In Crisis with Autism Spectrum Disorder

Review of the Evidence

Prepared for: Autism Nova Scotia

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ACRONYMS

ASD	Autism Spectrum Disorder
PHAC	Public Health Agency of Canada
WHO	World Health Organization

EXECUTIVE SUMMARY

According to the Public Health Agency of Canada, one in 68 children in Nova Scotia has a diagnosis of Autism Spectrum Disorder (ASD).[1] Individuals with ASD are vulnerable to experiencing a crisis due to inherent biopsychosocial sensitivities associated with the disorder, co-occurring intellectual disability, behavioural and mental health conditions, and the lack of environmental accommodations in society.[2,3,4] Collectively, these exacerbate the complexity of individuals' experiences of daily challenges and of course, the complexity of the supports and treatments they need to lead a fulfilling life.[5]

At least 80% of families supporting an individual with ASD report being at risk for a crisis.[6] When a crisis occurs, a major issue confronting children and adults with ASD and their families is access to appropriate, adequate behavioural and mental health services.[7] Historically and currently, for a growing number of Nova Scotians with ASD, there are a lack of ASD appropriate crisis prevention and treatment services resulting in a severe crisis that escalates into media coverage of high-profile cases, and human rights inquiries about the lack of appropriate care.[5]

This report is a review of the most recent evidence base on:

- what constitutes a crisis for individuals with ASD and their carers and how is it assessed;
- why individuals with ASD and their carers seek emergency services and what are their experiences using these services;
- a review of practices for preventing, identifying, and treating crisis in individuals with ASD; and
- available service delivery models that integrate crisis prevention, intervention, and management to effectively support individuals with ASD in their homes and communities.

Ensuring access to services and support is a critical part of an effective ASD crisis prevention strategy.[8–10] Research shows that access to preventative and community-based ASD mental health and behavioural services is either limited or nonexistent for children, youth, or adults with ASD, which forces families and support providers to turn to resource intensive emergency and inpatient services.[7] Currently, little is known about crisis prevention and treatment with adults with ASD[7] therefore, most of what has been reviewed in this paper focuses on children and youth with ASD. However, regardless of chronological age, the research on treatments and service systems underscore the importance of having preventative and responsive care pathways for individuals with ASD and providing positive ASD-specific behavioural therapies using a life-span approach with special attention to transitions (e.g., the transition from adolescence to adulthood).

Without adequate community-based behavioural and mental health care, the fundamental Canadian human right of living in the community will not be accessible to Nova Scotians with ASD. Aiming for successful transitions and leading a quality life will only possible for individuals with ASD when they have crisis prevention plans and responsive mental health services that support them to live in the community.[8,9,11–13] A coordinated wraparound system of care, with an interdisciplinary team, supporting and linking inpatient, community-based, and in-home services for people ASD who are at risk for a crisis, in crisis, or recovering from a crisis.[9] Such a service would specialize in behavioural and mental health prevention, treatment, and after-care, while also focusing on strengthening efficiencies and service outcomes.[8,9,11–13]

Crisis interventions for people with ASD and their families need to be informed by, as well as be developed and implemented in partnership with, members of the community and the organizations that serve them. The transition into adulthood for individuals with ASD, like all developmental disabilities, requires meaningful community options. Nova Scotians with ASD urgently need accessible and economically viable crisis prevention and intervention services and policies.[5]

Terminology

Throughout this document, you will see the term Autism Spectrum Disorder (ASD), and how it applies to individuals, referenced in several ways. Language within the Autism community is evolving as more is understood about the condition and how it impacts individuals and the lives they lead. Autism Nova Scotia represents a large and vibrant community — supporting individuals directly as well as providing support for families and caregivers. The self-advocates who contribute to Autism Nova Scotia have various preferences when it comes to how they would like to be identified. Some prefer identity-first language and wish to be called "Autistic", while others would rather people use "person-first" language such as "on the Autism Spectrum" or "Individual with Autism". One thing that we are very adamant about is that it is up to the individual themselves to determine how they wish to be identified. That is why you will notice we include these different representations throughout this paper, in the hopes that our members can all relate, and see themselves within this report.

American Psychological Association: Definitions of ASD, Intellectual Disability, and Developmental Disability[14]

ASD involves persistent deficits in social communication (i.e., social-emotional reciprocity, nonverbal communicative behaviours used for social interaction, and developing, maintaining, and understanding relationships). Restricted, repetitive patterns of behavior, interests, or activities (i.e., stereotyped or repetitive motor movements, use of objects, or speech, insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal-nonverbal behavior, highly restricted, fixated interests, and hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment) are also common.[14]

Intellectual disabilities involve intellectual and adaptive functioning deficits in conceptual, social, and practical domains. Intellectual functioning is reasoning, learning, and solving problems; adaptive behaviour is conceptual, social, and practical skills in everyday life. Intellectual disabilities are under the category of NDs and include global developmental delay and unspecified intellectual disability.[14]

Developmental disabilities are a group of conditions involving impairment in physical, learning, language, or behaviour areas of growth and development (e.g., Down syndrome, cerebral palsy, or muscular dystrophy).[14]

Autism spectrum disorder and intellectual disability do co-occur in 37% of females with ASD and 30% of males with ASD.[2] ASD also co-occurs with other mental health disorders (e.g., anxiety, depression, obsessive compulsive disorder) and are known as dual diagnosis.[15,16] With 70% of the ASD population receiving at least one co-occurring psychiatric disorder diagnosis and 41% with two or more diagnoses.[15,16] Having ASD with or without any of these variations of co-occurrence add to the complexity of individuals' experiences of daily challenges and of course, to the complexity of the solutions and treatment they need to lead fulfilling lives.

INTRODUCTION

According to the Public Health Agency of Canada, one in 68 children in Nova Scotia has a diagnosis of Autism Spectrum Disorder (ASD).[1] A major issue confronting children and adults with ASD and their families is access to appropriate, adequate behavioural and mental health services. For a growing number of Nova Scotians with ASD, there is both a historical and current lack of ASD appropriate crisis prevention and treatment services resulting in individuals with ASD, their families, or carers experiencing severe crisis, media coverage of high-profile cases, and human rights inquiries about the lack of appropriate care.[5]

These results should not be unexpected, evidence shows that in cases where home-based or community-based supports and treatments are unavailable or inappropriate, the human and social costs grow and become exponentially higher as they are pushed out into the health and social service landscape.[17] The magnitude of the crisis created by inadequate, maladapted support systems for persons with ASD cannot be overstated.[18] Without viable crisis prevention and intervention, the autistic population of Nova Scotia faces a high risk of developing even more complex needs and interventions. All of which cost individuals with ASD, their families, the Departments of Education and Community Services, Justice, and the Nova Scotia Health Authority more in the short- and long-term.[17]

Unfortunately, there are no simple or easy solutions that will meet the current crises for all people with ASD. Primarily because there is a variation in need among people with ASD spanning from complex, 24/7 care delivered in-home or in residential environments, to clinical crisis stabilization needs.[19,20] Moreover, the nature of these supports may vary significantly based on age, developmental stage, and family resources. For example, while some individuals may need the expertise of clinicians and coordinated supports within the family home, some may need to relocate into a stabilization service for treatment, while other individuals may have home environments where only respite or minimal assistance is required.

