mental Health Act
- Health Care Consent Act
- Substitute Decisions Act
- Personal Health Information Protection Act
- Criminal Code of Canada (Part XXI)
- Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act
- Guide to the Regulation on Quality Assurance Measures and specifically its Regulation 299/10, require that persons with developmental disabilities:
  - receive an education on the prevention, identification and reporting of abuse
  - receive an orientation and annual refreshers on the service agency’s Statement of Rights have an Individual Support Plan that that addresses their goals, preferences and needs
  - have greater independence and self-determination in all aspects of the supports they receive.

Many practical guides have been written specifically for people with developmental disabilities that outline their rights and how to exercise them. Community Living Ontario and People First of Ontario and Canada are important consulting sources. ARCH Disability Law Centre is the nation’s leading community legal aid clinic dedicated to defending and advancing the equality rights of people with disabilities in Ontario.

The Practical Guide to Mental Health and the Law in Ontario can help you understand the requirements of these acts.
Guideline 3: Supporting Informed Consent

It should never be assumed that an adult with a developmental disability and/or dual diagnosis is unable to make their own decisions and choices. Developing respectful relationships involves the ongoing participation and consent of the person involved.

When seeking a person’s consent to treatment or care, give them the time and support they need to make their decision properly. (An exception would be in the case of an emergency.)

It is important to ensure that the adult with a developmental disability understands the consequences of their treatment choices. Providing consent and voicing an opinion are fundamental legal rights and will give the individual a sense of control. Allowing the person to make their own decisions creates a feeling of ownership. This may increase the likelihood of success. Everyone involved in making decisions must understand that rights imply both a responsibility and respect for others.

If a Behaviour Support Plan (BSP) includes intrusive measures for managing challenging behaviour then the individual or the person acting on their behalf must be involved in the development of the plan. (Ref: Policy Directives For Service Agencies: 2.0 Supporting People with Challenging Behaviour). Discuss the plans with them. Plans need to be:

- consistent with the person’s legal rights
- consistent with the standards of professional practice
- sensitive to cultural issues.

Individuals have the right to stop interventions that involve restrictive and/or intrusive measures that are included in their behaviour treatment programs. A person acting on behalf of the person with a developmental disability also has the right to witness and stop intensive behaviour treatment programs involving intrusive measures.

For more comprehensive information regarding informed consent, please refer to Tools for the Primary Care of People with Developmental Disabilities.

As part of a health check-up, Graham was asked by the medical students whether they could take his blood pressure. Graham refused, and explained that due to his past medical experiences he was afraid of needles. Despite the students explaining to Graham that no needles are involved in the procedure and it is needed to see if he was healthy, he continued to refuse to have his blood pressure taken. The students respected Graham’s decision and did not take his blood pressure.

If it was essential for his health, additional measures should have been taken beforehand. For instance, his primary physician could use the development of a trusting relationship between Graham and themselves to better prepare him for the procedure. With time and clear communication, Graham could believe that no needles would be involved in taking his blood pressure. Additionally, Graham may benefit from professional help to address his needle phobia. However, he would need to consent to such help.
Guideline 4: Holistic Perspective

When developing individualized services and program plans, it is important to take a holistic approach. In other words, consider the "whole person." Care, support and treatment plans should take into account the person's perspective and encompass everything that is important to them, including culture and values.

This image illustrates some important components of a holistic (whole person) approach to one's fulfillment that should inform ISPs. The different colours serve to remind people are different from one another and constantly evolve and develop.

“We really thought George was going to be happy in his new apartment, a bachelor studio attached to one of the group homes. One day after moving in, he completely destroyed his place, including ripping out the toilet and most electric cabling and plumbing.

The apartment was repaired and his furniture was replaced. He destroyed everything again within two days. It was decided that he would have to help with the repairs and renovation.

After a week, no progress was made. When George was on his own one evening, his brother came in to help. For the next four weeks on evenings and weekends, George and his brother worked on his apartment until it was completed. Though it may not suit everyone, George has a home that is his own. His home is part of an ever-evolving support plan that also involves his possessions, privacy, choices, tranquility, stability, his brother, and carpentry classes.”
Guideline 5: Using the Bio-psychosocial Model

The bio-psychosocial model and its multidisciplinary strategies will help caregivers, supporters, and developmental services agencies understand the causes for challenging behaviours and find the right approaches to address them effectively. The model proposes that the following factors influence a person’s life:

- physical health
- mental/emotional health
- individual history
- life changes
- individual and family perspective
- day-to-day circumstances
- social factors
- environment

The multimodal diagnostic assessment model as well as diagnostically-based treatments are basic approaches agencies should integrate in support plans for people with developmental disabilities and challenging behaviours. The multimodal diagnostic assessment identifies bio-psycho-social interwoven influences that have contributed to or continue to represent risk factors. The diagnostically-based treatment approach considers a bio-psycho-social intervention that is integrated into a comprehensive treatment plan.

Biological Factors

Many biological factors can affect the health and wellness of individuals. They can account for a significant proportion of challenging behaviours in people with a developmental disability. Taking biological factors into account can help with the prevention, assessment and treatment of challenging behaviours. For example, dental problems, ear infections, digestive malfunctions or ingrown toenails, are often reported as causes of pain and discomfort that can lead to challenging behaviours especially when the person cannot clearly communicate their needs and wants.

Physical abnormalities present from birth such as sensory impairments, epilepsy and cerebral palsy are also conditions that can affect behaviour. Neurological deficits can also cause challenging behaviours.

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Nicole is 22 years old with a developmental disability and spina bifida that requires a shunt. When the shunt malfunctions, she engages in self-injurious behaviour (head banging). Her shunt then requires surgical adjustment. The combination of the pain and hospitalization upsets Nicole. By the time she is discharged, her self-injurious behaviours, as well as her emotional outbursts, have usually disappeared.

Jeff is 64 years old with a severe developmental delay, autism, and bipolar mood disorder (with agitated depression and mania). When he turned 60, his self-injurious behaviours increased significantly. In order to self-restrain, he began to constantly hide under his bed sheets. Eventually, the facility where he was living could no longer match his needs, and he had to be moved to another residence.

At the new residence, the staff, management, and primary care provider decided that Jeff should be assessed for physical ailments and sensory difficulties. Assessments showed he did not have any physical problems, but was sensitive to light and ambient sounds. The soles of his feet were extremely sensitive. Staff also found that Jeff’s glaucoma was getting worse and was likely causing vision problems. Jeff had his cataracts removed, received special socks, and had his room modified to accommodate his sensory issues. He also had access to a quiet room when he felt he needed it. Although Jeff still exhibits self-injurious behaviours at times, they have diminished in frequency and severity since the accommodations were made.

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Psychological Factors

How a person feels, learns, communicates, and adapts can impact behaviour. Therefore, an individual’s mental health should be considered. People with a developmental disability can understand what is happening around them and cope with their feelings. Consider the possibility that challenging behaviours may be a way of coping with sadness, grief, frustration, boredom or loneliness. It is imperative to help individuals feel emotionally and intellectually healthy. This can be done in many ways: through treatment and counselling or simply by helping a person develop and maintain friendships.

“Ross’s mother passed away three years ago. Ross has a severe developmental disability and is non-verbal. The family and the group home staff did not tell Ross that his Mom had died since they did not think he would be able to understand the concept of death. Instead, they told him she had gone to Heaven.

A year after his mother’s death, Ross began self-mutilating. Using various methods, the staff tried to protect him and put an end to his behaviours but nothing worked. One day his brother visited Ross and brought with him pictures of their mother at different times of her life. Ross became agitated and tried to break the picture frames and eventually needed to be restrained. One staff member decided to use this crisis as an opportunity to look for a different solution.

The agency found a grief counsellor who had experience working with people with developmental disabilities. The counsellor explained to the family and staff that Ross likely missed his mother and could not understand why she would not visit him.

They decided that it was time to tell Ross that his mom had passed away in order to help him deal with his loss. Helping Ross deal with his loss took several forms including counselling, visits to the cemetery, crying, and sitting with him in his grief.

It is difficult to know for sure if Ross understands that his mother has died, but in the past six months his self-injurious behaviours have diminished significantly”.

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Social and Environmental Factors

Regardless of age, many people with a developmental disability are socially isolated. Some depend entirely on their families for social support and company. In many cases, friendships or romantic relationships have not been allowed to develop. Often, the only relationships they have are with paid staff. Although direct support staff can offer a great deal, they change jobs frequently and/or take on new responsibilities. Staff turnover can be devastating to someone who is often alone or grouped with other adults with developmental disabilities who they may have little in common with. Just like anyone else, adults with a developmental disability seek comfort from family, friends and intimate relationships. Although human relationships are important, significant relationships with animals and nature can also develop.

