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KINARK

CHILDREN AND YOUTH

Putting Children and Youth First

Integrating Autism and Mental Health Services in Ontario

A Kinark Policy Paper - June 2019

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Contributors

This paper would not have been possible without the contributions, expertise, and passion of over 20 child and youth autism and mental health providers and leaders from across Ontario. Their commitment to this cohort and insight into this complex issue has helped Kinark to craft a relevant, robust and timely policy paper. Thank you to the parents of children and youth who have the lived experience of ASD and mental health for their contributions to this paper.

Map of Contributing Agencies

Contributing Associations

Children's Mental Health Ontario; Addictions and Mental Health Ontario; Empowered Kids Ontario; Ontario Association of Children's Aid Societies

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Introduction

There is an increasing awareness among service providers and clinicians that many children and youth with a developmental disorder, and specifically autism spectrum disorder (ASD), are also living with significant mental health issues. We know that up to 70% of children and youth with ASD will be diagnosed with a mental health issue in childhood (Weiss et al, 2016). As a provider of both autism and mental health services for children and youth, Kinark is committed to promoting the importance of integrated and effective services for this population and to supporting a better integrated provincial system.

Please see Appendix 1 for the definition of developmental disabilities (DD), intellectual disabilities (ID), and ASD as we have used them in this paper.

Based on our own experience of the increasing number of children and youth with ASD who are seeking mental health services, we began to educate ourselves about the evidence base for most effective service to this population. In addition to undertaking a comprehensive literature review of published and grey literature, we also consulted with experts in the areas of mental health, ASD, and developmental disabilities, other child and youth mental health and autism service providers, and families to understand their experiences with providing and seeking these services.

Despite strong evidence in the research literature that a high proportion of children and youth with ASD have or will have mental health needs, the child and youth services system in Ontario does not manage this intersection well. Public policy and funding for ASD and child and youth mental health (CYMH) services are discrete and siloed. It is not unusual to find that a diagnosis of ASD is an exclusionary criterion for mental health services and vice versa.

Parent

When my son was younger, I realize now that his tantrums were actually panic attacks (or sensory meltdowns). I was told he was just acting out. But they were panic attacks and I had been berating him, telling him to just calm down, even almost punishing him sometimes. Because that's what we were told to do. He was in grade nine when I was told about the anxiety and I was like 'what the eff?' I thought that was the autism. I was told there are 80 child psychiatrists in Ontario but none of them are trained in autism. There may be some but we (parents) don't know what's out there. But you know "if you don't know what is on the menu, you might as well not show up to the restaurant."

When a new government was elected in Ontario in June 2018, the government committed to improving services within the child and youth mental health and autism sectors. As part of this commitment, the child and youth mental health program has been moved under the Ministry of Health and Long-Term Care while autism has been realigned within the newly created Ministry of Children, Community and Social Services.

In February 2019, the government released its redesign of the funding for autism services. While the goal behind the new program is to ensure more children and youth with autism (particularly those on the wait list) receive services sooner, and families have increased choice in services, the new funding approach risks further siloing of programs and services for children and youth with ASD. Also in February, the Ontario government announced its intent to transform the health system with the introduction of local Ontario Health Teams (OHTs). OHTs will have responsibility for providing health services in a defined geography across the lifespan, including mental health and addictions. OHTs will not be responsible for autism services. This time of great transformation offers an ideal opportunity to consider how both CYMH and autism sectors can support coordination and integration of services to better meet the needs of children and youth.

The purpose of this paper is to spark discussion among policy makers, service providers, and families that will lead to greater integration in policy, service planning, and services for children and youth with ASD and mental health needs.

Evidence of a Relationship between Autism and Mental Health

Evidence suggests there are higher rates of mental health problems for individuals with ASD than for non-ASD peers. The direct causal or correlational relationship between all of these is largely unknown but the literature clearly shows the presence of ASD enhances the risk for comorbid mental health issues in children and youth.

We know that people with a developmental disability have a higher risk for developing mental health issues or other serious challenging behaviours (Weiss, 2012). Mental health problems are important in predicting overall poor physical health of individuals with DD (Weiss, 2012) (Brookman-Frazee et al., 2009; Weiss, 2012; Weiss, Ting, & Perry, 2016).