Taken together, this underscores the importance of having a better understanding of what constitutes a crisis for individuals with ASD and a plan forward with an integrated service pathway providing behavioural and mental health treatments. Most importantly, offering Nova Scotians services including prevention, treatment, and after-care for persons with ASD and their families with direct support from service providers and other stakeholders.

The Crisis Challenge

"Crisis" has different meanings depending on the person's or people's perception of the incident, setting, or circumstances. Accordingly, a crisis is a subjective experience "… of an event or situation as an intolerable difficulty that exceeds the person's current resources and coping mechanisms."[21(p9)] The ASD research literature shows that the experience of crisis is prevalent among individuals with ASD and their families[6,7,22,23] (e.g., at least 80% to 95% of families reported experiencing a crisis[6]).

> *"We are all in crisis - whether we realize it or not. Families are always trying to see their world through rose coloured glasses and ignore the reality of the crisis we are all living in daily. Nobody with a family member with an ASD is exempt!"*[9(p461)]

Research also shows that the events or situations that precipitate a crisis and drive families to seek emergency services are usually associated with externalizing behaviours that not only challenge parents and support providers but also exceed their ability to safely assist the individual with ASD to remain behaviourally stable.[7] Emergency service providers and other health professionals assess the underlying physiological conditions of the crisis and make recommendations, or when available, make referrals to specialists, for treatment and support.[7,24,25] However, the evidence from multiple studies suggests that the assessment and treatment of the conditions which cause a crisis in those with ASD require significant and specific clinical skills and experience, as well as, a responsive and integrated behavioural, medical, and social service system.[12] All of which, may be difficult for families in crisis to access in a timely manner.

Overview of the Report

The purpose of this report is to provide a narrative review of the current research focusing on crisis associated with ASD. The report is divided into four sections, and it will address the following questions:

1. What constitutes a crisis for individuals with ASD and their families, and how is it assessed?
2. Which individuals and families will seek services, and what are their experiences using emergency services?
3. What are the practices for preventing, identifying, and treating crisis in individuals with ASD?
4. Is there evidence for a service delivery model that integrates crisis prevention, intervention, and management for individuals with ASD and their family members?

The findings from this report will inform and shed light on some of the ‘‘unknowns’’ encountered in a crisis in the hopes that it will guide families and service providers on what is needed to prevent and respond to a crisis in individuals with ASD to overcome a crisis and become stable again.

The literature review methodology is described in Appendix A.

1. What constitutes a crisis for individuals with ASD and their families and how is a crisis assessed?

Individuals with ASD are vulnerable to crisis

Research has found that individuals with ASD are prone to distress and experiences of crisis because of the inherent difficulties associated with the core characteristics of ASD (i.e., sensory sensitivities, atypical social interactions and communication, and restrictive, perseverative behaviours).[14,26] These difficulties are exacerbated by many sensory and social experiences, certain environments, changes in routines, and most transitions.[27] In addition to these difficulties and exacerbating factors, there is also an increased risk for mental health conditions associated with ASD[4,3], with 70% of the ASD population receiving at least one co-occurring psychiatric disorder diagnosis and 41% with two or more diagnoses.[15,16] Individuals with ASD, who are verbally fluent, are likely to experience more depression and oppositional symptoms[28] and regardless of verbal ability, lower adaptive and coping skills are associated with increased behaviours.[29] Prevalence studies show that 40% of youth with ASD have an anxiety disorder[30], an estimated 21-30% also have a diagnosis of ADHD[15], and those with both a diagnosis of ASD and ADHD are more likely to be diagnosed with oppositional defiant disorder or conduct disorder[31]. In addition to mental health, individuals with ASD are also known to have higher rates of co-occurring medical disorders such as sleep, seizures, and gastrointestinal problems.[3,4] Altogether, the core characteristics of ASD, co-occurring mental and health conditions, as well as the environmental factors, can either collectively or individually, result in an individual with ASD engaging in externalizing behaviours, such as self-injury, aggression, and property destruction.[32] When evidence-based treatment and appropriate behavioural and mental health services are available to individuals with ASD, they can learn appropriate alternative behaviours which may mitigate crises and contribute to socially significant outcomes.[33] However, without access to ASD-specific treatments and services, these conditions and behaviours challenge the individual with ASD and those who provide support or treatment (i.e., parents, siblings, caregivers, paraprofessionals, teachers, or health professionals). At times, the challenges become too much for the individual with ASD, their family members, or support providers to manage and cope, resulting in a crisis.[34]

Conceptualizations of crisis

A recent study conducted with mothers of children diagnosed with ASD asked them to answer the following question, “People have different ideas of what a crisis is. In your own words, what would a crisis look like for you?”.[22(p986)] The analysis found that a crisis was as an interaction of issues in four major areas of family life: demands, internal capabilities, external resources, and subjective appraisal.[10] These four elements were described as follows:

1. Overwhelming demands were “chronic and acute… stemming from various factors: health problems, child emotional problems, caregiving, multiple stressors, school stress, death, life changes, child behavior, and family problems.” [10(p987)]

2. Loss of internal capability was characterized as mothers’ perceptions of failing to cope with their life challenges, including supporting their child to cope or losing their ability to function or meet responsibilities, resulting in a loss of quality of life.[10]

3. Difficulties with external resources including a lack of support, issues with accessing emergency services, financial problems, and losing resources or having absolutely no resources available to them. [10]

4. Significantly negative subjective appraisals of their life status and current life challenges resulting in extreme stress and hopelessness. [10]

For mothers of children with ASD, these four elements are not independent of one another, and they tend to interact with each other during experiences of a crisis.[10] When families reach the tipping point and acknowledge they are in crisis, it is with these issues, concerns, stressors, and fears, that they seek emergency services.

Assessing Risks and Level of a Crisis

At this point in time, there are only two standardized measures that have been specifically developed to assess in families and individuals with ASD: 1. The Brief Family Distress Scale (BFDS)[35] and 2. the Mental Health Crisis Assessment Scale (MCAS)[36].