Hélène is a 37 year-old woman with a developmental disability and a language disorder. Her parents died two years ago. A year ago when her regular group home staff was on vacation, she began to show severe self-injurious behaviour. Her sister was asked to care for her for a few months.

The family and Hélène subsequently decided with the agency to try a placement with a host family. The agency also helped her access additional primary care services from a nurse practitioner clinic. Her associate family is made up of seven grown children and sixteen grandchildren. Hélène has become very fond of their Labrador retriever and two cats, and she cares for these animals every day. She is also interested gardening and enjoys family activities such as Sunday dinner. Hélène’s self-injurious behaviour has significantly diminished after six months of living in her new home.

Living arrangements can also significantly impact a person’s behaviour. The number of people living in the same house and their compatibility are crucial factors.

Traditional group home routines can be “institutional” in nature and cause challenging behaviours. Lack of privacy and autonomy can provoke challenging behaviour.

Four men living together tended to exhibit aggressive behaviours after watching hockey games on television.

The home had a rule that during the week the television had to be turned off at 9:30 pm. If a game went into overtime, the men often missed the most exciting part. They were not able to express in words their frustration with the rule, and acted out instead.

The television rule no longer exists as the men are now responsible for deciding when to go to bed and when to wake up. They usually go to bed between 9 and 10:30 pm. Their autonomy with regards to their daily routine has given them the opportunity to learn that at times people need to get up for work, even if they would prefer to stay in bed. As they all love their jobs, this new responsibility has motivated them to go to bed earlier during the week, except when hockey games go on a bit longer.
Ontario is a multicultural society. The culture of the individual with a developmental disability and their family must be considered.

The bio-psychosocial model helps agencies and staff develop a holistic or global vision of the people being supported. This includes the nature of specific challenging behaviour(s), their causes (biological, sensory, psychological, social, environment), and what can be done to successfully address them.

Alcide is a 24-year-old man with a developmental disability. He is a nice man who likes to laugh and tease those around him. He can at times be aggressive and destructive so a behaviour support plan has been developed with him.

He spends Sundays with his family away from his usual residence. During this time, his parents always say he is well behaved and never causes problems. He actively participates in a two-hour church service where he loves to sing, dance and speak Creole.

After church he joins his family for a traditional meal. He enjoys the food and the company of family and friends. His Sundays with his family, church members and a Creole-speaking volunteer, Haitian meals, songs and dances, are some of the most important elements of his support plan.
Guideline 6: Knowing the Person

Too often we take an “outside-in” perspective. This refers to trying to fit a person’s behaviour into existing structures, programs or diagnoses. An “inside-out” perspective tries to understand a person’s behaviour by getting to know the person and their unique needs. Caregivers and clinicians who develop and implement interventions to prevent, diminish, or eliminate challenging behaviour must take the time to get to know the person they are working with. They need to know the person as a “whole” human being, not simply as someone who has challenging behaviours.

James is a tall, strong 22 year-old Cree man who loves to fish, hunt and track animals. With the help of his caregivers and care providers, he tries to deal with his developmental disability and speech-language delays partly by trying to further develop his adaptive skills. He has been trying to control his eating challenges for many years. Though his first language is Cree, he is able to communicate in English. He has a history of social conflicts, aggression and other inappropriate social behaviours. Because of these behaviours, James has been hospitalized in mental health units. He was also charged and served time for assault and misdemeanours. James feels sorry for his past actions and wants to be a better man.

A network involving clinical and community resources has been developed to support him. The network includes:

- a counsellor from his First Nations community
- a behavioural clinician
- a psychologist
- his doctor
- a discharge planner
- a CCAC nutritionist
- home care nursing
- adapted Community Living residential and vocational supports
- a center in Pittsburgh specializing in the treatment of Prader-Willi syndrome.

All have been critical in his successful treatment and care. James has now lost 75 pounds and is better able to control his eating. This has led to an improved self-image and has helped him find a more stable home. It has also made it easier for him to reconnect with his Native culture and community. His challenging behaviours have decreased. He has resumed fishing and tracking activities and looks forward to hunting again. In addition, he now plans to attend upcoming Pow Wows. His caregivers are optimistic that he has the necessary motivation and tools to help him get better and be happy.
Guideline 7: Involving Family Members and Close Ones

Parents, family members and advocates have personal and emotional bonds with people who are supported by developmental services agencies. Parents have life-long ties with them. Close ones such as parents, siblings, friends and even advocates can be important allies in understanding them and how best to help them. Support plans and strategies should also take into account the opinions and feelings of the people close to them.

Toni’s grandmother came to visit six months ago. She remembered that he had especially loved her pasta e fagioli when he visited her in Napoli in 2003. Toni lives in a 24 hour supported specialized home with two other men his age. At times, he can exhibit considerable self-injurious behaviours, and just before his grandmother’s visit he had a behaviour flare up. His grandmother brought over pasta e fagioli for Toni, the other residents and staff. She sang Napolitano songs with the group.

Pasta e fagioli is not a miracle cure for Toni’s self-injurious behaviours. However, knowing Toni’s cultural roots and his likes [singing, his Nonna, and pasta e fagioli] help the staff and his family provide a different type of support. They are better able to find non-medical, non-intrusive measures in order to lessen his behaviours. During his grandmother’s visit, Toni did not self-injure. Instead, he hummed along with her songs and ate her pasta.

Regular Italian meals, Louis Prima singing Napoli songs, and a weekly Skype session with his Nonna are now part of his life and support plan strategies.
Guideline 8: Supporting Caregivers and Families

Workers and family members must develop support plans that also work for them. Here are some things to consider when developing a support plan:

- What can you do to help workers increase each other’s level of safety and comfort when someone is displaying challenging and dangerous behaviour? Keep in mind Non-Violent Intervention (CPI) or Safe Management are required trainings for staff that work in the DS sector.

- What can you do to have more fun at work?

- How can the people you work with have more control over their schedule and input into decisions?

- How can your agency better support staff and/or family members?

Working all day with someone who engages in self-injurious behaviour or aggression can be emotionally draining. Staff members should be provided with safe spaces to debrief. This is important for the wellbeing of both the staff and the people they support.

It is painful for a family member to see their loved one self-mutilate or act aggressively toward others. It is also painful for people to have to let “strangers” look after their family member. Making families feel appreciated is important. Listen to them and acknowledge their experiences and feelings.

For many years, Mr. C. was in conflict with the staff in his son’s group home. For a few days at a time, his son Peter showed extreme self-injurious behaviour (hitting his face violently). When that occurred, procedures were put in place to protect him. These procedures involved severe restriction of Peter’s arm and leg movements. However, Mr. C. was against all forms of restraints. Mr. C. eventually consented for his son to be restrained, but the staff always felt bad about the situation.

The staff convinced the new house manager to arrange a meeting with Mr. C., Peter, and everyone involved in supporting him. Peter’s occupational therapist had worked at adapting equipment to stop Peter from hurting himself during an episode while giving him some autonomy of movement.

She brought this to the meeting to show Mr. C. He asked to be fitted with it and made some interesting suggestions to improve it. Mr. C. returned the next day to watch the equipment being used and was impressed by the amount of work done to accommodate his wishes.

He sent a thank you card to the staff. They were pleased to have found a form of support acceptable to both Mr. C. and Peter. As well, Mr. C. felt involved and was happy his suggestions were taken seriously and that they made a difference.
Support from Developmental Services Ontario

Developmental Services Ontario (DSO) is the single point of access to apply for Ministry of Community and Social Services-funded services and supports for adults with a developmental disability in Ontario.

Individuals and their families can turn to Development Services Ontario to find the supports and services within their communities they need to participate more fully in their communities. Examples of ministry-funded services and supports are:

- residential supports
- caregiver respite
- community participation supports
- professional and specialized services
- person-directed planning.

At times some services cannot be accessed temporarily. DSO can offer interim services and supports.

There are nine Developmental Services Ontario agencies across the province.

For more information, visit www.dsontario.ca.

“*It took three years for Anita to secure a spot in a local group home. While her challenging behaviours were exhausting at times for our family, the DSO was able to find regular respite services as well as speech therapy, behaviour therapy, and occupational therapy, services that helped us significantly*. “
Guideline 9: Training and Clinical Supervision

Experienced clinical managers have found over the years that placement breakdowns were not due to the presumed ‘difficulty’ of the individuals’ challenging behaviour or lack of staffing numbers, but consistently due to poor communication by management, insufficient staff training and lack of consistent clinical supervision and professional support. Research published in an important article by Broadhurst & Mansell confirms these findings.10

The Toronto Network of Specialized Care has used an initiative called the Quality Behavioural Competencies Strategy to train behaviour therapists, managers and front line staff. After the training, they found that the average number of incident reports relating to challenging behaviour decreased from 5.4 incidents to 3.2 incidents per month.