ASD often presents with a number of other comorbidities including intellectual disability, epilepsy, sleep disturbances, cerebral palsy, gastrointestinal issues, and feeding disorders (Vohra, Madhavan, Sambamoorthi, & St. Peter, 2014). Children and youth with ASD may also experience co-occurring mental health conditions such as attention deficit hyperactivity disorder (ADHD), anxiety, depression, bipolar disorder, and other conduct problems (Dickerson, Mayes, Calhoun, Murray, & Zahid, 2011; Simonoff, Pickles, Charman, Chandler, Loucas, & Baird, 2008). As well, studies show:

- 70% of children with ASD also had a comorbid mental health condition while 40% of them had two or more disorders (Fung, Lunsky, & Weiss, 2015).
- Those with ASD are vulnerable to depressive and anxiety related disorders, including phobias and obsessive-compulsive disorders, sleep disorders, followed by ADHD and to a lesser extent schizophrenia and psychosis (e.g., Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Lunsky, Lake, Balogh, Weiss, & Morris, 2013; Moss, Howlin, Savage, Bolton, & Rutter, 2015; Vasa et al., 2013).
- Depression is one of the most common mental health conditions for young people with ASD, with rates ranging from 40-58%, compared to about 12% in the general youth population (Fung, et al., 2015).
- A systematic review of 12 clinical studies revealed that for children, youth, and adults with ASD, prevalence of suicide attempts ranged from 7% to 47% and suicide ideation was found in as many as 72% of cases (Zahid & Upthegrove, 2017). Depression, behaviour problems, and peer victimization, were found to be risk factors for suicide ideation and suicide attempts among young people with ASD (Cassidy et al., 2014; Mayes et al., 2013; Shtayermman, 2007). In Sweden and the US, ASD has been linked to an increased risk of death by suicide among people of all ages (Hirvikoski et al., 2016; Kirby et al., 2019).

Mental health issues persist into adulthood if not addressed earlier in childhood or adolescence (Moss et al., 2015; Russell et al., 2016). Kerry's Place Autism Services noted that in a recent study of 76 of their adult clients with ASD, 50% had diagnosed mental health issues, demonstrating that this vulnerability (or 'propensity') for comorbidities is likely lifelong. The risks associated with comorbid ASD and mental health issues are significant and have a detrimental impact on people's lives:

- In Ontario, young adults (ages 18-24) with ASD were more likely to receive a psychiatric diagnosis and to visit a psychiatrist and/or a psychiatric emergency department than young adults without ASD (Weiss et al., 2018).

- People with ASD and mental health disorders have higher rates of hospitalization compared to those without a mental health disorder (Lunsky et al., 2013; Nayfack et al., 2014).
- People with ASD and mental health disorders have more emergency department visits and more repeat emergency department visits than the general population (Lunksy et al., 2013).
- Once in hospital, some DD studies have found higher use of chemical restraints (Stewart, Baiden, & Theall-Honey, 2012), behavioural interventions and secure isolation amongst those individuals with mental health disorder as compared to people without DD (Lunsky et al., 2013).
- Research has demonstrated the limiting effects of ASD/mental health comorbidity on accessing and remaining in post-secondary education (Taylor, Henninger, & Mailik, 2015) or the workforce (Schochet et al., 2016).
- Comorbid mental health disorders and ASD or other DD place individuals at higher risk for out-of-home placement and involvement with the criminal justice system (King & Murphy, 2014; Mayes, 2003; Robertson & MacGillivray, 2015).

The prevalence of mental health issues among people with ASD, means that the majority of children and youth with ASD may require some sort of mental health intervention over the course of their life. It is imperative to understand the evidence and best practices for effectively understanding, assessing and treating their needs. The following section outlines a number of considerations when determining the areas for further investigation or development in establishing a more coordinated system of care for those with this dual diagnosis.

Considerations for Service Provision

1. Assessment

Assessment | Diagnostic overshadowing:

One of the main challenges for professionals is separating out what is considered "typical" behaviour of those with ASD versus what behaviour is a symptom of a mental health disorder. An important clinical phenomenon is that of "diagnostic overshadowing." This refers to the negative bias in clinicians regarding co-occurring disorders in individuals who have ASD. Symptoms of behaviours that may be due to a specific mental health issue are attributed instead to ASD, "without considering alternative etiology" (Kanne, 2013). For example, symptoms for mood and anxiety disorders are often attributed to the developmental disability, thereby, "overshadowing" or missing any comorbid psychiatric diagnoses (Szeftel, Federico, Hakak, Szeftel, & Jacobson, 2012).

