CANADIAN PSYCHOLOGICAL ASSOCIATION

SOCIÉTÉ CANADIENNE DE PSYCHOLOGIE

Autism Brief to the Standing Senate Committee on Social Affairs, Science and Technology
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The Canadian Psychological Association (CPA) is pleased to have been invited by the Standing Senate Committee on Social Affairs, Science and Technology to contribute to its deliberations on the treatment of Autism in Canada. This brief will provide you with the position of the Canadian Psychological Association on the state of knowledge and treatment of Autism and Autism Spectrum Disorders. CPA's position is based upon the body of psychological knowledge that is central to the foundation of assessment and intervention in the field of autism and upon the research and practice roles and contributions psychologists have and continue to make along side our colleagues from other health professions and scientific disciplines.

In preparing this brief, we relied on the excellent literature reviews and treatment guidelines that have been prepared and referenced by the authors listed at the end of this document, most notably, the one prepared by psychologists, Drs. Adrienne Perry and Rosemary Condillac, for Children's Mental Health Ontario.

Definition: Autism is a pervasive developmental disorder, first identified by Kanner in 1943. Decades later, Autism came to be viewed as the more severe of the Autism Spectrum Disorders (ASD) which also include Asperger's Disorder. ASD is a heterogeneous disorder that includes a range of developmental impairments in the areas of social skills, verbal and non-verbal communication as well as restricted or repetitive interests or behaviours.

Prevalence and Etiology:

- Estimates of all Autism Spectrum Disorders range from 3 to 7 in 1000 persons with autism in particular ranging from 1-2 in 1000.

- Although there has been some concern about a rising incidence (i.e. new cases) of ASD, this appears attributable to the broader definitions of ASD as compared to Autistic Disorder, more awareness of ASD as well as more systematic assessments of the spectrum of disorders.

- The literature suggests that there appears to be a heritability factor in that siblings of persons with a diagnosed ASD are themselves at higher risk for the disorder.

- Boys with ASD outnumber girls by about 4:1. However, for the subset of children with ASD who also have profound cognitive impairment, boys and girls are represented in roughly equivalent numbers.

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- The age of onset for Autism is typically 1 to 3 years and is reliably diagnosed after age 2 years. The age of onset for Asperger's is later than 3 years and it is not typically diagnosed until the child is school-aged.

- Differential diagnoses can be complex when Autism is present in a child of higher intellectual functioning (e.g. it may be difficult to distinguish from Asperger's) and when other comorbidities (such as Tourette's Syndrome, Obsessive Compulsive Disorder, Attention Deficit Hyperactivity Disorder, other developmental or learning disorders) are present.

Symptoms and Impairments:

- Cognitive impairment is present in about 80% of persons diagnosed with Autism and general intellectual functioning is most often below average. Persons diagnosed with Asperger's Disorder have average to above average intellectual functioning.

- Visual spatial skills are a relative strength for persons with Autism and a relative weakness for persons with Asperger's.

- General motor skills are usually consistent with developmental level for those with autism but those with Asperger's present with motoric clumsiness.

- Verbal skills are a relative weakness for those with Autism and a strength of those with Asperger's. The more social functions of language are a weakness in both disorders.

- Although both Autism and Asperger's present with repetitive behaviour and interests, these are more likely repetitive physical movements in those with Autism and more likely repetitive verbal or cognitive behaviours and interests in those with Aspergers.

- Both disorders are characterized by what has been called a lack of 'theory of mind' – meaning a lack of understanding that others have mental states separate from one's own; an understanding that is necessary to the skills, like empathy, that are required of successful interpersonal interactions.

In sum, persons with ASD present with a wide range of impairments in cognition, language and behaviour which present in some common but reliably distinct ways between Autism and Asperger's disorders.

Assessment and Treatment

ASD research clearly indicates that children benefit from early screening, diagnosis and treatment. Screening and assessment should be empirically-based and include standardized measures of behavioural observation (e.g. social behaviour, problematic behaviours), cognitive functioning, developmental attainment, and medical investigations as appropriate. Assessments should take place across settings (e.g. home, school) and should include parental report and observation. Although screening and assessment often does and should involve a multidisciplinary team of health professionals, teachers, and parents, diagnosis is a restricted act in most Canadian jurisdictions and, in the case of autism, most often limited to physicians and psychologists.

The ASD popular and scientific literature is replete with many interventions advanced for the treatment of Autism and Asperger's Disorder. There are differences of opinion among parents, educators, scientists, and health professionals about treatment indications and effectiveness. The literature, however, gives a clear message that

- Treatments are not necessarily cures. Some reduce the severity of symptoms, some teach strategies to improve functioning and thereby quality of life, and some offer support to families.

- All treatments should be empirically-based.

- Consumers should inform themselves about the demonstrated effectiveness of any treatment they undertake for themselves or their children.

- When inquiring about treatment effectiveness, consumers should understand whether it has been shown to work (e.g. in controlled studies) and whether it works in the real world (i.e. whether it has been effective when used in clinical practice for persons with ASD).

- Treatments should be monitored for effectiveness on an ongoing basis.