Training for DS agencies is regularly funded by MCSS. Contact your Regional Office ministry for more details. CNSCs throughout the province offer numerous training opportunities (http://www.community-networks.ca/education/provincial-education-strategy/)

"Increased training and on-site clinical supervision have not only helped us deal more effectively with challenging behaviours when they occurred, but gave us confidence and helped us find ways to implement programs in a natural, personalized manner. In essence, we became better at helping our folks learn how to behave in acceptable manners in all aspects of their lives, not only in the residence, without narrowing our focus to be only on their behaviour plans".

Guideline 10: Seeking Cross-sector Partnerships

Supporting people with challenging behaviours requires working with agencies and/or services from other sectors, especially:

- health
- justice/police
- and emergency/first responders.

The following resources can be of help.

The Ministry of Health and Long-Term Care and the Ministry of Community and Social Services have recently worked on a new set of dual diagnosis guidelines entitled, the Dual Diagnosis Framework. The Framework:

“… defines expectations for systems management and service delivery strategies for adults with dual diagnosis. It outlines the Continuum of Services and Supports from both the health and social services sectors and provides a governance model. It also describes system and operational outcomes, along with accountability mechanisms to deliver high quality care responsive to the needs of adults with dual diagnosis and their families and caregivers.” 11

This document is comprehensive and will help agencies and their partners work cooperatively. You can get a copy from:

- Ministry of Community and Social Services Regional Offices
- Local Health Integrated Networks
- Developmental services agencies
- Community Networks of Specialized Care
  (They also offer examples of protocols for first responders, emergency services and police interventions.)

The Provincial Human Services and Justice Coordinating Committee has some very useful publications and contacts [http://www.hscc.on.ca/SitePages/Default.aspx](http://www.hscc.on.ca/SitePages/Default.aspx)

**Dual Diagnosis Justice Case Managers** are part of the Court Support and Court Diversion Services within the Province of Ontario and have been affiliated with the Community Networks of Specialized Care from the start. The case managers work with health, justice and corrections professionals to keep people with a dual diagnosis out of the criminal justice system and/or support them through the justice process.

**Autism Speaks** proposes excellent tips and resources for first responders. Go to [www.autismspeaks.org](http://www.autismspeaks.org) for more information.

Note on Assessment Strategies

Guidelines 11 - 20 recommend assessment strategies to help caregivers better understand what may be at the root of challenging behaviours and what can be done to address them. Without properly investigating the causes of the behaviour, we cannot develop the proper approach/method to address them. Assessments are important.

Although the assessment guidelines appear in a certain order, you do not have to follow that order. These guidelines should be adjusted for each individual.

We suggest agencies and their partners adopt the systematic approach to assessment as described in the Primary Care Guidelines posted on the Surrey Place Centre website. ([http://www.surreyplace.on.ca/primary-care](http://www.surreyplace.on.ca/primary-care)).

Finally, it is important to note that caregivers should not wait for all formal assessments to be completed before trying to find ways to help a person.
Guideline 11: Holistic Assessment Perspectives

Families and agencies should use a holistic, bio-psychosocial approach to assessments, interventions, and strategies. Just like everyone else, adults with a developmental disability and challenging behaviours have their own strengths and weaknesses, hopes, dreams, goals, likes and dislikes and their own stories to tell. They are social beings who need relationships.

“One of the most frequent reasons for referring a person with a developmental disability to a hospital or a clinic is because of aggression/self-injurious behaviours. Such behaviours are not only distressing to the individual, but are also challenging to the care provider. Unfortunately, quite often, there is no clear understanding of the reasons for the crisis, which inevitably leads to less than optimal interventions”. Dr. Jay Rao

“Difficult behaviours are messages which can tell us important things about a person and the quality of his or her life.” Dr. David Pitonyak

This diagram shows possible causes of challenging behaviour and ways to address them.

“One part of the human being does not stand on its own.”

Aleksandr Solzhenitsyn.

ASSESSING & ADDRESSING POSSIBLE CAUSES OF CHALLENGING BEHAVIOUR

**Assessing & looking for causes**

- Body/physical health
- Mind & emotions
- Mental health
- Disorders, syndromes, genetics
- Social environment

**Addressing possible causes**

- Physical environment
- Communication/speech & occupational
- Functions of behaviours
- Changes in the environment
- Medical treatments
- Activities/therapies
- Speech, occupational & physical therapies/activities
- Behaviour treatments BSPs
- Quality of life improvements

**ASSESSING & ADDRESSING POSSIBLE CAUSES OF CHALLENGING BEHAVIOUR**
Our living arrangements influence our behaviours and our wellbeing. When things aren’t right in our homes, workplaces and other environments, we can feel bad. Our behaviour and actions may be affected.

Dr. David Pitonyak likes to tell his audiences how he would feel if he came home one day after a trip and there was another woman in his home instead of his wife. And he was told “don’t worry, we have you covered”.12

Although fictional, this story is a reality for many adults with a developmental disability who have a residential arrangement staffed with caregivers. Changes to support staff or routines can be frustrating and stressful. Agencies can manage staff hours and turnover, but are we supporting long-lasting relationships? This is one of many different areas that should be explored when trying to assess if a person’s social/physical environment may be the source of someone’s challenging behaviours.

Here are some questions to ask:

- How stable are relationships with family members, friends and loved ones and staff?
- How well do the residents get along with each other and with staff?
- How did the residents get placed into the residence? Who lives there? Who doesn’t?
- Is the environment of the home inviting, nurturing and encourage relationships with families and friends?
- Are behavioural approaches consistent if residents show challenging behaviours?
- Whose home is it? If staff feel they are working in someone’s home, the more the environment will have the characteristics of a “real home.” An “institutional” environment can create conditions (lack of privacy, social status, intimacy, autonomy) that cause challenging behaviours.
- How much autonomy do people have? Can they come and go freely? Are house rules adapted to adults? Are privacy, intimacy, and ownership allowed?
- Is the environment physically comforting and aesthetically pleasing? What about noise and smells and lighting? Do the residents share mealtimes or eat by themselves? Is there help for people who have difficulty feeding themselves?
- How accessible is the house, both inside and outside? What’s the neighbourhood like? Are neighbours friendly and helpful?
- Can residents entertain family and friends? Does the environment reflect the cultural backgrounds of the residents? Do staff interact with residents in ways that are culturally sensitive?
- Do activities make sense? Are they appropriate for adults?

Guideline 12: Assessing the Environment Where the Person is Living

“As the ED of our Community Living agency, I was interested in staff compatibility with residents. I asked the union representatives if they would agree to look into this with us. They readily agreed. It turns out a number of people were not compatible and changes were made. It greatly improved the quality of life of all concerned”.

“Ted has been our neighbour for 30 years. He comes in regularly for a cup of coffee. He’s been the one constant person in the lives of people who live here. You’d be surprised how much he knows about the people living here and how much they like him.”

“We gradually replaced the Fisher Price shape sorting toys with a supported employment activity consisting of inserting products in shelves and containers. Not only is this activity more developmentally appropriate for Marie’s age, it is useful because she sees people and she has opportunities to expand the scope of her shape sorting “passion”. Her passion has lead to employment and increased skills development opportunities”.

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Guideline 13: Primary Care Assessment

Pain or discomfort arising from health problems can cause challenging behaviours such as aggression and self-injury. Common examples are:

- ear infections
- dental problems
- constipation
- in-grown toenails.

The first step in treating behavioural issues is to rule out the possibility of physical health problems. Have a health care professional (such as a family physician, nurse practitioner or a dentist) assess the individual to diagnose and address the person’s:

- sleep
- weight
- swallowing
- gastrointestinal system
- mouth
- dentition
- eyes
- ears
- heart
- respiratory system
- neurology/brain
- skin
- nails
- musculoskeletal system
- mobility
- genitourinary system
- sexual health
- female or male-specific health issues.

Referrals to specialists may be necessary for additional assessments.

Family members and/or caregivers who accompany people during their medical examinations should come prepared to provide information and answer questions. The forms suggested in *Tools for primary care of people with developmental disabilities* are a good resource.

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Steven is a 56 year-old man with a severe developmental disability. He has lived with the same host family for ten years since leaving a regional facility.

Two years ago he became increasingly aggressive towards others and his environment and was hospitalized in a mental health unit.

Following a suggestion made by his family physician, his treating psychiatrist referred him to an internal medicine specialist for testing and assessment. A tumour was found near his stomach, which was likely causing pain and discomfort. The tumour was removed.

Upon his discharge from the hospital, Steven’s aggressive behaviour ceased and has not reoccurred since. He continues to be regularly followed by his family physician with the support of his caregivers.
Agencies, families and clinicians will find the Health Care Access Research and Developmental Disabilities (https://www.porticonetwork.ca/web/hcardd) a good source of resources and information on health services for people with developmental disabilities.