> *My observation is that families often are very aware of what the child's needs are and what their family's needs are, and they are looking for a particular diagnosis. They often want an autism diagnosis because there is a sense that it opens doors for them and allows them to access services. And what I would really like to see is that we don't require a diagnosis to access autism services.*
>
> Pediatrician

An example of "missed" mental health diagnoses is found in a review of clinical charts of 45 people with a dual diagnosis. Of those individuals, 68% were diagnosed with a psychiatric disorder after their initial visit through telepsychiatry, compared to 27% of them who had received such a diagnosis (often from a primary care physician) prior to their telepsychiatry appointment (Szeftel et al., 2012). These "missed" diagnoses may be due to a lack of appropriate assessment instruments and the overall lack of training that mental health professionals receive regarding ASD or other developmental disabilities.

Lack of appropriate assessment instruments:

The key to achieving an accurate diagnosis is conducting a thorough assessment. The mental health assessment of those with ASD or other developmental disabilities may present a challenge if individuals have limited communication skills. Most assessments of mental health rely on some form of self-reporting of symptoms and when that is impaired, the ability to accurately diagnose emotional distress is also impaired (Lunsky et al., 2013).

> **Parent**
>
> *My son was suicidal for a number of years and I brought him in and said I need someone who knows ASD. They said they didn't have anyone. So I said, I've heard that everywhere but he's here on your doorstep now so find someone because it's on you. So we found a Psychiatrist, the chief of psychiatry, who said 'I'll be honest I don't know about ASD" and I said "well are you willing to learn?" So, we worked together.*

For example, Stewart et al. (2006) argue that the three most widely used diagnostic instruments for depression (i.e. Hamilton's Depression Scale [Depression Rating Scale], the short form of the Children's Depression Inventory [Children's Depression Inventory-Short; CDI-S], and the Beck Depression Inventory) ask clients to subjectively evaluate their mood and how they feel. Some assessments for depression focus on changes in appetite, sleep, and level of interest in activities and these may be interpreted as symptoms of ASD rather than symptoms of depression (Stewart et al., 2006).

Limited resources for assessment:

Clinicians identified that a thorough multidisciplinary assessment is key to obtaining a differential diagnosis of ASD or mental health. However, most community mental health agencies report limited resources for psychiatry and psychology supports. As discussed earlier, even within those professions, there is a lack of use of established diagnostic tools for ASD which may contribute to misdiagnosis.

> *Family physicians, primary care providers, I don't think they all necessarily recognize the early signs of autism. It's probably quite variable.*
>
> **Pediatrician**
>
> *Families who are on the wait list for autism services are being told to seek mental health services while they wait because we do not have much of a wait list for service. Clinicians reach back to autism professionals with little support or direction on how to assist families.*
>
> **Service Provider**

In a sample of 250 children and youth with ASD accessing services through a national health population survey, speech therapy (93%) was the most frequently received service and 65% received occupational therapy. Fewer than 6% received behavioural therapy and 11% received mental health services (Bilaver, Cushing & Cutter, 2016, p. 564). There was no assessment of how many people actually required behavioural or mental health services, despite the awareness that this is a need within this population.

2. Clinician Training

Most often, primary care physicians and pediatricians are the first point of contact for families with concerns about their child's development. Beyond that, for the 0-6 population, professionals such as speech and language clinicians often provide an early flag that there may be concerns about ASD.

Critical to improving services for this group is to train autism and mental health clinicians to recognize and treat individuals who have co-occurring mental health issues with ASD (Brookman-Frazee et al., 2009). Yet, Lunsky et al. (2013) noted there remains inadequate training and curricula for students in psychology, psychiatry, medical school, and social work.

In a survey of 100 therapists in community-based CYMH clinics in California, Brookman-Frazee, Drahota, Stadnick, and Palinkas (2012) found that 76% had served a child with ASD, and children with diagnosed or suspected ASD represented about 20.7% of therapists' current caseloads. Only 48% of respondents indicated they had received some training about ASD.

Clinicians in community-based CYMH settings (e.g. social workers, child and youth workers, psychotherapists) are unlikely to have received training to develop the required capacity to respond to the comorbidity of ASD and mental health (Norris, 2014).