- Treatments should involve, or take into consideration, the many settings and persons involved in the life of the child with ASD (e.g. home, school, parents, siblings, teachers, health practitioners).

- Some interventions advanced for the treatment of ASD or Autism appear more effective than others.

There is a variety of interventions, some delivered singly or in combination, that target one or more of the impairments characteristic of ASD. These include those that aim to improve the quality of social interactions, language and communication, sensory and motor functioning, and challenging or problematic behaviours (e.g. repetitive behaviours, aggressive behaviours).

A review of the treatment literature is beyond the scope of this brief (an excellent review is found in Perry and Condillac, 2003). However, a summary of effectiveness is as follows:

- some techniques to improve social interactions and communication have some demonstrated effectiveness (although some communication techniques such as facilitated communication appear ineffective and may be harmful),

- techniques that target sensory and motor functioning have not demonstrated effectiveness,

- positive behavioural supports have demonstrated effectiveness in reducing problematic and increasing more successful behaviour

- there is no one indicated medical treatment or cure for ASD, or any of their core symptoms, but some medications can help with specific symptoms and/or comorbid disorders and can facilitate the effectiveness of other behavioural treatments.

- psychotherapies, notably, Cogntive-Behavioural Therapy, may be of help to those persons with higher intellectual functioning in managing behaviour and redressing comorbid mood disturbance

In addition to the specific types of interventions listed above, delivered singly or in combination, there are comprehensive programs, specialized for treatment of ASD. These programs use a combination of interventions which collectively target educational and skill development as well as problematic behaviour and are most often delivered by multidisciplinary treatment teams.

There are many different comprehensive programs but all are geared to early intervention and most are behaviourally-focused. There is general consensus that these programs should be tailored to the individual needs of the child and should be evidenced-based.

One such programme is Intensive Behavioural Intervention (IBI). IBI, developed by psychologist Dr. OIvar Lovaas, is based on the psychological principles and techniques of applied behavioural analysis. IBI is

- an intensive intervention (administered 20 to 30 hours per week over the course of 1 to 2 years),

- based on and tailored to a child's individual needs,

- designed to reinforce and shape the behaviours necessary to developing and maintaining successful social, language and academic functioning.

- is typically carried out by specifically trained therapists, under the supervision of psychologists.

There are a variety of institutes, colleges and universities that offer training and certification in applied behavioural analysis upon which IBI is based. Among other comprehensive programs, IBI appears to have the strongest evidence base and is generally considered to be an effective intervention for ASD. Consensus Panels, groups of experts representing a range of disciplines as well as theoretical orientations, is the gold standard of how to undertake a literature review and

develop treatment guidelines for a specific condition or disorder. According to Perry and Condillac (2003), IBI and applied behavioural analysis are consistently endorsed by Consensus Panels on ASD.

In addition to the interventions and intervention programs described above, there is evidence that the families, and in particular the mothers, of children with ASD experience significant stress, depression and other mental health difficulties in comparison to the families of children with other or no disabilities. There is a need for intervention to help children and families cope with the stressful and emotional consequences of this pervasive disorder. In addition there is an especial need to support both the child with ASD, and his or her family, at important transition points – from pre-school to elementary school, elementary to high school, high school to further study and/or early adulthood.

The unique stressors of ASD in comparison to other kinds of disabilities include

- a poor understanding of the disorder by the general community
- its symptoms can be very socially disruptive and lead to public discomfort
- the behaviour of an autistic child, when witnessed by others, often results in blaming parents and parenting for the child's behaviour – in effect creating considerable social stigma
- lack of access to prompt and accurate assessment and treatment

Challenges and Opportunities

Research: More funding is needed to support more research into the causes and etiology of ASD – one of the best results of which will contribute to the early and reliable identification and diagnosis of a spectrum of disorders which appears best redressed by early intervention. However, even if a definitive biomedical cause of ASD is demonstrated, it is likely that, as is the case for many genetically or biochemically determined brain disorders, people are left with a disorder of clearer etiology that still has to be lived with and managed. For this reason, research into the development and refinement of psychological, psychosocial, psychoeducational, and communicative treatments for ASD needs equivalent funding and support.

Treatment: At present, there are single and comprehensive psychological treatments for ASD for which there is an evidence base of effectiveness. It is clear that there is no single treatment, medical or psychological, which promises to cure ASD or which is the single best treatment of choice for everyone diagnosed with an ASD. Although the comprehensive behavioural programs, like IBI, appear to have the best demonstrated effectiveness, they are targeted for young children and are not necessarily the treatment of choice for older youth or adults or those with Asperger's Disorder. That being said, early identification and treatment for ASD may well result in a lesser need for service and intervention in later life.

It is important for the Committee to consider that the treatments that appear most effective for persons with ASD – disorders which have pervasive effects on individual's functioning and quality of life – are not the medical ones required by the Canada Health Act or those consistently provided by the country's public health insurance plans.