All aspects of a person’s health must be monitored. The person’s primary care provider should perform an actual physical examination and not depend only on third party information.

Medication reviews should be performed regularly.

Sandra is a 35 year-old woman living at home with her parents in an attached suite. She had never shown aggressive behaviour until one day she started kicking the walls and the people around her.

After months of trying to stop her, her parents contacted their local Developmental Services Ontario office and were referred to a health agency.

A nurse practitioner went for a brief visit and Sandra allowed the nurse to examine her. The nurse discovered that under her nail polish Sandra had ingrown toenails on both of her feet.

Referrals were made to a local community hospital for Sandra to undergo day surgery in order to have her ingrown toenails treated. While Sandra was sedated for her procedure, the doctor also decided to look at her dentition and found several issues.

Arrangements were made with a community health centre for Sandra to receive dental treatment.

Within eight months, Sandra’s ingrown toenails had healed and her teeth had been repaired. Her kicking stopped with treatment of her feet and she has not shown any further aggression.

She continues to be cared for by her primary care provider and a nurse practitioner at a Nurse Practitioner-led clinic.
Guideline 14: Functional Assessment

To understand and effectively respond to challenging behaviours, professionals have to perform a comprehensive functional assessment of the behaviours displayed. A Board Certified Behaviour Analyst and/or a Psychologist can perform these assessments. A functional assessment can be used to try and answer the following:

- What motivates the behaviour? What are the triggers for the behaviour? What are the consequences of the behaviour?
- Does the person have another way to get what they want? If yes, why is it not being used or how is it not effective? If not, what behaviour could be taught to achieve the desired function?
- How can the environment, activities, and interactions be changed to prevent the challenging behaviour from occurring?
- If the person has the skill, can the environment or interactions be changed to encourage the person to act appropriately and in a way that can be reinforced whenever the challenging behaviour occurs?

“It took a while, but we were finally able to establish that Joakim’s destructive behaviour in his apartment was caused by his attention to detail, and his need to have everything placed exactly as he wants. If someone moves an object when he is not home, he will smash the object.

Joakim also has trouble when he meets someone he doesn’t know in his home. Being non-verbal, he found alternative ways to communicate his feelings through hitting people and damaging his apartment.

Finally, we observed that when Robert (staff) worked with Joakim he became aggressive.

We made the following adjustments to accommodate him: we let him place his objects and clean his apartment; when introducing staff, we showed him pictures and asked his opinion about potential new hires. We also transferred Robert to another home.

Some have questioned whether we have given Joakim too much power, but we feel strongly that we should give him space to feel “at home”.

It was important for us to realize that we were the key triggers to his outbursts. We are happy that the behaviour analyst helped us understand this so that we were able to improve his life.”
Guideline 15: Considering Trauma as Part of Understanding a Person’s History, Life Events and Stressors

Note. The upcoming tools for the care, support and treatment of people with a developmental disability and challenging behaviours will suggest many resources that can be useful to caregivers supporting individuals who are potentially suffering from trauma, something that could help understand and better support some individuals with challenging behaviour.

Examining challenging behaviours from a mental health perspective involves considering the possibility of trauma. Trauma can be caused by a number of events such as:

- grief
- sexual abuse
- physical abuse
- psychological abuse.

There is growing interest in understanding the psychological consequences of life events for people with a developmental disability.

“Deciding whether something is traumatic is influenced not only by the event itself but by how the person experienced the event. Something that may seem small or insignificant could be very traumatic to the person with a developmental disability. Furthermore, because the concept of time can be confusing for someone with a developmental disability, an event that happened a long time ago may still have a major impact. For some individuals, such as someone with autism spectrum disorder, the “replaying” of an event may not lessen over time, so that if it is remembered, it is with the same vividness as when it happened. This can be very distressing. Thus it is important to understand not only what the traumatic event was, but the context of the event, how it was handled or explained to the person then and how it is remembered or thought of by the person now.” Yona Lunsky, CAMH

When Josephine was seven, she was picked up after school and brought to a provincial institution where she resided for the next 30 years. She had a moderate developmental disability and became non-verbal from that point on. Her parents had both died in a house fire, and she was only supposed to stay for a few weeks in the institution. However, no family member came forward, and the village mayor and the local Children’s Aid Society representative made arrangements for her to be permanently placed at the institution.

She was never told why she was taken away and what happened to her parents. She spent 30 years screaming at night.

Her life at the institution was not always pleasant. When Josephine’s facility was scheduled to be closed, she was evaluated for a community placement. The institution and community psychologists suggested that it would be a good idea to explain to Josephine that her parents had died. This was not an easy task considering Josephine’s comprehension level.

A few weeks after she had moved into her new home, two clinicians and a staff member from the home brought Josephine to the cemetery where her parents were buried. Using pictures, they explained to her that they had died.

Despite some initial difficulty, she eventually seemed to accept that her parents had died and left flowers at the gravesite.

She has now been in her home for five years. She visits her parents’ grave at least once a month and leaves flowers when in season. She takes care of the site with her support staff. Josephine seems to be comforted by her visits and she screams less often at night.
Distinguishing traumatic events from life events can be difficult. Studies suggest that the range of potentially traumatic experiences can be greater in people with a developmental disability compared to the general population. The Spectrum Institute Disability and Abuse Project [www.disabilityandabuse.org](http://www.disabilityandabuse.org)\(^\text{13}\) as well as the Horner-Johnson & Drum article\(^\text{14}\) focus on the high prevalence of abuse and possible traumatic effects with people with a developmental disability. Both documents will be included in the tools.

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A mental disorder can at times explain aggression and self-injury. The diagnosis and treatment of challenging behaviours must consider the possibility of mental health problems.

“... At least 40% of individuals with an intellectual disability have an additional mental disorder; this rate is 3 or 4 times greater than what is observed in the general population. Some psychiatric illnesses, like schizophrenia, are more prevalent, and others like substance abuse, are less prevalent than in the general population. Some disorders, for example, self-injury and pica, are rarely seen other than in persons with severe intellectual disability.” 15

People with a developmental disability are vulnerable to the same psychiatric conditions as anyone else. However, it is challenging to adapt standard psychiatric diagnosis criteria to those who may not communicate verbally, or clearly. A specialist consultation is crucial to make a definitive psychiatric diagnosis.

Agencies should be aware that the field of mental health is now into its fifth Diagnostic and Statistical Manual of Mental Disorders, (DSM-5). We encourage you to consult with experts and clinicians in this field to better understand the possible consequences for the people you support.

“Generally, when figuring out if someone has a psychiatric disorder, one would compare that person’s symptoms and behaviours to other people and understand how different they are from the norm. When determining whether someone with a developmental disability has a psychiatric disorder, it is much more important to understand that person’s baseline. What is “normal” for that person may be quite unique. The question becomes how different are the person’s behaviours or symptoms now, from their baseline or when they were at their best. Standard psychiatric diagnostic criteria are helpful, but may not be sufficient”. Yona Lunsky, CAMH

Guideline 16: Mental Disorders/Mental Health Assessment

IMPORTANT: Be aware of “diagnostic overshadowing.” Sometimes professionals unintentionally attribute challenging behaviours to the person’s developmental disability and do not look for further causes, such as a physical or mental illness.

Guideline 17: Psychological Assessments

A comprehensive psychological assessment explores and evaluates social, emotional, personal and cognitive functioning. It can be useful in:

- identifying or diagnosing a psychological issue
- understanding the issue
- identifying strategies or treatments that may lessen the distress along with any possible barriers to treatment.

Many adults with a developmental disability have not had a comprehensive psychological assessment for many years, if ever. For those who show challenging behaviours, such an assessment or reassessment could be important to change perceptions about the person in the environment.

As with other assessments, caregivers should make sure, as much as possible, that the person is comfortable with the procedures involved and gives consent.

A recent psychological evaluation showed Susan was able to understand and reason much more than originally believed. It took many sessions to evaluate and develop a consistent cognitive profile because she is non-verbal.

As a result of the assessment, her parents and support workers are more likely to speak to her with the belief that she understands.

This has led to the use of a tablet, which she enjoys for communicating, watching videos and playing games.

Her mother recently said to a worker: “It turns out that Susan is quite intelligent in her own way. She understands naturally how we feel”.

Her assessments also showed some emotional difficulties related to her grandmother’s death many years ago which are now being addressed.
Guideline 18: Speech and Communication Assessments

As caregivers, you may be focused on challenging behaviours and their causes. However, you also need to pay attention to what the behaviours may be trying to communicate. Considering a person’s functioning can provide clues as to what supports and treatment may be needed. Help individuals reduce or eliminate risky behaviours by encouraging them to develop ways to express their needs in more adaptive ways. By doing so, they are less likely to resort to self-injury or aggressiveness, be better equipped to manage their day-to-day living and have a greater opportunity to be socially included.