Studies show the challenging attitudes that some mental health clinicians hold about working with this population. These are often rooted in a lack of understanding and training about children and youth with ASD, including:

- frustration because of the child's slow progress
- belief that this group is more aggressive and dangerous than those without mental health issues (Stewart et al., 2012; Weiss, 2012)
- difficulty in building rapport
- frustration with the required coordination of care and other services (Brookman-Frazee et al., 2012)
- lack of knowledge of major research findings in the field of autism (Heidergerten, Geffken, Modi and Frakey 2005)
- belief that children can outgrow ASD (Heidergerten, Geffken, Modi and Frakey 2005)
- belief that children with ASD were deliberately noncompliant. (Heidergerten, Geffken, Modi and Frakey 2005)

Parent

A lot of people in agencies think they're experts and they're not.

I think most mothers feel intimidated by doctors. I've never challenged one. And the point is it doesn't matter because they're always right (sarcasm). You know how you can tell that, because they call you "mom" and not even THE mom or by your name.

I'd like to add that we are talking about doctors and clinicians not having the training, but teachers also don't have the training. How discouraging for a family, when you're sitting at school and no one knows what to do or how to help Special Ed teachers. They get this title Special Ed but what training do they really have?

My sister is a social worker and became a social worker for children with autism and she had to do two workshops to get that. She often calls me and I'm not the one with the specialization. That's when someone gets dangerous, when someone has a title or specialization but not enough training.

Program Profile | Surrey Place

One autism services provider, Surrey Place, has established an ongoing partnership with the University of Toronto to infuse training and education about working with those with various developmental disabilities into the curriculum for medical students. Surrey Place also supports student internship placements to experience working clinically with those with autism or another DD.

The lack of training in working with individuals with ASD contributes to therapists' attitudes and perceptions of working with an ASD population (Drahota, Stadnick, & Brookman-Frazee, 2014). Recognizing the lack of adequate training resources, Lunsky (2017) noted that the Centre for Addiction and Mental Health has developed an online course focused on mental health and DD in adults as part of its Continuing Education and Professional Development curriculum.

There are few training programs focusing on children and youth. The Child and Parent Resource Institute has some professional development courses available for clinicians focused on these comorbidities (e.g. Anxiety in Young People with Intellectual Disability, CPRI, 2018). The Holland-Bloorview Kids Rehabilitation Hospital is working with Project Echo to link experts with community clinicians. These "learning communities" help community-based clinicians "develop the skills they need to diagnose and treat a condition such as ASD."

College programs are emerging that provide more specific training for working with a DD (or ASD) population. For example, in addition to post-graduate training in ASD, there are now degree-granting programs at some Ontario colleges in community health or behavioural psychology.

3. The Impact of Age and Functioning

Fung and her colleagues (2015) noted that the onset pattern of depression in children and youth with ASD tends to mirror the pattern seen in non-ASD children and youth—prevalence rates of depression increase in adolescence and subside in adulthood. There are several reasons proposed by researchers:

- Internalizing disorders tend to manifest once there is a certain degree of cognition and social awareness about one's self. This level of self-awareness develops in adolescence, and so issues of depression and anxiety show up then, both for typically developing youth (Fung et al., 2015) and for those with ASD (Schochet et al., 2016).
- The research of Shochet et al. (2016) shows that adolescents with ASD who are higher functioning (54%) are more at risk for depression than those who are lower functioning (42%). Higher functioning youth are more interested in social interaction, may have more insight into their ASD impairments, and are more aware of their difficulties in social interactions. They experience more loneliness because of their lack of friendships, and more distress when their interaction attempts fail. This affects their sense of self-esteem and increases their risk for depression and being bullied.
- Youth with ASD also face all of the same issues as their typically developing peers. However, because of their ASD (challenges in communication, affect regulation and self-expression) adolescence can be even more difficult. These challenges reduce youths' ability to develop coping strategies to manage their moods or stress, and ultimately the likelihood of them seeking help (Schochet et al., 2016). This puts them at a higher risk for depression (Fung et al., 2015).

The findings of Fung et al. (2015) and Shochet et al. (2016) are of particular importance because they focus on individuals with higher functioning ASD while most research has been done with younger children and children with more severe ASD. Youth who are higher functioning may be more amenable to traditional therapies such as cognitive behavioural therapy (CBT)/dialectical behaviour therapy (DBT).

4. Prevention and Early Intervention

Two important inter-related factors have been identified that mitigate the development or severity of depressive symptoms in adolescents: a sense of belonging (school connectedness), and the capacity of self- and affect-regulation when faced with stress (e.g. resilience) (Shochet et al., 2016).