The BFDS was developed to provide a rapid assessment of the level of distress and crisis in families supporting a child or adult with ASD. The BFDS ask respondents to rate their family’s distress on a 10-point scale (i.e., “Please circle where you and your family currently are right now, in terms of crisis, by picking one of the following statements.”).[35(p527)] A rating of 1 would indicate that “Everything is fine, my family and I are not in crisis at all.” A rating of 4 or 5 would indicate a family was functioning and managing their stress (i.e., ‘‘Things are often stressful, but we are managing to deal with problems when they arise’’).[35(p527)] Whereas a rating of 6 or 7 would indicate a family was at high risk of experiencing crisis (i.e., ‘‘We have to work extremely hard every moment of every day to avoid having a crisis’’ or ‘‘We won’t be able to handle things soon. If one more thing goes wrong—we will be in crisis’’).[35(p527)] Ratings of 8, 9, or 10 indicate that families are currently experiencing a crisis.[35]

While the BFDS measures families’ distress and ability to cope with their child with ASD and family life, the MCAS asks parents to rate the severity of their children’s emotional and behavioural symptoms. Parents then select the behaviour they perceive as the most dangerous behaviour and rate their own ability to effectively manage this behaviour. The MCAS is a 28-item parent report measure with three sections.[36]

> “The first section is a 14-item list of various mental health behaviors seen in ASD. Parents are asked to rate the severity of each behavior within the last 3 months on a 4-point Likert scale, ranging from ‘Not a problem’ to a ‘Severe problem’. The second section consists of one question only, which asks parents to identify ‘the single behavior that could cause the greatest harm to your child or others’ from the 14 items listed in Section 1. Section 3 consists of 13 questions that ask parents to report their concerns about the dangerousness of the child’s behavior to self and others (termed ‘acuity’; items 1–8) as well as their ability to manage this behavior (termed ‘behavioral efficacy’; items 9– 13). All items in Section 3 are reported on the single most difficult behavior identified in Section 2 … Higher MCAS scores represent a greater probability of a mental health crisis.”[36(p50)]

Both the BFDS and the MCAS provide valuable information that could illuminate areas of concern and help to focus treatment efforts of clinicians, support providers, and emergency services in a crisis. Not only do these tools identify the main difficulties families may be experiencing, but they also provide a snapshot of their capacity or lack of capacity to carry out treatment recommendations.

2. Which individuals and families will seek services and what are their experiences using emergency services?

Predictors of a crisis associated with individuals with ASD and families

When crisis strikes, families and carers seek out emergency services for treatment and support. The strongest predictors for which individuals with ASD who would be most likely to seek emergency services were those with previous emergency service use in the last year, a history of aggression, and having no structured daytime activities.[18,7] The strongest predictors for which families would be most likely to seek emergency services were those experiencing high levels of family distress, having had two or more negative life events (e.g., death of a family member, job loss, or moving to a new residence), and a history of using emergency services.[18] Together, these findings portray the crisis as having an impact on both the family and the individual with ASD, suggesting that a crisis has a bi-directional effect. For example, it may be that the struggles of the individual with ASD place a strain on family members and their reactions in turn place a strain on the individual with ASD. Alternatively, family life puts a strain on the individual with ASD, and his or her reactions puts an additional strain on the family. Regardless, either scenario suggests that when families are seeking emergency services, it is essential for health professionals to take a holistic view of both the individual with ASD and their family members or carers who are providing support or actioning the treatment recommendations. A holistic approach determines the best course of action for treatment as well as the necessary support for both the individual and their carers. Most importantly, because a prior history of emergency service use was predictive of both families and individuals seeking services, it also suggests that preventative, emergency and treatment services may be inaccessible or insufficient to resolve the underlying and primary conditions that cause a crisis, which means that over time, families and individuals with ASD cycle in and out of crisis.

Primary conditions associated with using emergency services

Several studies have investigated the primary reason and most severe presenting issue for individuals with ASD seeking access to emergency services including hospital emergency staff, paramedics, and police officers.[37–39] Evidence suggests that two-thirds of the emergencies were primarily medical in nature, and an injury accounted for over half of these visits. Almost one in four of these injuries were directly related to behavioural issues (e.g., needing stitches because of headbanging due to an angry outburst or aggressive behaviour due to an unrecognized urinary tract infection). Also regardless of whether the emergency service visit was for medical, behavioural, or mental health reasons, 23% of the time individuals with ASD were either sedated or restrained when accessing emergency services.[7]

Individuals with ASD seeking treatment specifically for a mental health crisis (i.e., psychiatric issues or clinically significant behavioural issues) accounted for over one-third of all emergency service visits by individuals with ASD. [34] The most common issues were aggression and problems with psychotropic medication (e.g., stimulants, antidepressants, antipsychotics, mood stabilizers, anti-anxiety agents).[34] When compared, children with ASD were more likely to use emergency and crisis services than children without ASD.[26] Evidence suggests this could be partially explained by the complexities and challenges that primary and emergency health care professionals face when differentiating, diagnosing, and treating behavioural and co-occurring psychiatric conditions in those with an ASD diagnosis, especially in emergencies.[37–39] These findings may indicate that primary and emergency care services need more resources (e.g., more clinical time and access to other professionals such as social work, psychiatry, or behavioural interventionists) and an ASD-specific pathway with preventative and specialized services to bolster primary care delivery.

Families' Experiences with Emergency Care Services

Families seeking emergency care services experience many challenges. Possible experiences include the exacerbating interaction of their child's communication, sensory, and behavioural difficulties with a high-intensity situation and environment. Other experiences include communication issues, inappropriate care processes, and staff demonstrating an insufficient knowledge of ASD and dismissing parents' knowledge.[40]

The clinical environment in an emergency department holds unique sensory obstacles for individuals with ASD such as bright lighting, high-pitched sounds, and indiscriminate noises[41] all of which could be triggering and stress-evoking adding to the experience of crisis.

The care process may also be stressful.[40] Negative experiences with the care process include multiple encounters, with a multitude of health care staff, with each administering intrusive assessment and treatment procedures.[40] As well as, waiting for diagnostic tests, each located in different areas of the hospital, necessitating multiple transitions, and in some cases being moved on a gurney and not knowing where they were going or what was going to happen.[40]

Communication with emergency service professionals can also be problematic.[42] Parents reported that ASD is not a "visible" disability and as such had to weigh the risks and benefits of disclosing their child's diagnosis, mainly because in their experience clinicians either over-estimated or under-estimated their child's ability to self-report their symptoms.[42] Parents also expressed concerns about speaking about their children's condition and having them internalize their symptoms as labels and stigma.[42] These and other communication difficulties led to misinterpretations or under-identification of their health concerns.[42]