Changing the way that you communicate with an individual by providing simple language, shortening instructions or using visual supports can all help individuals better understand what is happening around them and can decrease frustration related to being unsure of what others have said or asked them to do.

Speech and Language Pathologists or Speech and Language Pathologist Assistants can also help in developing individual functional communication methods. An individual who is unable to communicate their needs will become frustrated. As will someone who does not fully understand what is being asked of them. If people cannot express their experience of physical or emotional pain, they will likely express their distress as a challenging behaviour. Consider speech and communication assessments for individuals who have difficulties with verbal and non-verbal communication to provide information on how to best to communicate with that individual and support him or her to express himself.

Brian is a 48 year-old man with severe intellectual limitations and cerebral palsy. His ability to communicate verbally has decreased significantly over the past several years. His support workers felt that his increasing self-injurious behaviours and aggression towards them were caused in part by his frustration at not being able to communicate his needs, as well as living in an environment that was not adapted to his needs.

A staff member brought her tablet to work to see if Brian could use one of the communications and personal aid supports applications she had available. When she saw Brian responded positively, she asked her house manager to see if the agency’s communications specialist and occupational therapist could assess him in collaboration with a speech pathologist and a behaviour analyst.

The clinical team assessed Brian and recommended specific tablet communication and environment management aid applications. Brian now has his own tablet which he can use to communicate with others in the voice of John Wayne. In addition, he uses it for games and to manage his daily activities, e.g. eating, going out in the community and doing chores.

By making accommodations to Brian’s home and routine, the supports that caregivers provide have changed. For instance, he was able to Skype with his brother who lives in British Columbia using his John Wayne voice. Although his self-injurious behaviours have significantly been reduced, Brian can be aggressive when his tablet is not available to him. His brother asks that Brian have his tablet always available to him. His brother will also be attending his upcoming support plan meeting through Skype.
Guideline 19: Occupational Therapy Assessments

According to the Canadian Association of Occupational Therapists Code of Ethics (2007), "the primary goal of occupational therapy is to enable people to participate in the activities of everyday life."

Struggles in everyday activities, self-care skills and changes in the person’s environment can all cause challenging behaviour. Occupational therapists can help a person develop new skills, by reducing barriers and increasing coping skills to improve interactions with the person’s immediate environment and their community. Occupational therapists help by understanding the person, the environment and the activity the person wants to engage in. OT’s often assist by completing assessments and treatment in functional capacity, home & mobility safety and sensory processing. Involving an occupational therapist can improve a person’s independence, quality of life and emotional stability.

“My daughter Akhila has a developmental disability. We live together, just the two of us. She was diagnosed with anxiety and depression five years ago. She cried easily and was severely anxious and overwhelmed by her work, her household chores, and daily activities. Just getting out of bed, getting dressed, and making her lunch to go to work was beyond her.

She was hospitalized after several years of medication and counselling had not been effective. She received occupational therapy services while in the hospital’s inpatient and day programs. The occupational therapist provided a practical approach for her daily tasks and suggested ways to maximize her ability to participate in the activities in a meaningful way. She taught us to break down tasks in order to prevent anxiety and frustration, whether that task involved getting dressed or setting the table for dinner.

The occupational therapist also made a home visit to evaluate how the environment could be modified to best support her — with a plan for what to do when she was experiencing distress during work or when she went out with friends. She helped us draw up lists or schedules posted at home to minimize anxiety and remind us of the coping skills available to both. She works closely with us and Akhila’s psychiatrist."
Many factors contribute to challenging behaviours. Care providers and specialists may have to do more investigating when the above options have been exhausted.

It is important to know whether a person showing consistent challenging behaviour has any additional issues such as:

- Autism Spectrum Disorder (ASD)
- dementia
- addictions
- a condition such as Fetal Alcohol Syndrome.

Many genetic conditions related to developmental disabilities can contribute to challenging behaviours. As mentioned in Guideline 16, mental health concerns can be assessed and addressed by specialized multidisciplinary teams in that sector. The Primary Care Guidelines for adults with developmental disabilities can help care providers and caregivers start exploring further medical possibilities relating to developmental disabilities and challenging behaviour.

Guideline 20: Additional Assessments

Amy has a moderate to severe developmental disability. At age 15, she developed posturing, stalling, freezing, sudden episodes of frenzied agitation, hyperactivity and screaming, severe hair pulling, accompanied by pinching herself causing bruising, interspaced with episodes of complete calm. Her daily living skills deteriorated and she no longer showed interest in her artwork.

Despite being assessed multiple times by her family doctor and paediatric team, being involved in medication trials, and visiting the emergency room, her distress behaviours increased in severity and frequency over the next year.

Extensive medical, including neurological, investigations did not identify any medical cause for her deterioration and changed behaviour. Psychiatric diagnoses included mood disorder, ADHD, tic disorder, general anxiety disorder and OCD; standard treatment for these disorders did not result in any recovery.

Assessment by the multidisciplinary team identified probable ASD as well as specific sound, light and touch sensitivities (she preferred quiet dim places and loved to touch and stroke her hair), proprioceptive and deep pressure needs (frenzied hyperactivity when she would seek out strong pressure input e.g., from pinching herself), freezing and stalling behaviours around transitions, negative response to emotionally charged overheard conversations (even though these were not about her), and anxiety about others, especially female family members.

A sensory adapted environment was instituted based on her needs. After several months with these supports in place, Amy’s hair started to grow back normally and her frenzied episodes and catatonic-like behaviours decreased.
Note on Treatment, Approaches and Activities to Help Prevent, Diminish or Eliminate Challenging Behaviours

Guidelines 21 - 31 recommend a holistic, biopsychosocial vision of treatment, approaches and activities to help prevent, diminish or eliminate challenging behaviours. Many treatments involve clinical expertise and interventions that are beyond the scope of families and most developmental services agencies. In these instances, caregivers act as partners in treatment. Close cooperation with health partners, as well as justice or educational partners and specialized developmental services providers is needed to help people get the treatment they need so they can “come back home” when ready. Ideally people could remain at home while receiving additional, mobile supports. They may need to continue receiving supports from partner agencies.

For the last 30 years, behavioural management/treatment has been the method of choice for people being supported by developmental services agencies and their families. However, we encourage caregivers to explore a range of treatments and approaches. This includes evidence supported talk therapies, together with evidence-based behaviour treatment, when needed.

In January 2015, the Ministry of Community and Social Services published the *Behavioural Support Plan Reference Guide for Adult Developmental Services*. It sets out definitions and requirements on:

- behaviour support plans,
- challenging behaviour,
- intrusive behaviour intervention,
- positive behaviour intervention,
- training, and
- third party review committee.

The guide also clarifies the requirements on behaviour support plans as set out in:

- Ontario Regulation 299/10 Quality Assurance Measures (QAM), Part III, Behaviour Intervention Strategies
- Policy Directives for Service Agencies, Number 2.0: Support People with Challenging Behaviour

Under Regulation 299/10 (QAM), each service agency shall develop an individual behaviour support plan for each person with a developmental disability who has challenging behaviour.

These requirements only apply to service agencies that provide any of the following types of services and supports:

- supported group living residences
- intensive support residences
- community participation services and supports
- activities of daily living services and supports
- caregiver respite services and supports.

Our guidelines may be used as an additional resource to support service agencies compliance with the quality assurance measures requirements.
Guideline 22: Psychological Therapies

We tend to assume that the person’s developmental disability is the cause of the behaviour. We need to consider other possibilities.

People with a developmental disability experience trauma at a very high rate, which can result in challenging behaviours. Examples of trauma include:

- being bullied (e.g. teased, laughed at, or called names)
- being devalued
- being harassed
- being physically, sexually, or financially abused.

Challenging behaviours can also be symptomatic of various mental health conditions. If you suspect an individual in your care has a mental health issue, consult with their primary care providers and/or a mental health professional. The Canadian Mental Health Association and regional Community Networks of Specialized Care are excellent sources of information and can help you find the right services.

It is recommended to explore psychotherapy as a treatment option for some individuals. Psychotherapy is a general term for treating mental health problems by talking with a psychiatrist, psychologist or other mental health provider. During psychotherapy, people learn about their condition, their mood, feelings, thoughts and behaviours. Psychotherapy can help a person develop healthy coping skills to deal with challenging situations.

There are many types of psychotherapy. Each one has its own approach. The right type of psychotherapy depends on the individual. Therapy can help a person gain control over the fear that resulted from a traumatic event. The person and the health care professional can discuss what type of therapy or combination of therapies may best meet the person’s needs. People may try individual therapy, group therapy or both. Group therapy can offer a way to connect with others going through similar experiences.