Deficits in social skill are a strong risk factor for mental health problems. A study by Ratliffe et al. (2015) investigated the association between social skills and mental health in a community sample of 292 students (aged 6-13 with ASD and without ID). Using teacher- and parent-completed measures of social responsiveness and social skills, the authors found that mental health difficulties were correlated with social responsiveness difficulties and poorer social skills overall.

Prevention programs targeting social skills and affect regulation may help to prevent mental health conditions or the need for more significant interventions (Ratliffe et al., 2015; Shochet et al., 2016; White et al., 2015).

The education system is an ideal place to develop a support network for these children and youth, and to establish prevention and intervention programs. Schools are well positioned to develop programs that promote social skills, school connectedness, and affect regulation. There is a growing body of research looking at preventative mental health programs in schools like DBT, mindfulness, and zones of regulation. Further research should be undertaken to better understand which student populations most benefit from these programs. Lunsky (2017) advocated that school nursing staff are ideally positioned to be trained to recognize issues of mental health early, to support this population and refer to appropriate treatment.

There is substantial evidence showing the benefits of early intervention in treating both mental health and autism (CMHA, 2018; Horlin, 2014; Jacobson, 1998; PCMH, 2018; Synergies, 2013).

While the initial costs of early intervention with behavioural services in autism can be high, the cost to society for those not receiving early intervention was estimated at approximately $1 million over the individual's lifetime. The cost to society decreases greatly when children with ASD are supported early to have greater independence and workplace productivity (Wendy Ungar, Institute of Health Policy, Management, and Evaluation, University of Toronto, 2018).

Early intervention programs for mental health are also some of the highest-yielding health-related investments. For every dollar spent on early intervention by families, there are estimated savings of $11 (Rupert, 2018). At the provincial level, for every dollar spent on early intervention, it has been estimated that $7 would be saved (Parents for Children's Mental Health, 2018).

Cost-benefit analyses of early intervention in autism and mental health suggest significant potential savings and suggest similar benefits for effectively intervening with those with both diagnoses.

Program Profile | Facing Your Fears

Facing Your Fears (FYF) is an example of an evidence-based family-focused group intervention for children and youth with ASD (high-functioning autism) aged 7-14 who also experience anxiety. FYF is a cognitive-behavioural (CBT) program and consists of 14 weekly sessions, each lasting 1½ hours. FYF draws upon a number of empirically supported CBT approaches for treating anxiety in the general pediatric population such as Coping Cat (Kendall & Hedtke, 2006), but makes adaptations for youth with high-functioning ASD (Reaven, Blakeley-Smith, Nichols, & Hepburn, 2011). Over 100 families have participated in effectiveness studies of the FYF intervention since the inception of the program in 2004, including randomized control studies.

Program Profile | AIM HI

Brookman-Frazee and colleagues (2012) studied the An Individualized Mental Health Intervention for Children with ASD (AIM-HI) program. This is a package of evidence-based parent-mediated and child-focused strategies based on the principles of applied behavioural analysis. It is designed to reduce behavioural problems of children with ASD aged 5-13 who are clients in CYMH clinics. The program teaches parents behavioural techniques to help their children with self-regulation and social skills. The intent is to improve the functioning of their child while also addressing the underlying issues contributing to the behaviour.

5. Evidence-Based Practices (EBP)

There are established EBPs for children and youth with ASD (Perry and Condillac, 2003) and for children and youth with mental health issues (e.g. cognitive behavioural and dialectical behavioural therapies). However, there is little research or evidence on treatment programs for children and youth with both ASD and mental health issues.

The few studies that have been conducted for those with comorbid ASD and mental health diagnoses focus on the use of behavioural interventions and psychotherapy (Lunsky et al., 2013) and there is some evidence to suggest the effectiveness of this particular combination of therapeutic treatment.

A key consideration in planning for interventions and treatment is the ability of clinicians to engage and retain families in the treatment process. Comorbid mental health issues can be a complicating factor in treatment success and continuation.

One research study showed 67% of families with children with ASD dropped out of psychotherapy at an outpatient clinic, a rate that was 2-3 times that of non-ASD children and their families (Ballard, Crane, Harper, Fawcett, & Sandberg, 2016). Reasons for this may include that services do not meet a child's needs, and/or the demands of parenting a child with ASD may make it hard to attend regular appointments. Increased availability of in-home services may better support families. Clinicians should work with parents and caregivers to address potential barriers and explore better ways to ensure clients receive the service they need with the time they are able to give to mental health services (Ballard et al., 2016).