Parents reported trying to tell the health care providers that the techniques that usually work for typically developing children would not work for their child with ASD.[40] However, in some cases, parents' advice went unheeded, and it was only when the usual way of working had failed that professionals heeded their advice.[40] By this point, more intrusive supports were required and "several parents reported that restraint, including sedation, was used on their child so that procedures could be completed as quickly as possible."[40(p418)] Therefore, while best practice guidelines recommend caution and specific procedures when managing agitated patients with ASD, emergency service staff currently receive minimal formal training and have limited experience with individuals with ASD.[43,44] "As a result of their limited training, individuals with ASD have difficulty in receiving timely and appropriate medical care." [43(p92)]

Overall, these concerns about limited expertise and mental health care for individuals with ASD in crisis are substantiated by evidence found in several studies.[43,40,44] However, families of individuals with ASD report that during a crisis, interactions with emergency services are both necessary and harrowing, even when health care practitioners are well-versed in ASD.[40] Experts explain that diagnosing possible health and mental health conditions is complex and challenging "due to symptom overlap, diagnostic overshadowing, and ambiguous symptom presentation in ASD".[39(p40)] As such, the symptom presentation of co-occurring conditions may reflect a 'true', co-occurring disorder, with symptom presentation identical to that seen in non-ASD youth,[37,38] or ASD symptoms which manifest similarly to symptoms of the co-occurring condition, but are better explained by ASD-related challenges. [39,45]

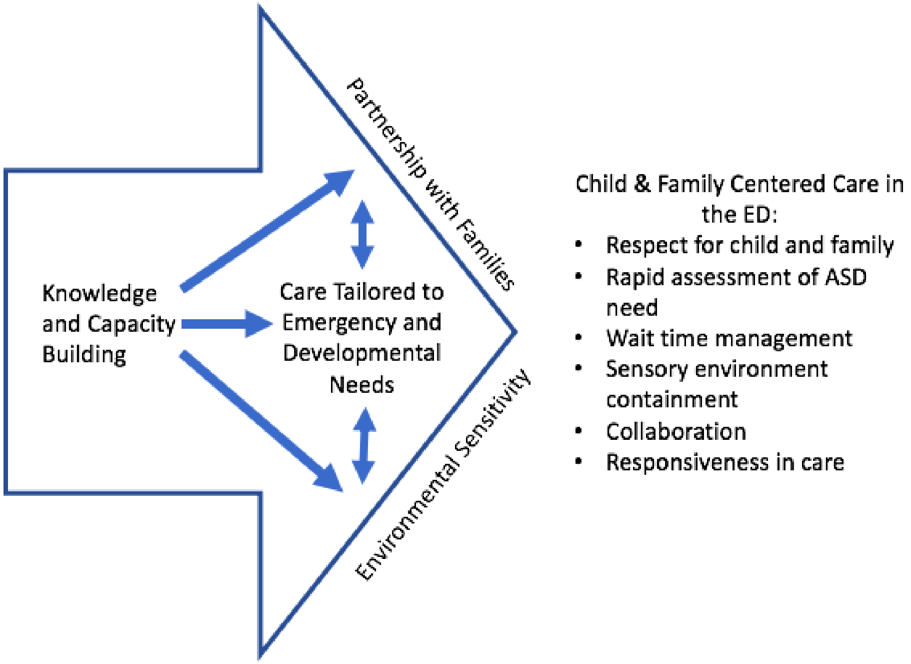
Given the difficulties with diagnosing behavioural, mental, and physical health conditions in the ASD population, emergency service practitioners may recommend a referral to a psychiatric specialty service. However, a survey of psychiatrists in the United States has found that not all psychiatrists are willing or able to treat individuals with ASD. How or whether child psychiatrists might manage and treat these mental health crises depends on a few conditions (i.e., their willingness to work with those with a history of a mental health crisis, their comfort level in managing a mental health crisis, and the availability of external resources during a crisis).[23] These conditions limited the number of child psychiatrists willing to provide treatment to individuals with ASD for many had limited access to external consultation resources and mental health evaluation centers. Based on their professional experience, child psychiatrists have also expressed concerns about the ability of emergency department professionals and emergency responders to manage mental health crises for those with ASD in a safe and developmentally appropriate manner.[23]

3. What are the ASD practices for preventing, identifying, and treating crisis?

ASD-related Person- and Family-Centered Care and Least Restrictive Treatment Model

Multiple studies have identified the emergency and crisis service and its delivery of care as insufficient to meet the unique needs of individuals with ASD.[43,40,44] A recent study convened parents of children with ASD, and emergency department clinicians and administrators to develop the following recommendations to meet the needs of families and individuals with ASD: "ASD-focused preparedness for ED procedures and processes, wait time management, proactive strategies for sedation and restraint, child-focused support, health care provider capacity building, post-ED follow-up resources, and transition planning to adult care. Heightened child- and family-centered care were strongly recommended."[46(pS205)] The key components from this study were captured in a proposed model for ASD-related family-centered care in the emergency department (see Figure 1 below).[40(p423)]

Figure 1: ASD-related Family-centered Care in the Emergency Department [40(p423)]



McGonigle et al. (2014) suggest using several accommodations to support individuals with ASD in emergency departments and clinical environments. [43] The accommodations range from the least intrusive and restrictive to the most intrusive and restrictive.[43] They also suggest the several strategies for preventing and addressing acute agitation meant to improve patient care in emergency departments and clinical environments.[43] The strategies are as follows:

1. Conducting a brief functional behavioural and medical assessment.[43]

2. Adapting the clinical environment including physical space, low lighting, quiet space, which includes carers/family members/support staff, and emergency department staff.[43]

3. Adapting ways of communicating by using pictures/visuals/sequential/First Then/demonstrate/model.[43]

4. Using Behavioural and Cognitive Management (primary and secondary incentives and rewards, e.g., stickers, edibles, cognitive behavior therapy).[43]

5. Using Sensory and Relaxation strategies and if warranted, PRN (Pro Re Nata) medications (caution noted with PRNs because individuals with ASD may not react to medications in similar ways to those without ASD).[43]

6. Directing individual with support to calm area with less stimulation.[43]

7. Using blocking techniques such as pillows/pads/cushions instead of hands-on techniques or physical restraints.[43]

8. Planning for safety, if less intrusive or restrictive approaches are ineffective and there is a risk of danger to self or others use restraints and/or isolation.[43]

Based on the evidence, it appears that hospital and emergency care services may not be meeting the needs of individuals with ASD and their families. Particularly around emergency care processes, identification and diagnosis, and in the provision of treatment options. Therefore, individuals with ASD, families, and carers cannot approach these services, assuming health care providers will know what is needed or how to treat an individual with ASD. One parent of a child with ASD who is non-verbal has this advice for parents:

> *"Don't be afraid to articulate your wants and needs in reference to your child being different, and requiring different care. Always feel free to articulate the needs and wants of your child and your child's challenges to the staff because they're not going to know."*[40(p421)]