Guideline 22: Psychological Therapies

We were trying to help Joan find ways to cope with her distress and her fears. She had been self-injuring for the past few months.

We knew of a therapist that used group therapy and role-playing. We convinced her to take Joan on as a patient.

Though the therapist needed to adapt her approach to work with Joan, it was easier than originally anticipated.

The therapist gradually included Joan in her groups. The groups helped Joan by permitting her to express things she never talked about. It helped her a lot.

As well, Joan is now a member of our village theatre group. She has landed a few small parts but she mostly enjoys being a stagehand. It has become a passion. She still sees her therapist a few times a year and enjoys group therapy.

Psychotherapy is also known as:

- talk therapy
- counselling
- psychosocial therapy, or simply
- therapy.
Guideline 23: Alternative Therapies and Activities

Individuals with a developmental disability and challenging behaviours can at times benefit from alternative therapies or activities such as art, music, theatre, mindfulness, yoga, meditation.

Leisure activities involving such activities can promote communication and learning in people with a developmental disability. Caregivers should help individuals include these in their personal development plans. Other benefits include:

- learning social behaviours,
- improving patience
- learning how to use different creative mediums
- working on fine-motor skills and orientation
- fostering imagination
- promoting appropriate sensory stimulation.

The activities involved in art and music therapy develop positive social interactions. Whether the art is being used as a therapeutic medium or just to have fun, visual and performing art activities are pleasant forms of recreation for everyone involved.

“Ricardo had been quite frustrated lately because he was not able to propel his wheelchair. Ricardo’s occupational therapist was trying to get him to use a “sip-n-puff” device so that he could move his wheelchair using his breath. However, he was afraid of the device and since he does not speak English he did not understand what the therapist wanted him to do. I had been working with him for a while, and Ricardo has a song that he likes to sing. I got him to play the song on a recorder with me. I turned the mouthpiece of that recorder around so that I could play the notes while he blew into the instrument to play his favourite song. We were able to use this technique to work on the muscles and coordination needed to use the wheelchair device and transfer the skills to the wheelchair. Music helped him to learn the skills he needed, develop the musculature required, calm his fears and confusion, so that he could successfully drive his wheelchair”.

Johanne has seen a lot of positive changes in her patients’ lives, including improving social skills and fine motor ability. When asked about her technique in reaching her patients, she replied, “We utilize a variety of music-based interventions such as playing music, listening to music, moving to music, and music-based games and activities. The medium of music we use is dependent on the individual client. We tailor the music activity to meet their preference”.

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Guideline 24: Behaviour Support Plans are intended to improve an individual’s quality of life

Behaviour Support Plans constitute an important tool when helping individuals cope with their challenging behaviours. Used in conjunction with other approaches and disciplines referred to previously, BSPs should be living documents with evolving strategies as the needs and lifestyle of an individual changes. Long term success of BSPs involve them being part of a bigger picture, one that addresses the individual’s health and well-being as a whole. Successful BSPs take into account all the things that are important to the individual, such as:

- relationships
- positive community engagement
- social integration
- physical exercise
- proper eating
- meaningful activities
- leisure and recreation.

“Phùng is 51, has autism spectrum disorder and a moderate developmental disability. Phùng finds it difficult to cope with certain aspects of everyday life, for example, interacting with other people. Living in a group home didn’t work for him. He found sharing communal areas and tasks difficult. He was also anxious about being right and was sometimes physically confrontational to those around him.

Phùng eventually moved to an apartment complex, but his need to be liked and to please people became an issue with his neighbours. He would visit them even when he was not invited and some of his elderly neighbours felt scared.

His behaviour resulted in being placed in three different units and two respite placements. In all of the places, he demonstrated severe aggressive behaviours that required police and emergency hospital interventions.

After his previous support provider decided they could no longer support Phùng, we were asked to provide a variety of supports for him. Our multidisciplinary behaviour support team focused on ASD related assessments and interventions and put in place a plan to minimize challenging behaviour and enhance the quality of Phùng’s life.

Phùng was instrumental in defining many parts of this plan. After years of living in places that made him unhappy and uncomfortable, Phùng now lives in his own home and is supported by a team of people he helped to hire. Since Phùng has been supported in this way, he has stopped exhibiting challenging behaviour and he is now known as a friendly, happy and caring man.”
Adam has for many years exhibited severe self-injurious behaviours in the form of hitting himself with his knees and hands, eye gouging, and attacking others by scratching and biting. Admitted to an intensive support residence, his behaviours at times required significant restraints.

An intensive, short-term intrusive behaviour support plan was put into place. It lasted 6 weeks, at which point the intrusiveness was gradually diminished and eliminated and new activities were introduced, including swimming which required that Adam be involved in the community.

He remained in the intensive support home for six months, during which time staff from his former residence were involved in his plan to come back home.

The agency managing the intensive support home offered on-site ongoing supports for a month when he integrated his former residence and then gradually faded this out.

It took a few months for Adam to adjust. He remains vulnerable to engaging in self-injury and aggressiveness, but things have significantly improved. On-site clinical supervision and coaching has helped, but more training and supports are necessary.

Staff members have to learn that Adam’s needs include a life that does not revolve around his difficulties, something that remains a challenge since their perception has been in the past, “Adam who hurts himself”. This is a learning process for all involved.
Guideline 25: Level of Service Intensity

The level and intensity of services a person receives should be adjusted as their needs change and evolve.

A person showing challenging behaviours, will at times, need more supports and intensive services. At other times, they will need less. Treating challenging behaviours successfully often involves adapting to the behavioural highs and lows (regression and progression) of an individual over time.

From a clinical and staffing perspective, agencies should plan and organize for such cycles by developing treatment and care partnerships with more specialized services in the developmental services and mental health fields.

“It took three years to get Paula to stop her self-injurious behaviours. There were many bumps on her journey, many highs and many lows, but she progressed nonetheless. With close observation and support, the interdisciplinary team was able to determine the causes/functions of her self-injurious behaviour.

Two years passed without a single self-injurious behaviour incident. Then last year, her self-injuring returned suddenly at a level comparable to what it was five years ago. We had to invest in more staff support and reinstitute intensive behaviour supports, as well as have Paula reassessed and tested for mental and physical health issues. She was admitted to the hospital to be stabilized and undergo further testing. A stomach ulcer was diagnosed and treated, and her self-injurious behaviours lessened. It took six months to get her back to not engaging in any self-injuring. We are now monitoring her more closely so we can detect possible/eventual reoccurrences.”
Agencies should systematically and continuously evaluate the effectiveness of interventions. Using Applied Behaviour Analysis techniques for instance can help assist in shaping challenging behaviours and teach new functional skills. With ongoing oversight and data collection the clinical team is better able to determine if the intervention has been beneficial to the individual.

If educational, medical, environmental, and behavioural approaches are not working, and the behaviours continue to be putting the physical safety of the person or others in jeopardy, further assessments and clinical partnerships are required. Continuing to use approaches that don’t work will usually make matters worse.

Guideline 26: Treatment Efficacy

Peggy is 64 years old with a severe developmental delay, autism, and bipolar mood disorder (with agitated depression and mania). She lived for 50 years in a provincial facility where she experienced episodes of prolonged screaming, self-injurious behaviours (pulling out hair on her head, pinching, scratching, hitting her ears, banging her head on the floor), physical aggression (pushing, hitting, slapping), and property destruction.

She moved to a four-person group home with a Community Living agency in 2006. Various interventions were offered but none were successful in treating and managing her behaviour or addressing her psychosocial needs. Psychiatric and behavioural approaches were tried with inconsistent results.

In December 2009 she was admitted to a mental health facility for a complete medication review. Attempts to re-introduce former medications were ineffective.

Extensive consultation efforts between hospital and community psychiatry and psychology helped to find the right treatment for her, resulting in significant results in reduction of the challenging behaviours.

Weekly follow-ups and treatment which allowed for positive results over time resulted in successful re-introduction to a new community setting and close to the hospital where she continues to be treated as an out-patient.
Guideline 27: Supporting People Showing Severe Challenging Behaviours

Community-based agencies that plan to support people showing severe forms of aggressive, self-injurious, or challenging behaviours need to be prepared for a long-term commitment. Good intentions and positive values are essential, but not enough.

Agencies need to:

- develop physical and social environments that respond to the individual’s needs by offering treatment opportunities for improving the quality of life, while at the same time, protecting people and the community.

- organize services so there is consistent clinical supervision and ongoing and targeted staff training. (Please refer to Guidelines No. 9: Training and Clinical Supervision.)

- be part of a continuum of services that includes:

  - specialized developmental services agencies
  - health services
  - first responders.