Program Profile | Behavioural Stabilization

Kinark Child and Family Services implemented the Behavioural Stabilization and Consultation (BSCT) program in 2013 as an intensive in-home treatment program. The BSCT pilot program offered up to six months of intensive consultation and coaching services for caregivers of children under age 12 who were at risk of residential placement or family breakdown due to severe behavioural issues. The majority of clients referred to the BSCT program had a history of trauma or attachment disorder, however 72% were also diagnosed with ASD or another developmental disability (38% ASD only). The BSCT program was piloted at Kinark over a two-year period, and then became part of regular service delivery. In evaluating the outcomes of 17 BSCT participants and their families, Kinark found that clinical assessments showed improvements. The children, caregivers and staff also reported improvement. Further research is required on BSCT and its theoretical underpinnings for use with a comorbid ASD and CYMH population.

Parent/Caregiver Outcomes: increased use of BSCT behaviour strategies; increased confidence in parenting; increased commitment to supporting their child; increased awareness of the parenting role; increased understanding of the child; and, improved family relationships.

Child Outcomes: housing stability; reduction in problematic behaviour; improved emotion regulation; and, improved family relationships.

6. Family and Caregiver Support

Parental mental health and external stressors to the family are significant contributors to the mental well-being of children and youth with ASD. This can be the result of a direct risk factor or when parental issues and child behaviour impact and influence each other over time (Fung et al., 2015).

Caregiver Mental Health

Studies suggest that provision of support and intervention for families and caregivers may be just as important in improving a child's outcomes as the actual intervention with the child (Weiss et al., 2016). White et al. (2015) noted that parents with high levels of anxiety were associated with higher levels of anxiety in their children and poorer treatment outcomes. Feldman and colleagues (2012) found that low parent support and high parental mental health issues predicted their child's outcomes.

Parent

We read a lot of stuff about supporting the caregiver. What will support me as a caregiver is professionals who know what they're doing. I do not need a yoga class or meditation. Mindfulness and yoga don't fix my problems of worrying because we don't have money for treatment, and I'm going to die and my kid will be alone without the supports he needs to be without me. I need...services...that don't exist.

Caregiver Stress

Challenging child behaviour is highly correlated with parental stress (Lunsky et al., 2013). The very nature of parenting children with ASD and mental health issues is stressful to families (Weiss, 2012).

Addressing the needs of parents and caregivers through the use of more respite care, parent training and support can improve the lives of their children, including:

- reductions in hospitalizations and other negative child outcomes (Mandell, Xie, Morales, Lawler, McCarthy, & Marcus, 2012; Weiss 2012)
- improved family functioning and parent well-being (Samadi, McConkey, & Kelly, 2013)
- more effective parent strategies and a reduction in child conduct problems (Webster-Stratton & Hammond, 1988)
- improved use of services for both the parent and child (Olfson et al., 2003; Weissman et al. 2006)
- psychological well-being for both the child and parent (Bitsika & Sharpley, 2000; Weiss, 2012).

Program Profile | Brief Family Distress Scale

The issue of caregiver stress and family crisis is so critical, that researchers at the Centre for Addiction and Mental Health have piloted a new measure to assess families in crisis who have children with a dual diagnosis. This measure (Brief Family Distress Scale; Weiss & Lunsky, 2011) is being tested in several specialized DD programs for children and youth with ASD in Ontario as part of the standard intake and evaluation process to assist professionals in intervening quickly (Weiss, 2012).

Involvement with Child Protection

In a group of 10 parents of children all with ASD and mental health issues, all reported some sort of involvement with child protection services. In a study conducted by one Ontario childrens' treatment centre, 70% of referrals from child welfare for complex special needs services had autism. Some families indicated that providers suggested involvement of child welfare was the most appropriate way to address the challenges they were experiencing:

When our kids were growing up I had never heard of Asperger's. It wasn't even in their scope of thinking that it was autism. My son was diagnosed with schizophrenia. I was told to turn my son over to CAS and I did. I knew in my gut that it was wrong. It was the worst time of my life.

For others, child protection services were contacted as a result of the parent's disclosure of their own mental health or stress. This resulted in a fear and reluctance in parents to disclose how they were feeling:

I was told to pick my son up and take him to the hospital. When I questioned them 'why' since we both knew the hospital wasn't going to be able to do anything for him...there's always an underlying threat that CAS will take them away if we don't go to the hospital. It's a total waste of time.