Regardless whether health care professionals have ASD skills or not, when an individual with ASD and their family members or carers access emergency and crisis services, they are professionally responsible for diagnosing and possibly suggesting a treatment regime. In some cases, emergency department staff may provide a referral to another service or recommend admission to the hospital for diagnosis and more intensive treatments. Such resources have been developed. Lunsky et al. (2016) have developed a toolkit of resources to support primary care and emergency care providers delivery.[47]

Predictors of Admission for Inpatient Treatment

Research has shown that individuals who are severely affected by ASD are at high risk for hospitalization, particularly for individuals with lower adaptive functioning, including those who are minimally verbal and have an intellectual disability.[48] A recent study of psychiatric inpatients with ASD found that once assessed; three main aetiologies were predicting an initial hospitalization. Most underlying or presenting conditions could be classified as biological, environmental, and/or psychiatric problems. [49] Common biological or health factors included epilepsy, sleep disturbance, chronic constipation, tooth decay, and urinary tract infections.[50,49,51] Environmental conditions included a lack or failure of treatments, living in a single parent home, and illness or death of the primary caregiver. [50,49] Non-ASD psychiatric conditions included major depressive disorder, bipolar disorder, obsessive compulsive disorder, catatonia, and schizophrenia. [50,49] These primary conditions frequently co-occur with and/or are aggravated by secondary conditions. Experienced clinicians recognize that primary and secondary conditions in individuals with ASD may be masked by self-injurious or externalizing behaviours.

Survey research has shown that engaging in self-injurious behaviour (SIB) and aggressive behaviour[50,51], and externalizing behaviour are among the most common reason for hospitalization in the ASD population.[52] However, SIB is the most significant concern[53] as it often has a complex etiology and involves behaviours such as headbanging or self-slapping as well as self-biting, hair pulling, skin-picking, and scratching.[54] An estimated 25–50% of individuals with ASD engage in SIB at some point in their lives.[53,55,56] The risk factors associated with the severity of SIB include lower IQ, the severity of impulsivity, and stereotypy (i.e., repetitive body movements).[54] Chronic and severe forms of SIB are extremely resistant to treatment[57], and as such, without early and effective interventions, it will likely lead to acute or chronic hospital admissions for individuals with ASD.[58]

Although many individuals with ASD who experience crisis present with some form of behavioural disturbance, identifying the aetiologies of crisis behaviour can be challenging for health care providers, especially in individuals with ASD who have difficulty self-reporting their health concerns. In these cases, referral and admission to either a general or specialized psychiatry unit for further assessment and treatment are recommended (e.g., 11% of children with ASD in the United States are hospitalized for psychiatric reasons before the age of 21[50]).

Assessment and Care Processes for Behavioural or Mental Health Conditions

If a behavioural or a mental health condition is suspected, the decision to admit an individual with ASD into a general or a specialized psychiatric hospital unit is usually contingent on logistics and availability. However, if both options are available, evidence suggests that specialized inpatient psychiatric units, those that exclusively treat individuals with ASD and intellectual disability, provide effective and optimal care with lasting improvements in behavioural conditions.[59,60,11]

It is well-established that individuals with ASD who are admitted to general psychiatric treatment units have different needs than most psychiatric patients, and as a result, their treatment needs also differ.[25] A consequence of these differences is that general psychiatric units practices are not necessarily conducive to the types of treatments required for ASD. For example, general psychiatric inpatient services are developed primarily for internalizing psychiatric disorders, verbal interventions, and group therapy. In contrast, individuals with ASD have primarily externalizing behavioural symptoms, experience difficulty with verbal interventions, and may not be able to manage the social interactions in group therapy.[12] To address this disparity, leaders of specialized psychiatric units serving the ASD population have developed best practice recommendations for the inpatient care of youth with ASD and ID in specialized or in general treatment units.[32] Recommendations included:

1. Obtaining information specific to the individual with ASD/ID and their support system in the initial admission assessment.[32]
2. Screening for a medical cause of the presenting problems.[32]
3. Assessing for psychiatric co-morbidity and using evidence-informed pharmacotherapy.[32]
4. Assessing and supporting communication and occupational therapy needs.[32]
5. Conducting a behavioural assessment and collecting behavioural data.[32]
6. Adapting the unit environment and programming to create therapeutic spaces and activities appropriate for ASD or ID.[32]
7. Providing structured educational services to facilitate the transition back to school.[32]
8. Providing ASD population-specific training to direct care staff.[32]
9. Providing a longer length of stay to treat changing patterns of behaviour[32], and
10. Interpreting medical practice criteria in the context of the developmental disorder.[32]

In accordance with these practice recommendations, assessments and care processes and staff training have been developed for practitioners serving individuals with ASD.

Assessment

In a crisis, regardless of what conditions are causing the emergency for the individual with ASD, the most observable symptom is typically externalizing behaviour. However, the behaviour is just the "tip of the iceberg" of what is going on under the surface for the individual with ASD. The Iceberg Assessment Interview (IAI) was developed to organize and identify the issues underlying behaviours that challenge behavioural challenges.[61*] "Summarized IAI data includes the presenting crisis behaviours, caregiver-perceived environmental conditions, and underlying psychosocial and medical problems."[61(p3468)] An investigation into possible trauma is also recommended as part of the differential investigation for underlying contributions to the behaviour.[62] The IAI supports information gathering for clinical decision-making and treatment regimes in both specialized and general psychiatric hospital units.[61]

Care Processes

A review of specialized psychiatry units showed the most common clinical care processes included an

> "intensive diagnostic assessment, removal of psychotropic medications when possible, development of an individualized behavioral plan based upon principles of applied behavior analysis and positive behavioral supports, targeted psychopharmacology, treatment of medical issues, functional communication training, occupational therapy, milieu therapy, special education, and family therapy. … the program addressed both the acute symptomatology as well as the key underlying chronic factors that contributed to unsafe behavior. For example, identifying that an aggressive non-verbal child has no communication system might prompt treatment of the aggression with medication and implementation of functional communication strategies, such as choice boards, first-then prompts, "break please" cards, etc."[11(pp3027-3028)]

Recommendations included, adding to or adapting general care processes to include additional patient information, individualized interventions, and assigning a consistent subset of staff to use ASD strategies.[43] The following points provide a few ways to demonstrate how to apply these recommendations into practice when assessing and treating children or adults with ASD in any psychiatric hospital unit.[43]

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[*] The term 'behaviours that challenge' or specifically recognizing behaviour as a form of communication changes the way we (i.e. health care professionals) perceive behaviour. We can't change any patient's complexity, but we can work to understand them. I think it is important to take the focus off the person with the IDD and put it where the responsibility lies with the persons who are receiving the communication (caregivers, health care providers, and policy makers; personal communication, Dr. Karen McNeil, May 2019).