The Partnership between Specialized and Community Services

Service partnerships should be individualized and facilitate joint treatment, inter-agency service plans and emergency intervention protocols. Developmental services community agencies and their specialized partners must collaborate with each other to provide the individuals they support with continuous care and treatment.

Community agencies supporting people with extreme aggression may have to admit their service users to specialized developmental services and health agency programs when “step-up” treatment and supports are needed. In turn, specialized developmental services and health agencies will need to rely on the support of their community partners when discharging people back to their homes and when “step-down” treatment and less specialized supports are needed.

Admissions to hospitals and other residential treatment facilities for these individuals will usually be temporary.

The next paragraph and story are excerpts and an adaptation from the CAMH submission to the Select Committee on Developmental Services. We believe the issues highlighted by CAMH illustrate the need for more comprehensive and adapted services in the community and better coordination between specialized and community services. Many of the people featured in our guidelines have the same difficulties as those who are involved with CAMH.

“People with a dual diagnosis have higher rates of psychiatric hospitalizations and re-hospitalizations than people without a developmental disability. They also visit emergency rooms more, are younger when admitted to hospital, display higher rates of aggression and have significantly longer inpatient stays. The average length of stay for current clients in CAMH’s Dual Diagnosis program is 23 months. Most of these individuals are young males with autism who have displayed serious aggression or inflicted life-threatening self-injury. Most were admitted to hospital after many visits to emergency departments and/or brief hospitalizations and all of them were over-medicated at the time of admission. In approximately 4 months, CAMH was able to treat these individuals with the tertiary care that was needed, but 90% of these individuals are now stable and cannot be discharged due to a lack of appropriate services in the community. This long-term hospitalization not only jeopardizes the clinical gains made by these clients, but makes access to these specialized beds for other clients with dual diagnosis virtually impossible. Ironically, the cost of a long-stay hospitalization is more than double that of high support community based housing – a far better alternative for these clients who experience a much better quality of life.”

16 Centre for Addiction and Mental Health (CAMH). (2013). Submission to the Select Committee on Developmental Services.
“Although at times it might be necessary for a person to leave home to get treatment services, there are approaches where this can be done in the community. A treatment/support plan for the more complex situations that is developed from an inter-disciplinary approach, taught to care providers working with the individuals, well-monitored and supervised, and adjusted based on proper evaluation and assessment has the most potential of positive success for all concerned.” Wade Durling, Ongwanada Executive Director; Lead, South East CNSC.

Inter-agency Collaboration

An inter-disciplinary approach offers the most potential of positive results for everyone concerned.

While inter-agency collaboration is important when supporting people with more complex, or extreme, challenging behaviours, an inter-disciplinary approach to treatment and care is essential. Problems arise when the various disciplines in the psychosocial, health, education, psychological, or medical fields work in isolation of each other. This does not foster a true bio-psychosocial approach to planning and support. All disciplines must collaborate with the individual and their close ones to jointly define the best treatment strategy and approach.

“Sean is a young man in his 20’s who has been diagnosed with a mild intellectual disability, a neurodevelopmental disorder and Post Traumatic Stress Disorder along with various medical difficulties. As a young adult, Sean’s family were unable to care for him. Sean tried living in many different community settings, but was unsuccessful due to his mental health issues, his emotional intensity and reactivity, his impulsivity, and his self-injurious behaviours. These behaviours led to frequent use of emergency room services and also often required police to intervene. Over the last few years he has primarily lived in hospitals, jails and shelters.

Sean was discharged from our treatment facility in July 2011 after a 20-month stay. His discharge followed intensive planning and collaboration between our programs, specialized housing and other agencies that had also worked with him for many years (developmental services and mental health agencies). Sean was involved with planning his transition and made visits to the home prior to his discharge. A crisis prevention and management plan was established to try to minimize emergency room usage. Upon transfer to the community program, Sean was in the home for only a few days before his challenging behaviours started again. He ended up in a shelter, spent time in jail and was then re-admitted to our treatment facility in May 2013 where he remains today. Reflecting on his last discharge, it is clear that Sean needs intensive outpatient clinical supports and a less controlled environment (as the more controlled environment results is an increase in his challenging behaviour). Discharge planning at this time is focused on finding a rural location with the capacity for less intrusive observation and the ability to provide more specialized clinical supports that are appropriate to the behaviours associated with his condition”.

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Guideline 28: Supporting People Showing Sexually Inappropriate Behaviour

Sexuality is an area that developmental services agencies need to learn more about. The right to a fulfilling sexual life is not always recognized as a right for this population. We are often uncomfortable with supporting people in leading a healthy sexual life. By neglecting support in this area, we do not treat them as adults. Some individuals with a developmental disability sometimes show inappropriate sexualized behaviour, or more rarely, commit sexual offences. It is important to explore the factors that could have led to such behaviours or offenses. Some of these factors could include a lack of education, lack of adapted supports for sexual fulfillment, and at times, a caregiver’s refusal to acknowledge that sexuality is a basic human need.

Agencies should make sure a person showing inappropriate sexual behaviour receives the right expert help. We recommend that psychologists or sexologists conduct sexual knowledge and risk assessments when necessary. Remember that the specialists you choose must have the appropriate skills and experience to work effectively with people with a developmental disability.

A good reference for such challenging behaviour is Dr. Dorothy Griffiths from Brock University.

Joel was 23 years old when he was charged with soliciting a minor. The girl was 15 and the age of consent in Canada is 16. His parents were desperate to help him through the justice system. However, the group home that supported him had little knowledge about this area, and as one of the staff members said: "We don't know how to treat a pedophile. We are not a treatment home".

The parents had never seen evidence that Joel was interested in children in a sexual way. Joel’s family was uncomfortable discussing sexual things and had never talked to Joel about sex or intimate relationships. In school he had been excluded from health class because of his disability, (mild intellectual disability and autism) so Joel attempted to learn more about sex on the Internet. The Internet was also where he met Carole, the girl he eventually became involved with. Carole had posed as a girl of 18 and Joel believed her.

The parents looked for someone who was experienced in dual diagnosis and who had knowledge about people with intellectual disabilities who have sexually offended. They found a consultant at their local clinical developmental services/mental health services.

The consultant conducted a sexual knowledge assessment and found that Joel was naïve about sexual matters. When exploring his sexual preferences through a card sort, the consultant found no evidence that he had any interest in children and that he was interested in adult females. The consultant found this measure sufficient to determine that Joel did not intend to solicit a child. In combination with the emails that showed that Carole had lied about her age, there was enough evidence to have the charges against Joel dropped. Joel was freed under recommendation that he receive proper sexual education and instruction, as well as how to be cautious on the Internet.

If your agency is supporting a person who is at risk of police or emergency interventions, you should approach your local police and first responders and develop individualized intervention protocols and offer support to educate their staff.

The Community Networks of Specialized Cares have developed general guides for emergency protocols involving police and ambulance/emergency departments. These protocols should be individualized. Cross-sector training initiatives can complement the protocols. Here are some suggestions:

- Invite representatives from the local police, ambulance/emergency departments to a session to learn about developmental disabilities and dual diagnosis.
- Help caregivers understand emergency procedures and protocols.
- If you are concerned about a specific client, invite local police officers to the residence. Introduce them to the individual and explain the person’s needs.

Work together to develop specific protocols. The officers will be able to respond more effectively should they be called to the home.

As mentioned in Guideline 10, Seeking cross-sector partnerships, Autism Speaks has excellent tips and resources for first responders. Go to www.autismspeaks.org for more information.

A good practice is to educate first care responders about individual care plans before an emergency happens. You can do this by contacting the liaison officer at your local police department.

When you call a first responder, explain that the individual has a developmental disability. Tell them how to interact with the person.

Follow-up with the first responders after the incident to make sure they have the appropriate information in their system. If another situation occurs, the first responder may be able to bring additional help, such as mental health workers.

Guideline 29: Collaboration with First Responders

 André had been arrested many times and was incarcerated for violent crimes before he came to live at his new home. His new home is managed by a community based developmental services agency with experience in supporting individuals with complex needs such as his. The OPP detachment was approached and a protocol was developed in collaboration with André, his parents and his caregivers. The first few interventions went well and the officers were able to calm André and reason with him. They also brought him along for a ride with flashing lights and sirens so that they could get to know each other and perhaps avoid problems. The agency had to convince police to avoid these “joy rides” as André was quick to understand he could get one if he showed aggressive behaviour.

A two-day training program for emergency responders was subsequently developed by the Community Network for Specialized Care. The training program was specifically held for those who deal with individuals with a dual diagnosis that demonstrate dangerous behaviour. They based their training on a program that was developed for emergency responders in mental-health related situations.