As a caregiver, I had a psychiatric breakdown and the doctor insinuated that I couldn't take care of my kids. I was terrified that I could not disclose to anyone how I felt or they would take my kids away ...

Finally, others reinforced the idea that it is imperative for child and youth mental health workers to understand the nature of autism and how behaviours might manifest. When families perceive that they are being considered 'unable to cope' with their child, it may put a wedge between families and the providers of the services their children need.

7. Availability of Integrated Services

Children and youth with any sort of developmental disability, including ASD, face greater barriers to accessing quality health care than those without developmental issues. This is particularly true for those who have a comorbid mental health diagnosis (Stewart et al, 2012). These individuals have frequent contacts with numerous providers, experience health disorders that often remain undiagnosed, and receive uncoordinated services (Bradley et al. 2001). Caregivers of this group report greater levels of unmet needs, issues with access to services, and dissatisfaction with the quality of care, compared to caregivers of children without ASD (Vohra et al, 2014).

Families have also spoken about the challenges in either having to identify and coordinate their own multidisciplinary teams in order to access the services their child needs or not having that coordination capacity at all.

My son's team was a psychiatrist, psychologist, neurologist, occupational therapist, speech and language, developmental pediatrician (with special permission to continue seeing my kid no matter how old he is). We've also accessed Surrey Place, Sick Kids. I was told to get as much knowledge as I could because the parents who know more are going to get more (services). Then I was able to access more help. But I paid for that team. I had a nice big team that I paid $125,000 a year for and there are families who can't even afford their bus tickets to get here.

My team [the other parents] is pretty much at this table. I don't have a big family. I'm the team.

Program Profile | CPRI

One provincial provider, the Child and Parent Resource Institute (CPRI), does provide more specialized services for dual diagnosis children and youth, receiving some of the most complex clients referred from other agencies (an autism service provider will refer a client for whom they suspect a mental health issue because autism evidence-based services are not effective; K. Johnston, personal communication, 2017). Often, children and youth arrive at CPRI with 6-10 different diagnoses, one of which might be ASD, as well as multiple medications.

Opportunities within Ontario's Current Transformations

The former Ontario government launched several transformation initiatives for children and youth with ASD and/or a mental health diagnosis and/or other special needs. Since June 2018, the new provincial government has committed to improving access to services specifically in the CYMH and autism sectors. However, the program areas remain separate from one another perpetuating a siloed system of care.

The focus of the government and service providers in this area could provide opportunities for improving services to this population. The chart below describes the government's goals in related areas of transformation.

Autism Services	Child and Youth Mental Health Services	Coordinated Service Planning (CSP)
The recently announced new Ontario Autism Program (OAP) will: • provide more children with critical intervention earlier • introduce childhood budgets to provide more families with access to a broader range of services • double funding to five autism diagnostic hubs • establish a family-focused, independent intake agency • seek mechanisms to define and support the complexity of needs	**The government's goals are:** • a coordinated, collaborative and integrated service • a flexible continuum of timely and appropriate services and supports • an enhanced understanding of, and ability to respond to child and youth mental health needs through the provision of effective services and supports • accountable, well-managed, and accessible mental health and addiction services	**CSP is focused on ensuring families and children/youth with multiple and/or complex needs will:** • have a clear point of contact for CSP • have a service planning coordinator accountable for developing and monitoring their child/youth's CSP • not have to repeat their stories and goals to multiple providers • have a single CSP that involves all team members and is responsive to their child/youth's goals, strengths, and needs • experience a family-centred process

Recommendations for Action

This report has identified some of the main issues associated with the lack of coordinated, effective, and efficient service delivery for children and youth with comorbid autism and mental health issues. The complex nature of this work means that a multi-faceted approach is required by service providers and by government.

Providers and others from autism and child and youth mental health sectors have developed four overarching recommendations for consideration. Our goal is to develop a system that will support children, youth and their families to access more effective treatment and supports that will reduce their reliance on short-term, repeated and costly use of hospital resources.