Collecting Additional Patient Information to Produce a One-Page Tip Sheet for Unit Staff[43]

- Communication strategies or devices
- Early signs of agitation (e.g., movements)
- Food, object, activity, and sensory preferences and aversions
- Transitional objects and strategies
- Calming items and strategies
- Specific information on dangerous behaviours and effective responses or restraints[43]

In addition to collecting additional information and tip sheets, developing a plan with useful relational, behavioural, and communication interventions and strategies that can be shared with support staff and family members by:

- Applying communication strategies and techniques (e.g., minimizing verbal directions, simplifying language, using visuals cues, allowing the individual time to process, giving space when the individual is agitated)
- Defining two behaviours that challenge
- Utilizing a behavioural plan
- Targeting medications and reducing polypharmacy
- Providing visual supports for communication of schedules and routines with alternative/ preferred/ or less preferred activities
- Providing a calendar with a road map of goals to use on the unit and when they go home
- Teaching feelings and coping strategies (modelling taking deep breaths/giving space) with designated quiet calming areas on the unit.
- Conveying successful strategies to support staff and parents[43]

Experts applying these ASD specific intervention strategies emphasize that adopting these adaptations it is critically important for improving care in specialized and general psychiatric units.

Training for ASD-specific Intervention Strategies

The ASD Care Pathway (ASD-CP)[*] was developed to improve care in general psychiatric units through staff training and a package of autism-specific intervention strategies.[13] ASD-CP is based on positive behavioural support (PBS) and uses the acronym 'PATHWay' (i.e.,

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[*] An evaluation of the effectiveness of the ASD-CP in a public hospital child psychiatric service compared 18 months (n = 17) versus 18 months (n = 20) post implementation. Average length of hospital stay decreased 40% (22.4–13.4 days) and use of crisis interventions decreased 77% (holds/restraints; 0.65/day to 0.15/day), though each result only approached statistical significance (p = 0.07; 0.057).

Predictability, **A**ctivity, **T**otal communication, **H**igh reward, and **WAY** to cope) to emphasize the core principles.[13]

The ASD-CP consists of modular staff training, a toolkit, and prescribed ASD practices. The training is structured as four 45-minute modules consisting of lecture, video examples, interactive exercises, and role-play. The first module introduces ASD, including prevalence, diagnosis, and core characteristics and gives an overview of foundational principles for intervention. The final three modules cover components of the ASD-CP using the acronym 'PATHWay' (i.e., Module 2: **P**redictability, **A**ctivity; Module 3: **T**otal communication, **H**igh reward; Module 4: **WAY** to cope). The tools have also been developed to apply these strategies, for example, a Tip Sheet, Visual Schedules, First-Then Cards, and activity plans for engaging patients in developmentally appropriate activities with sensory-motor breaks.[13]

Preliminary evaluation of the ASD-CP in child psychiatric services has shown, that once implemented, it decreased the average length of hospital stay by 40% and the use of holds and restraints by 77%.[13] This study provides preliminary evidence for improved processes after implementation of an ASD-CP that may also reduce risks associated with crisis intervention (e.g., injuries to patients and staff) as well as the costs associated with extended stays in hospital.[13]

It should be noted that some proponents of ASD specialized assessments, strategies, and treatments have argued that residential treatment facilities might also offer these services as part of the continuum of service options.[63] However, the advantage of residential treatment facilities is realized when there is a close connection with families and other community-based services.[63]

> "Residential treatment facilities (RTFs) can offer many advantages, which include a multidisciplinary professional staff, a continuum of care, and a safe therapy and training space for families and discharge providers. These advantages, combined with the best evidence-based treatment, staff training, and staff supervision interventions can make an RTF the first and optimal choice for treatment. Contemporary proponents of residential treatment are answering critics through development of specialized and intensive models of treatment that show significant promise in ameliorating SBD [Serious Behavioural Disturbance] in children with ASD/ID".[63(p112)]

When weighing how to treat crisis and where treatment should take place, keeping individuals with ASD in their homes and community must be a priority.[8] However, once a crisis has occurred, it is likely that resources in the home and community have been depleted, making it very difficult to implement treatment in those settings without an infusion of resources and support. Therefore, divesting treatment to community-based services and families' homes without the development of preventative, appropriate, and accessible services to support individuals with ASD is typically not feasible, effective, or sustainable.[64]

4. Is there evidence for a service delivery model that integrates crisis prevention and treatment for individuals with ASD?

One of the underlying principles that guide an efficient and effective systemic response to a crisis is finding the right balance of least to most restrictive care and interventions.[8] This is why the infrastructure for treating crisis in an individual with ASD requires a multi-pronged and multi-disciplinary approach.[8] For example, whether care is delivered in the hospital, in a community-based residential option, or in the family home, there needs to be coordination among the physicians and nurses altering medications, the psychologists and behavioural analysts developing behavioural treatments, guiding interventionists implementing treatment protocols, and infusing in-home or out-of-home therapeutic respite services to provide support to the individual and the family.[65]

The START Model: Prevention, Intervention, and Crisis Management

The START (Systemic Therapeutic Assessment, Respite, and Treatment) model is a coordinated wraparound system of care. It is led by an interdisciplinary team of specialists, supporting and linking inpatient, community-based, and in-home services for people with intellectual and development disability (including ASD) who are at risk for a crisis, in crisis, or recovering from a crisis. Specializing in behavioural and mental health prevention, treatment, and after-care, while also focusing on strengthening efficiencies and service outcomes. Based on a public health prevention model, there are three levels of care[66,67,9]:

1. **Crisis prevention (Primary Care)**: Improving access to services, treatment planning, integration of health and wellness, and development of service linkages. "Effective Strategies Changing the Odds".[9]
2. **Crisis Intervention (Secondary)**: Identification of individual/family stressors, crisis planning/prevention, respite services, medication monitoring, and crisis intervention services. "Improved Supports for Beating the Odds".[9]
3. **Crisis Management (Tertiary)**: Emergency room, hospitalizations, and law enforcement interventions. "Accurate Response for Facing the Odds."[9]

Please note that the following are direct excerpts from Beasley, Klein, and Weigle[9] and provide details about each of these levels (i.e., prevention, intervention, and management).

"Level 1: Prevention[9]

In the START program, prevention ("primary prevention") includes strengthening the service system's ability to successfully engage individuals with IDD by focusing on quality of life, improving access to services, identifying gaps in the system, and improving competencies for all including self-advocates, families, direct support staff, and clinically trained professionals.