When it was offered, they anticipated that fifteen responders would show up. Forty did. The OPP, two local municipal forces and ambulance workers were present (their superior officers, in full uniforms, were present for a press conference before the event). The training was very helpful and appreciated by emergency responders.

As for André, his aggressive behaviours eventually lessened but he still liked to boast that he was “picked up” by police.
Guideline 30: Collaboration with Hospitals

Agencies should develop protocols with the emergency departments of their local/regional hospitals. Protocols can be developed with other hospital departments if required. Protocols can cover a number of issues such as:

- the support your agency can offer to hospital staff when a person is hospitalized
- joint discharge procedures
- special hospital admission processes
- agreements with hospitals when patients, who have been hospitalized for long periods, are discharged
- emergency room protocols
- access to hospitals and health services in general.

Access to Health Services

Each Community Network of Specialized Care in Ontario has a HealthCare Facilitator. This person helps agencies improve access to primary care and develop collaborations/protocols with hospitals.

Regions throughout Ontario have developed and/or use a variety of tools to help people work with the health system. The Eastern Region has developed the Health Information Profile. It is designed to wrap around a person’s health card so that both can documents can be presented when the person is seeking medical care.

Access to Health Services

The Health Information Profile was modified for use in Ottawa. Another version is being used in Thunder Bay. Ottawa is also using the About Me Tool. The North Region uses the Health Passport that was developed in the United States. Many tools have been developed and are being used around the province.

For more information, contact your Community Networks of Specialized Care Health Care Facilitator. Visit their website at www.community-networks.ca.

Guideline 30: Collaboration with Hospitals

“Dag is a 50 year-old man with a mild developmental disability and severe physical impairments. He had been hospitalized for three years due to a lack of adapted services and supports in the community. He was increasingly showing challenging behaviours, which included aggression and self-injury. We had a home that was dedicated to one of our service users in a rural area. It was developed to help care for a younger man named Sam who exhibited severe aggressive behaviours, but had stabilized following his move to the house.

The house is big enough for three autonomous apartments. We were asked to consider admitting Dag to this home. We negotiated an agreement with the hospital, through our Local Health Integration Network, for transitional funding upon his discharge and developed protocols for readmission if and when Dag would need hospital care in the future. He has now lived in our house for two years and has not been re-admitted to the hospital. Dag has his own apartment and enjoys it. We haven’t had a single incident. Both men prefer to live on their own, and they are able to have their own routines and lives.”

For more information on access to health services, visit the Health Care Access Research and Developmental Disabilities website at: www.porticonetwork.ca.

You will find references to articles and links to videos, such as the one referred to in Guideline 29 on the use of emergency rooms by clients with developmental disabilities.
Guideline 31: Organizational Policies

Agencies that support adults with a dual diagnosis and/or showing challenging behaviour should develop organizational policies that are:

- compatible with the individuals they support;
- in compliance with the policies and requirements developed by the Ministry of Community and Social Services.


Visit the Developmental Services Section of the Ministry of Community and Social Services at www.ontario.ca/community for more information on ministry policies, requirements and regulations.

If you are interested in reading what other developmental services agencies have developed, your best source would be your local Community Network of Specialized Care or the agency itself.

During our consultation phase, Community Living Essex County submitted policies it has developed over time since 1993. Should you be interested to learn more, contact the agency at contact@communitylivingessex.org

The following policies it developed and continues to regularly update might be of interest with regards to the guidelines:

- Abuse Prevention and Reporting
- Audio/Video Monitoring Support System
- Behaviour Support
- Communication in Support Services
- Crisis Intervention
- Medication and Treatment
- Serious Occurrence

Agencies should also work with partners across sectors to develop policies on accessing specialized treatment when needed. The proposed Dual Diagnosis Framework provides essential systemic strategies in that regard.
Appendix 1: People We Consulted

March 2014 Symposium
Keith Anderson, Muhammad Ayoub, Leanne Baldwin, Beverly Byrne Reitsma, Carol Blaind, Debbie Boardman, Joanne Boulard, Bob Butella, John Caruso, Jaynee Champagne, Sam Curtin, Daren Rene, Jacynthe Desaulniers, Mary Jane Cripps, Diana Cutting, Laurie Dart, Jo-Ann Demick, Wade Durling, Anna Marie Eckensweiller, Maurice Feldman, Gerry Franklin, Gerry Fucile, Jennifer Gleeson, Mark Graham, Caroline Granger, Lorrie Hefferman, Chris Higgins, Sandie Hoskin, Coleen Hua, Jim Hughes, Melanie Kelly, Claire Kislinsky, Kim Lenahan, Lisa Louttit, Anne Moloney, Ann Marcotte, Karen Menzies, Joel McCarney, Ron McCauley, Reshmi Majumder, Marnie McDermott, JoAnne Nugent, Joe Persaud, Nancy Pilon, Jim Preston, Dr. Jay Rao, Chantal Séguin, Allana Shore, Sandy Stemp, Louise Spicer, Jim Turner, Tom Turner, Paul Van de Laar, Helen Ward, Julia Williams, Dawne Wyers, Peter Wyngaarden, Mary Westerof, and Emma Willer as well as the CNSC Leads and Coordinators

Focus Group Meeting Held in Belleville, September 2014
Zahra Habib, Sherry Baum, Wade Durling, Ingrid Dykstra, Greg Edmundson, Gisèle Forrest, Mark Graham, Andrew Lewis, John Klassen, Janet Lorimer, Krista Manson, Ron McCauley, Geoff McMullen, Brad Saunders, Nancy Wallace Gero, and Emma Willer, as well as the Wallace Gero, and Emma Willer, as well as the CNSC Leads

Focus Group Meetings Held in February-March, 2015

Central East Region
Andrew Walker, Barbara Andrew, Carol Blaind, Deb Ryan, Gerry Fucile, Jim Hughes, John Erskine-Kelie, Julie Graham Thirgood, Karen Chartier, Karen Hirstwood, Linda Littell, Mark Graham, Diana Li, Nancy Pilon, Sandie Hoskin, Tracy Mansell, Mira Wesolowski, Marnie McDermott, Tony Vipond

Central West Region
Trevor Lumb, Debra Rose, James Duncan, Judy Pryde, Denise Gruber, Sheryl Chandler, Bob Butella, Janet Lorimer, Kelly Stockdale, Tara Hyatt, Yvonne Bowes, Chuck MacLean, Kim McDonald, Maria de Boer, Ann Bilodeau, Daryn Kifloyle, Susanne Robinson, Don Walker, Alayne Langerak, Allana Shore, Bonnie Corey, Katherine Loveys, Annette Hrab, Laurie Ridler, Louise Lepp, Leanne Baldwin

South East Region
Anne Moloney, Steve Edmiston, Alex Conant, Vicky Huehn, Lorrie Hefferman, Debbi Tryon, Sandra Harrison, Susan Treverton-Bird, Tom Turner, Julie Golding, Karen Menzies, Wade Durling, Lisa Holmes

Southern Region
Bill Mckee, Tom McCullum, David Katzman, Anita Bacon, Kathy Strauss, Rick Hill, Nancy Wallace Gero, Marg McCollan, Mike Town, Rosanne Perron, Deanna Finch Smith, Heather Bruce, Bonnie Filipchuk, Leo Massi, Sherry Parsley, Stella Barker, Kevin Berswick Shelley McCarthy, Sam Curtin, Brian Davies, Jason Young, Liz Froese

Eastern Region
Patricia Dostie, Marc Richer, Danielle Duranceau, Caroline Granger, Louis Renaud, Camille Bigras, Hélène Fournier, Andrea Podruski, Gail McKay Webster, Judy Bernstein, Debbie Boardman, Chantal Prieur, Lisa St-Pierre, Kim Caron, Mary Beth Colton, Susie Desjarlais, Liz Kacew
North Region

Toronto region
Paul Van de Laar, Dean Johnson, Bill Gapen, Sandy Stemp, Debbie Irish, Kathryn Gardner, Joe Persaud, Beth Eisenberg, Dunja Monaghan, Brad Saunders, Inge Secor, Angie Gonzales, Megan Thomas, Antonet Orlando, Gerald Nganjue, Steve Finlay, Sandra Bricker, Terri Hewitt, Tracey Switzer, Karen Farber

Tools Development Resource Group: 2015-16
Jennifer Altosaar, Heather Bailey, Terry Broda, Carmela Campanella-Borraccia, Peter Gravelle, Patti Hancock, Amanda Hendry, Lisa Holmes, Tara Hyatt, Melanie Kelly, Mackenzie Ketchell, Cathy Kuehn, Tanya Makela, Marnie McDermott, Kristin May, Joel McCartney, Pat McCoy, Meg McQueen, Megan Primeau, Daren Rene, Judy Russell, Anne Sprack