1. Enhance service coordination and integrated program planning
2. Build an evidence base for more effective policy and program development
3. Strengthen cross-professional practice through awareness, education, and integrated service models
4. Strengthen all supports around children and youth by providing supports and services to their families

Specific Strategies for Government and Providers

Government

- Develop policy and funding frameworks to ensure services for children and youth with ASD and mental health issues are better integrated, including information sharing and integrated planning at cross-ministerial and provincial levels.
- Establish research grants for service provider/ academic partnerships to promote research and evaluation in this area.
- Consider standardizing the scope of practice and competencies of professionals working with this cohort to establish a standard of quality. This may include regulating BCBAs across the province.
- MOHLTC and MCCSS should work with the Ministry of Training, Colleges and Universities to ensure that relevant education and training programs (including medical schools) build knowledge about mental health and autism, include opportunities for learners to meet children with ASD.

Providers

- CYMH providers should review their programs where ASD is explicitly or implicitly an exclusionary criterion to create opportunities to serve children and youth with ASD.
- Co-locate, and seek opportunities to co-deliver, services through organizational or local planning table partnerships.
- Collect data about children and youth seeking ASD and mental health services and measure satisfaction with services.
- Establish clear service pathways for children and youth with ASD and mental health issues, distinguishing between those who require mental health supports and mental health treatment.
- Prioritize opportunities for continuing education for providers in mental health and ASD sectors, leveraging existing courses where appropriate or developing courses as required.
- Establish partnerships with adult mental health and autism services to better support parents living with their own MH or ASD issues.

Government and Providers

- Support up to five sites to pilot the provision of integrated and enhanced services to children and youth with ASD and mental health issues—including the identification or development of evidence-based interventions to support better diagnosis, treatment and evaluation.
- Support a provincial forum for mental health and autism policy makers and providers to explore evidence and advance an action plan for better outcomes for this cohort of children and youth.
- Consider opportunities to leverage or strengthen coordinated service planning for this cohort.

Conclusion

There was once a time when “autism” was a single diagnosis. Then research showed that autism was on a spectrum with varying degrees of developmental and functional impairment. Now research is indicating that autism is often paired with a mental health issue. It is clear that early intervention is critical to enable better lifelong outcomes for individuals with autism and mental health. The government is working to redesign autism and mental health systems to better serve children and youth. We have an opportunity during this time of transformation to make a difference, to influence how the system transforms, to serve the unique needs of the majority of children and youth with autism who also have mental health needs. Let’s put children and youth first.

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Appendix 1 | Definitions

The following is a brief description of the three key terms of Developmental Disability (DD), Autism Spectrum Disorder (ASD) and Intellectual Disability (ID). These are the three most frequently cited and studied comorbid disabilities in the literature with mental health. While this paper is focused on the intersect between ASD and mental health, within the literature, DD, ASD and ID are often included together in the research samples making it difficult to separate out the distinct needs of those with ASD.

Developmental Disability: Developmental disability (DD) is an umbrella term used to define chronic life-long impairments attributable to significant cognitive and/or physical limitations (AIDD, 2017). Developmental disabilities cause functional limitations in three or more of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency.

Intellectual Disability: Intellectual disability (ID) is defined as having significantly sub-average intellectual functioning impairments, typically two standard deviations below the mean IQ of 70 (American Psychiatric Association, 2013). ID may include significant limitations in conceptual and social skills, and in the practical domain (self-management of personal care, job responsibilities etc.). Intellectual disabilities are chronic, originate before the age of 18, and often co-occur with depression, attention-deficit/hyperactivity disorder, and/or frequently, autism spectrum disorder (Centre for Disease Control and Prevention, 2014).

Autism Spectrum Disorder: Within the broad spectrum of Developmental Disability, Autism Spectrum Disorder (ASD) is a lifelong, neurodevelopmental disorder distinguished by deficits in social communication and social interaction, and restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013). While prevalence rates of ASD have been rising dramatically, statistics for the actual prevalence of ASD vary:

- The National Epidemiologic Database for the Study of Autism in Canada (NEDSAC) estimated that 1 in 94 children was diagnosed with ASD (NEDSAC, 2012)
- Autism Speaks Canada (2016) states that Canadian rates match the prevalence rates in the United States, 1 in 68.
- In Ontario, the most recent statistics state that there are an estimated 40,000 children and youth with ASD (Ministry of Children and Youth Services, 2017).
- Perhaps due to the changes in practices for diagnosing autism, the CDC rates have increased by 78% over the last decade (1 in 150 (CDC, 2002); 1 in 110 (CDC, 2006); 1 in 88 (CDC, 2008); 1 in 68 (CDC, 2014).

Appendix 2 | References

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