Linkages across systems allow for the sharing of knowledge and resources. Direct services provided by START programs in this stage specifically include: identifying gaps in service systems and helping to build the infrastructure to fill them; providing hands-on training to providers of direct support, caregivers, professionals, and community participants (e.g., police, emergency room staff); sharing technical information and advice among participants, families, service providers; and ensuring there is a coordinated continuum of care in place to respond to individuals' arising needs. This level of intervention provides universal benefit to START service recipients as well as to the service system and communities as a whole."[9(p4)]

"Stage 2: Intervention[9]

The START Intervention ("secondary prevention") activities are centered on individual service recipients and include: integration of health and wellness activities; ongoing assessment of all bio-psycho-social factors and proper intervention; clear delineation of communication abilities and interventions as needed; identification of triggers that lead to crises for an individual; robust cross-systems crisis prevention and intervention planning that includes access to the START therapeutic Center for planned supports and crisis prevention/intervention services; determination of appropriate ongoing interventions and supports to decrease the likelihood of crises; and development of interdisciplinary teams around an individual to continually work toward improving quality of life and adaptive functioning for that person."[9(p5)]

"Stage 3: Crisis Management [9]

The third prevention level can be considered management of crises when they do occur despite best efforts to avoid them. The Management level is clearly outlined in the cross-systems crisis prevention and intervention plans; thus, the tools to address the situation are outlined and all participants have previously agreed upon the steps that will follow in managing the crisis. This level includes more intensive care such as the use of after-hours crisis response, START Center Emergency beds, in-home emergency supports, psychiatric hospitals, and crisis stabilization units. The level of recidivism in using these intensive services decreases over time in the context of the START program. Also, START provides direction and support in bringing the persons to stabilization and helping them return to prior levels of functioning in their home environments through ongoing support, training, and development of newly identified interventions as clinically indicated."[9(p5)]

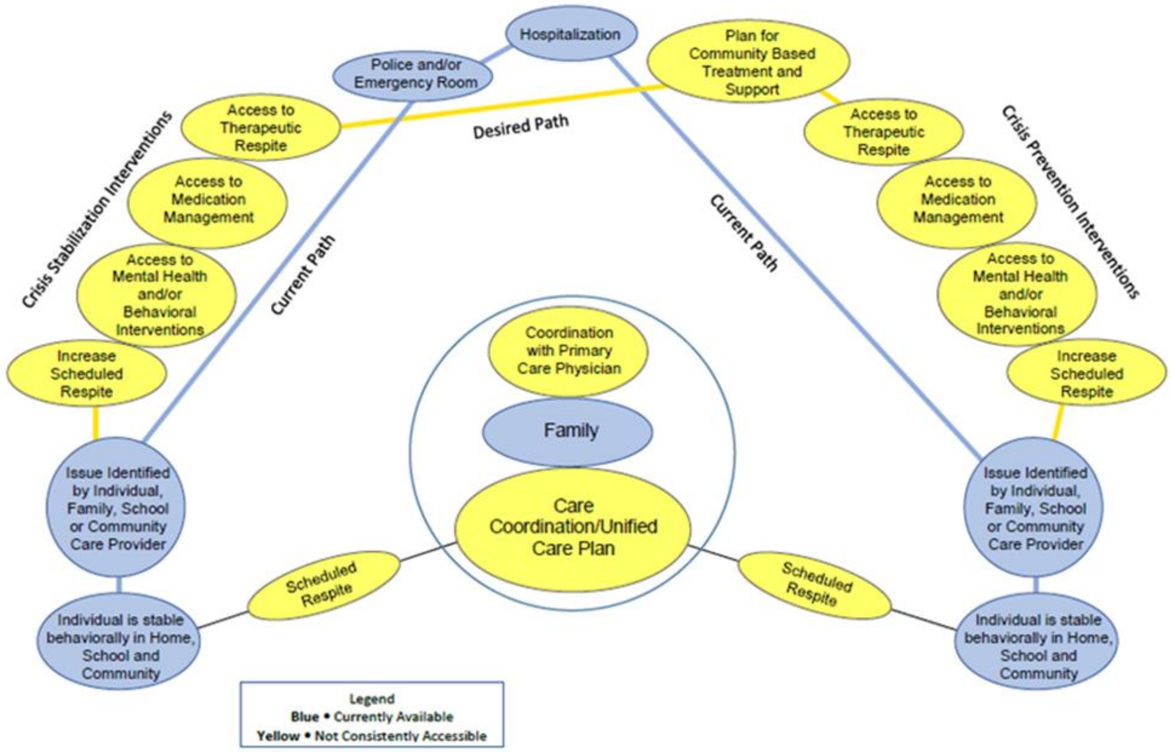
It is important to note that respite services are embedded in the START model. Both preventative and therapeutic respite services can be beneficial for the individual and the family to prevent and treat crisis. Results from an analysis of children with ASD living in the United States found that "Each $1000 increase in spending on respite care during the preceding 60 days resulted in an 8% decrease in the odds of hospitalization in adjusted analysis."[68] There are advantages to both residential- and home-based support, depending on the nature and needs of the individual. Home-based support was associated with stability and flexibility if the family could provide support at home. However, if the family had no capacity, home-based options could also be detrimental. It could also be offered as an additional period of support after discharge from in-patient care.

In cases where out-of-home respite care is warranted for a crisis, evaluation has demonstrated that this option has benefits as well.[65] In a Canadian study, service users, referring organizations, and staff members of the out-of-home respite service all identified that the service was much needed and that its role was an effective alternative to more intrusive forms of crisis support.[65] Most importantly, out-of-home respite service was considered a safe place for individuals with ASD to transition from a state of crisis and a transition place to take a break and work on behavioural life goals.[65]

As one part of the continuum of care, there is growing evidence around the effectiveness of therapeutic respite services for addressing crises, whether it is delivered in-home or out-of-home. Overall, therapeutic respite is a less intrusive form of crisis intervention, and it has been positively evaluated.[65] The most effective interventions reduce clinical admissions, focus on providing strategies that can be used in natural environments. The success of future mental health crisis respite programs will depend on policymakers taking an evidence-based, best-practice approach that meets the needs of both consumers and clinicians.[69] The World Health Organization's statement on good public health and mental health indicates that effective primary prevention strategies can "change the odds" to reduce emergency service needs.[9] A supportive infrastructure focusing on primary prevention builds capacity within and around the individual with ASD and improves outcomes when the secondary and tertiary levels are needed.[9] The third level of services typically have the most significant financial costs to the system and emotional costs for the individual and the family.[67,9]

An evaluation of the access to mental health services in Colorado for individuals with a dual diagnoses (i.e., intellectual and/or developmental disabilities and a mental and/or behavioral health disorder) provides a visual depiction of how a traditional service pathway would change after the START program was implemented (Figure 5).[70] The traditional service pathway for crisis (in blue) shows that when an issue is identified, individuals go directly to the police and emergency room which may lead to hospitalization. The START model provides both crisis prevention and stabilization interventions which allow most individuals to by-pass costly and inefficient traditional service pathways involving the police, emergency room services, or hospitalization.[70] Instead, those at-risk for a crisis have a plan for community-based treatment and support, which guides the coordination of respite care and therapeutic respite care and provides access to pharmacological, mental health, and behavioural interventions.