These treatments, although publicly funded in some jurisdictions (e.g. British Columbia, Manitoba, Prince Edward Island, Alberta, Ontario, Quebec and the Yukon), often provide insufficient coverage, for an insufficient period of time or amount of intervention. Wait lists for publicly funded service are long and it is still possible that, in some jurisdictions, when one's name comes to the top of the wait list for treatment, one is beyond the age eligibility requirement for the publicly funded service. Although families can and do pursue treatment provided outside the public sector, they do so at tremendous personal cost in the tens of thousands of dollars.

The Canadian Psychological Association's concern about Canada's health care system has long been that our jurisdictions fund designated providers rather than needed service. In other words, the public system will pay for most services provided by physicians, no matter where they practice or will pay for the services provided by other health care practitioners if they are a salaried resourced of public institutions like hospitals, schools, and correctional facilities. However, our public health care system does not pay for the service indicated and needed by a patient with a particular problem. In the current instance, the system does not cover the best available treatment for the ASD because this treatment, although clearly a 'health' treatment (i.e. psychologists are regulated health service providers) is not a 'medical' treatment.

In CPA's view, the barriers to accessibility of treatments for ASD are a severe and expensive instance of the many mental health treatments that are not funded by our country's health systems. Psychologists are the single largest regulated group of specialized mental health service providers in the country. The science and practice of the profession of psychology forms the basis for many of the best treatments for many mental health conditions and disorders and yet the services of psychologists are not accessible to many Canadians.

By 2010, approximately 70% of psychological services will be provided by psychologists in private practice and therefore outside of the publicly funded system. The increase in private versus public practice of the country's psychologists is not driven by the profession but rather by funding cuts and decisions made by the publicly-funded institutions which have historically employed psychologists. CPA's concern about the public's access to service is not to ensure more work for psychologists – the country's private practitioners tell us that they are amply self-employed, many with wait lists for their privately-provided services – but rather to meet the mental health needs of Canadians.

Canada needs an action plan for mental health, including diseases and disorders of mental function. The Canadian Psychological Association supports the establishment of a mental health commission that can be charged with this plan.

CPA's Answers to some of the Committee's questions

- Are there effective treatments for ASD? Yes, there are treatments with demonstrated effectiveness but further refinement and development in the form of funded and supported research is needed.

- Should Canada fund the best-indicated and non-medical treatment for this severe and disabling disorder? Yes, we have a responsibility to provide people with the health care they need, not just the health care that has been historically available. We need a health care system that covers needed treatments rather than only treatments provided by designated providers.

- Are there barriers to accessing treatments for ASD? Yes, the barriers are related to cost and availability of needed and indicated treatment delivered by, or under the supervision of, trained and regulated health care providers.

- Should funding be provided based on demonstration of treatment effectiveness? Yes. There are treatments and treatment programmes for ASD which have demonstrated effectiveness and these should be funded. However, funding should not be provided based on demonstration of treatment effectiveness for ASD any more or less than it should be for the treatment of any other health condition. Health care providers are regulated in this country and by virtue of regulation are required to meet rigourous standards of education and continuing education and to meet the professional standards of practice within their stated areas of competence. It is the responsibility of the regulatory bodies of the country's health professionals, bodies which are accountable to the public, to ensure that practitioners meet professional standards of evidence-based treatment. It is not the responsibility of publicly or privately funded insurers. To this end, treatments for any disorder should have clear and consistent guidelines and should be delivered by, or under the supervision of, regulated health care practitioners. It is the position of the CPA, that there should be national standards for the training of behavioural specialists providing treatment of ASD and that they should themselves be, or be supervised by, registered psychologists.

- Who should provide screening, assessment and treatment of ASD? Screening, assessment and treatment of ASD should be a multidisciplinary collaboration among parents, teachers and health care providers. Although the act of diagnosis is controlled in many jurisdictions, and thereby limited to physicians and psychologists, parents and other health professionals (e.g. speech language pathologists, occupational therapists) play important roles in screening, assessment and treatment. It is CPA's position that all health care should be delivered by regulated health care providers or by providers who work under the supervision of regulated health care providers. Standardized assessment measures, as well as the behavioural interventions that have shown the most effective for persons with ASD, are principally psychological ones and, in CPA's view need to involve health care providers, with training in the area of autism, who are either psychologists or who work under the supervision of psychologists. Other assessments techniques, interventions and components of interventions should similarly require the involvement of

the regulated health care practitioners whose training and scope of practice include them (e.g. medical tests and medication administered by a physician, speech-language intervention administered by a speech-language pathologist)

- Where should treatment be provided? Children and people live in and across many sectors and service should be accessible and coordinated across these sectors. In the instance of early intervention for children with ASD, the literature suggests that the many people (i.e. parents, teachers, siblings, health care practitioners) and settings (i.e. home, school community) involved in the life of the child with ASD need to be involved in successful and comprehensive treatment programs. Treatment should be provided in the venue or venues where they will have the biggest impact and afford some degree of flexibility in meeting the unique needs of the child, his or her family and environment.

In closing, the CPA commends the Standing Senate Committee for the attention it is turning to conditions of mental function and, in particular, to Autism Spectrum Disorders. We hope that our input will receive your earnest consideration as you deliberate this important health issue. We remain available to you for further information or assistance.

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