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**BRIEF TO THE
ALL-PARTY COMMITTEE
ON
MENTAL HEALTH AND ADDICTIONS**

July 2015



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Good Morning.

Here is a brief overview of my presentation.

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We believe critical solutions that can be implemented immediately to improve the mental health of persons with Autism and their families & caregivers include:

1. Screen all children for autism between 30 and 36 months of age through the Public Health system
2. Add “medically diagnosed anxiety” to the criteria for allocation of student assistant support to students with ASD in inclusive classrooms
3. Develop and implement a 3-year comprehensive action plan for effective training of all educators and Student Assistants “in the field” about ASD and “best practice’ teaching strategies
4. End the use of IQ 70 as the sole criteria for service provision to children, youth and adults – add an “adaptive function measure” to remove the discrimination
5. Create a central intake clinic for adults with developmental disorders, including autism

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I want to begin by acknowledging the important work being done by the All-Party Committee. We all understand the challenges presented to loved ones and friends by poor mental health. Too many families continue to be impacted each week.

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Today I officially represent Autism Society, Newfoundland Labrador (ASNL). I can just as easily be speaking as an individual, as a father. I nearly lost one of my two daughters to suicide five years ago. A firefighter and paramedic, her attempt followed many years of misdiagnosis, incorrect medications and frequent prescription changes. It’s easy to place blame; there were some in the healthcare system who did fail my daughter. But there were others in the system who did recognize the errors. After the attempt, a correct diagnosis was made, all medications were removed immediately. It ultimately saved her and gave her a new life, a whole life, a happy life.

Some of you may know I worked for 37 years as an educator, 30 as a Principal, in several of the largest schools in the province. I can just as easily be speaking as an educator. Mental illness was a priority concern of my staff and I way back in 1995 when too many of our students were suffering but had no access, certainly no timely access, to badly needed support services. Educators live with these challenges daily and provide individual and group counselling as best they can. My Guidance Counsellors and I advocated for services and supports for students and families who trusted us for many, many years. I remember speaking with, and sending letters too, government ministers of the day, 13 years ago, detailing our perspective on the problems, our concerns for student safety, and requesting the placement of mental health advocates within a couple specific government departments.

We all know too many youth and adults have been lost to suicide over the years. Many moms and dads have not been as fortunate as me. But despite the suffering and suicides, things remain the same. Nothing has really changed. Until now! Today I have hope.

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This process you've invited us to engage in gives me real hope that we've turned a corner, that collectively we've been shocked into taking action that begins to really address issues. Some immediately, I hope; some in the near term; and perhaps others will come in the longer term. We have the ability to develop an effective strategy that will improve quality of life for the many that are affected by mental illness. We can save lives, we can save families! I've never doubted that for a moment. Do we have the will to face this difficult challenge? I believe we do.

Acknowledging the challenge has been an important first step. It won't be easy. Forming this All-Party Committee on Mental Health and Addictions is an even more important second step. The third step is most important.

We must create a "provincial strategy", an action plan, with urgency, and dedicate resources to implementing real solutions that help improve people's lives, give an opportunity for happiness, enjoyment, strong, lasting relationships, employment and careers – and suitable housing. It has to be a provincial priority.

This issue goes way beyond challenges with budgets, financial resources, and deficits. Nothing is more important than providing supports and services that guarantee quality life and good overall health for residents of our province. Nothing is more important. When reductions become necessary, when cuts are to be made, mental health supports and services must remain priorities that cannot be reduced or eliminated. Some things are just too important to family, to community, to life – some things will always be priorities because they are the “right things to do”.

Some may wonder why the Executive Director with Autism Society, Newfoundland Labrador, is speaking at a mental health forum. I speak because Autism Spectrum Disorder is a mental health concern.

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The standard criteria for diagnosing autism are found in the *Diagnostic and Statistical Manual for Mental Disorders (5th Edition)*, published by the American Psychiatric Society. The DSM-V refers to a set of conditions called Pervasive Developmental Disorders (PDD), connected by a symptom set including impairments in reciprocal social interaction and in verbal and nonverbal communication skills and by the presence of restricted, repetitive and stereotyped patterns of behaviour.

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These signs all begin before a child is three years old, and affect information processing in the brain. The three disorders known as the Autism Spectrum Disorders are autistic disorder, Asperger’s, and PDD-NOS.

The National Institute of Mental Health in the United States also includes ASD’s in their database of mental and psychiatric disorders.

The diagnosis of an ASD is made by an expert diagnostician or interdisciplinary team, based on the child’s developmental history and direct behavioural observation. This type of assessment requires a high level of training and experience on the part of the assessors. The diagnosis of an ASD is typically made by physicians - child psychiatrists and pediatricians, in particular.

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A very real concern for those with autism is co-morbidity. ***Co-morbidities*** are common, including eating disorders, schizo-affective disorders, gastro-intestinal disorders, epilepsy and mental health issues. Studies have repeatedly found that 80% of those diagnosed with autism also have depression and/or severe anxiety. While most people with autism are diagnosed early in their lives, autism is not a childhood disorder, contrary to popular myth. The prevalence of autism among males is higher than that for females; four out of five people with autism are male. People with autism enjoy the same longevity as people without autism.