Figure 5. Crisis Intervention and Prevention Model for Children and Adults with Dual Diagnosis



START outcomes include a significant reduction in emergency service use, increases over time in planned supports and service use, and satisfaction with service experiences for individuals and their families.[70] Research results suggest START was effective in improving caregivers' evaluation of service experiences, problem behaviours, and emergency psychiatric service use.[36,71,24] In a prospective study of individuals living in paid support settings, the I-START program (delivered primarily in the rural region of Iowa), showed improvements in behaviours and a decrease in both hospitalizations and emergency department visits after one year.[72] Researchers attributed the 50% reduction in urgent and acute service use after only one year of I-START to the preventative and active support provided before and during a crisis (e.g., cross-systems crisis planning, 24-hour crisis response, outreach, and clinical/medical consultation services).[72]

START Program Certification and Network Options

The Center for START Services provides a comprehensive process for developing, implementing, and evaluating behavioural and mental health services for individuals with dual diagnosis and complex care needs. The START service model provides support to develop an interdisciplinary cross systems collaborative approach to information sharing that enriches community capacity. It also provides guidelines and training to provide a fidelity based, evidence-informed model to crisis prevention and intervention. Most importantly, this model has demonstrated its effectiveness in managing complex conditions and cases in rural and urban areas[*], with individuals living in their families' home and in residential settings. START is fueled by collaboration, built on professional networking, mentoring, and training, and it is strengthened by continuous evaluation and research. The resources to lay the foundation for a START service include developing a START Professional Learning Community, eco-mapping the current system to identify strengths and gaps, and operation protocols for linking existing programs into a START system. These processes are available and have been tested to maximize accessibility, appropriate levels of care, and accountability for services as well as the health outcomes.

5. Summing Up

At least 80% of families supporting an individual with ASD are at risk for a crisis. Individuals with ASD are vulnerable to experiencing a crisis due to inherent biopsychosocial sensitivities associated with the disorder and the lack of environmental accommodations in society. For individuals with ASD, most crises present as a behavioural problem, however once assessed the underlying condition might be environmental, medical, mental, and behavioural. Families subjectively appraise crisis as an overwhelming demand that exceeds their capabilities and resources. This causes distress and an inability to cope with daily life. When accessing emergency services, families encounter barriers including environments that exacerbate the crisis, communication difficulties with health professionals, inadequate and a lack of ASD-specific care processes and treatment regimens that put further demand on already depleted family resources. Research shows that access to preventative and community-based ASD mental health services is either limited or nonexistent, which forces families to turn to emergency and inpatient services. However, general mental health inpatient and outpatient services primarily focus on internalizing psychiatric disorders using verbal interventions and group therapy. Therefore, inappropriate for individuals with ASD who have primarily externalizing behavioural symptoms, experience difficulty with verbal interventions, and may not be able to manage the social interactions in group therapy. ASD researchers and clinicians recommend ASD-related family-centered care with the least restrictive treatment models. The Training using the ASD Care Pathway Predictability, Activity, Total communication, High reward, and WAY to cope. The START (Systemic Therapeutic Assessment, Respite, and Treatment) model is a coordinated wraparound system of care. The START service model is led by an interdisciplinary team of specialists, supporting and linking inpatient, community-based, and in-home services for people with intellectual and development disability (including ASD) who are at risk for a crisis, in crisis, or recovering from a crisis. Specializing in behavioural and mental health prevention, treatment, and after-care, while also focusing on strengthening

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[*] START began in New Hampshire and has been successfully replicated in 9 states across America (i.e., Washington, Colorado, Iowa, Oklahoma, Arkansas, Texas, North Carolina, Virginia, New York).

efficiencies and service outcomes. Regardless of the service delivery model, enhancing access to ASD-appropriate services is essential for the prevention, assessment, and treatment of behavioural and mental health conditions. Access to care and supports must be inclusive, timely, and community-based. The appropriateness of care is reflected in the ability of providers to meet the needs of an individual with ASD. Outreach, training, and collaboration are imperative for improving the appropriateness of services. Service systems must be accountable to everyone involved including practitioners and patients with ASD.

Appendix A: Methodology

The purpose of this review is to provide evidence-based guidance on crisis for individuals with ASD and their families. There are several factors to consider when choosing the methodology, such as managing the scope of the review. The Rapid Review methodology, a research methodology outlined by the National Collaborating Center for Methods and Tools provides a timely and valid view of the evidence. A Rapid Narrative Review is a form of knowledge synthesis that follows the systematic review process and simplifies or omits components of the process to produce information in a timely way.

The review covered peer-reviewed articles and documents available online between 2010 and 2018. Where there were gaps in the literature for certain topic areas, the review was extended to include evaluation reports. By following the National Collaborating Center for Methods and Tools (NCCMT) Search Pyramid approach that supports efficient searches of evidence that have already been systematically synthesized. Searches start at the top of the pyramid with the most synthesized evidence documented in summaries and move down to synopses of syntheses (e.g., descriptions of systematic reviews or meta-analyses) and syntheses (e.g., systematic reviews and meta-analyses) and single studies. Pre-appraised evidence was used first, and single studies were only used when there were gaps in published systematic reviews. As anticipated, this latter search method was mainly employed when searching for evidence related to specific understudied topics, such as preventing and treating crisis experienced by people with ASD who are non-verbal and struggling with behavioural and mental health disorders.

An array of keyword searches was used that address the continuum of ASD issues, practices, related to crisis. Databases that provided pre-appraised evidence were searched first, such as the Cochrane Database of Systematic Reviews. Bibliographic databases such as PsycNET, MEDLINE, Google Scholar, and CINHAL (Cumulative Index to Nursing and Allied Health Literature) were searched for individual studies. Reference sections of relevant research were searched (i.e., backward search) and forward searches were also conducted (i.e., who cited the pertinent research). The report focused on peer-reviewed, mainly academic literature, and included some best practices documents.

One of the limitations of this review was the small body of research on individuals, especially adults, with ASD and crisis. What is presented here is a narrative overview of the evidence as it relates to supporting individuals with ASD. It is hoped that much ‘deeper dives” into some of the topics can be completed to provide for a fuller picture of the complexity of some of the issues. Consistent interpretation of different findings has also been difficult due to varied sample size, sampling procedures, differences in diagnostic criteria over time, a wide range of age, differences in measures used, and imprecise and/or poor-quality data.

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