Raising children and youth with ASD, and looking after adult sons and daughters with ASD, can be very stressful for parents and caregivers. Without the proper supports and services, including respite care, parents and caregivers can often suffer from poor mental health as well. Loss of employment, lost careers, broken marriages, lack of supports and services create the very concerns we are discussing here today.

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So, today I speak in my capacity as dad, educator, citizen – and autism advocate. ***Autism presents significant mental health concerns and this has to be recognized by the All-Party Committee.*** Autism is the fastest growing developmental disorder in Canada, and I believe it constitutes a public health emergency. Success with reducing the impacts of autism requires a strategy – a clear action plan, a commitment to resources and a timeline.

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The Autism Society presented to the Mental Health Commission four years ago, in 2011. We contracted MUN to complete a research project for us in 2012. ASNL completed a provincial *Autism Needs Assessment* in 2015. The Canadian Autism Spectrum Disorders Alliance (CASDA) has been working to secure the federal government's commitment to the development of a National Autism Action Plan. It completed Canada's first ever *National Autism Needs Assessment Survey* in 2014.

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Of particular interest for this Committee is that this CASDA study received a significant number of responses “directly” from adults with Asperger’s (Self-Advocates).

The level of mental health problems they reported was significant. Their identification of issues related to anxiety, depression, OCD and ADHD provides dramatic insight into the need for more mental health support services and transition planning for this group of individuals with ASD.

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Concerns and needs that were highlighted each time remain priority needs for the autism community in Newfoundland Labrador. We believe action on these priorities can significantly improve the mental health of those with autism and their families & caregivers. They include:

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1. Recognition of ASD as a mental health condition, and programs/services/supports are provided free of charge to families and adult individuals, as per the Canada Health Act;

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2. All children undergo an automatic screening & assessment between 24 and 36 months by Public Health within each Regional Health Authority (there are implications for training of Public Health Nurses) because diagnosis and early intervention is critical; we know it positively impacts the lives of individuals and families affected by autism;

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3. Better assessment and diagnostic capabilities that will flow from more personnel and more efficient means of assessment and diagnosis;

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4. Follow-up services in OT and SLP have unacceptably high waitlists (18+ months in Eastern Region; longer elsewhere); they must be available within a 3-month period following a diagnosis since they are important components of the critically needed early intervention;

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5. Establish a minimum number of hours of ABA Therapy to be provided, and, if delayed because of lengthy or late diagnosis, extend it beyond age 8 and/or the Grade 3 school year;

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6. Establish an adult clinic for ASD and other developmental delays in the province – none exists - and require that medical doctors accept adult referrals for the purpose of diagnosis and/or treatment;

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7. Provide better in-school supports, and more of them, and add to the criteria for Student Assistant Allocation, to ensure success with inclusion and student learning; provide comprehensive, in-depth regular training, as per a 3-year plan, for Regular Classroom Teachers, Instructional Resource Teachers, Pervasive Needs Teachers and Student Assistants;

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8. Establish and enforce a maximum number of days a student can be removed from the school setting because of behaviour and safety concerns; mandate timely implementation of specific Individualized Education Plans for return to school; when children are at home, provide ABA Therapy and Respite Care so parents do not have to give up employment and end their careers; provide regular school work to children who must stay at home;

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9. Alternate schooling has to become a reality and be provided if and whenever a child or youth is deemed too severe a safety risk to attend regular school;

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10. IEP Meetings, Transition Meetings between grades, schools and post-secondary schools and/or the workforce, and regulations around them, need to be included in legislation, in the School's Act; professionals have to be held accountable when and if there is non-compliance;

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11. Government must ***discontinue*** the discriminatory policy of using just an IQ test to deny services to people with autism; instead, add to the criteria an ‘adaptive functioning assessment’ to determine needs of children, youth and adults;

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12. Prepare a plan for independent living in the community for people with autism to the extent their abilities permit, and provide alternate community-based housing for individuals requiring it;

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13. Implement and fund the research-based, three-year Continuing Professional Development Plan (CPD) that ASNL presented to the Minister of Health & Community Services in the spring of 2013; the cost is \$300,000

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The Autism Society believes its proposed solutions will help. The 5 priority needs identified at the beginning, and again here now, are not cost-prohibitive and they will bring positive results for many with ASD who experience significant mental health challenges. These things are achievable in the near, medium and longer terms in the context of a provincial strategy.

In conclusion, priority solutions we believe can be immediately implemented are:

1. Screening of all children for autism between 30 and 36 months of age through the Public Health system
2. Addition of “medically diagnosed anxiety” to the criteria for allocation of student assistant support to students with ASD in inclusive classrooms
3. Development and implementation of a 3-year comprehensive action plan for effective training of all educators and Student assistants “in the field” about ASD and “best practice” teaching strategies
4. Ending the use of IQ 70 as the sole criteria for service provision to children, youth and adults and adding an “adaptive function measure” to remove the discrimination
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I sincerely thank members of the All-Party Committee for this opportunity. If there are any questions, I will be happy to try and provide more clarity.