“Your Attention, Please”:

Improving Access for ADHD Patients

A Policy Paper by BC’s Physicians | February 2009

BRITISH COLUMBIA MEDICAL ASSOCIATION

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A Call to Improve Access to Care for ADHD Patients

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Introduction

It was arguably the greatest story from the 2008 Olympic Games. American swimmer Michael Phelps took home a record-breaking eight gold medals, setting multiple world records in the process. Although the feat itself would have earned the attention of the entire world, it was even more remarkable given his background, for mentioned in nearly every news story about his successes was the fact that Michael suffered from Attention Deficit/Hyperactivity Disorder (ADHD) (Bagnall 2008; Winerip 2008).

ADHD is a chronic behavioural disorder with symptoms including hyperactivity, impulsivity, and inattention, and it is associated with sometimes severe impairment in functioning at school, in social settings, and at work. Current research suggests the disorder is approximately 80% genetic and 20% a product of one's environment (Faraone and Khan 2006).

ADHD is a chronic behavioural disorder with symptoms including hyperactivity, impulsivity, and inattention.

Phelps' success in overcoming ADHD to swim to Olympic victory will certainly bring additional attention to the disorder. There has been scepticism around ADHD (Stevens 2007) – despite being perhaps the most well researched childhood psychiatric disorder (Pliszka 2007) and supported by evidence of its neurological basis (Arnsten 2006). This may have led policymakers to place greater emphasis on other mental illnesses.

As resources and attention are devoted elsewhere, ADHD patients experience two main difficulties in accessing care for their condition:

1. Too few cases of ADHD are recognized. The prevalence of ADHD is estimated at 2-9% of the population (Pelham, Foster et al. 2007). Using a conservative prevalence of 3.3% and a child and youth (4-17) population estimate of 936,500 from 2002, BC's youth ADHD population was estimated to be 30,900 (Ministry of Children and Family Development 2003). In a 2007 study of US children, Froehlich et al. found that less than half of children meeting DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, fourth edition) criteria report receiving either a diagnosis of ADHD or regular medication treatment.

Too few cases of ADHD are recognized … too few ADHD patients can be treated appropriately.

2. Too few ADHD patients can be treated appropriately. In Canada, it takes more than 18 months for a patient with ADHD to be treated after first contact with a physician (World Federation for Mental Health 2004). Once diagnosed, only half of children and as few as 11% of adults receive treatment (Kessler, Adler et al. 2006; Reich, Huang et al. 2006). As the waitlist for the BC Children's Hospital ADHD Clinic shows, demand for such services greatly exceeds supply.

The resulting health, social, and economic consequences are larger than many would assume. Children with ADHD are prone to delinquency, crime, substance abuse, teen pregnancy, and traffic accidents, as well as a decrease in workplace effectiveness (Matza, Paramore et al. 2005). Among adults, impairment from ADHD can lead to additional missed work days, difficulty accomplishing tasks in the workplace, and less job stability (Birnbaum, Kessler et al. 2005; Matza, Paramore et al. 2005). Taking into account the direct health, education, and justice-related costs associated with ADHD, the total costs to the government of British Columbia may exceed $500 million each year – enough money to pay for nearly half of BC's $1.061 billion PharmaCare budget or more than all of the Ministry's capital plan budget for 2008/09 (Ministry of Health 2008).

Such economic, social, and health costs are unnecessary. While ADHD itself is not preventable, the negative consequences stemming from the untreated disorder are. Research suggests that evidence-based behavioural and pharmacological interventions can reduce the incidence of criminality, school drop-out, and substance abuse among those suffering from ADHD (Wilens 2003). The burden of ADHD can be reduced, but only once access to care is improved.

This policy paper on ADHD will propose ways to improve access to care for patients with ADHD. The first section begins by reviewing the economic and social costs of the disorder, followed by an examination of provincial policy and the delivery of care in British Columbia. The paper continues with a discussion of quality of care issues and concludes with recommendations for government and other health care stakeholders.

Economic and Social Costs of ADHD

ADHD poses a significant economic and public health burden. Research has demonstrated that, on average, people with ADHD access health care services more frequently, require special educational services, and possess elevated rates of other psychiatric conditions such as anxiety and oppositional defiant disorder (Matza, Paramore et al. 2005). Further research has indicated that as they enter adolescence and adulthood, they are prone to delinquency, crime, substance abuse, teen pregnancy, and traffic accidents, as well as a decrease in workplace effectiveness (Matza, Paramore et al. 2005).

Preliminary research also found that persons with ADHD have almost a three-fold increased risk of committing suicide (James, Lai et al. 2004).

These data translate into significant direct and indirect costs to the health care, education, and justice systems:

- ***Health costs.*** Health costs associated with ADHD are typically separated between pharmacological and other health care costs including physician fees, psychosocial mental health treatments, and hospital services. According to a review of the economic burden of ADHD published in 2007 by Pelham et al., the mean cost of pharmacologic therapy in the United States is US$459 per patient (Pelham, Foster et al. 2007). Studies of health care costs other than medication range from US$438 per year (Matza, Paramore et al. 2005) to US$1,580 per year (Birnbaum, Kessler et al. 2005). Average total health care costs associated with children with ADHD in the United States total US$2,636 per year.

- ***Education costs.*** ADHD is the most frequently encountered behavioural challenge in the classroom (Pelham, Foster et al. 2007). Children with ADHD are prone to poor academic achievement, disruptive classroom behaviour, and learning disabilities. Several American studies have examined educational costs linked to ADHD, with one finding that the average incremental annual cost to educate a child with ADHD from kindergarten to grade 12 is more than 18 times that of non-ADHD children (Pelham, Foster et al. 2007).

- ***Justice system costs.*** Much of ADHD's cost of illness stems from costs linked to criminal behaviour and the resulting burden on the justice system (Pelham, Foster et al. 2007). Longitudinal studies in the US have correlated ADHD with a significantly higher juvenile arrest rate of 46%, versus 11% among a control population. Similarly, adults with ADHD were found to have a 21% chance of having been arrested in the past, versus just 1% among normal control subjects (Matza 2005). One study estimated the economic impact of criminality associated with ADHD during adolescence and teenage-years at $12,868, versus $498 for controls (Matza 2005).

- ***Adult ADHD.*** ADHD in adulthood is linked to poorer job performance, an average of 35 annual absences from work (Birnbaum 2005), lower educational achievement, lower occupational status, and less job stability compared to adults without the disorder (Matza 2005). A preliminary and limited estimate of the cost of adult ADHD posited a cost of US$31.6 billion per year (Birnbaum, Kessler et al. 2005). Pelham projected a rough estimate of total annual US costs of the entire lifespan of individuals with ADHD at US$74.1 billion (Pelham et al).

There are some gaps in the research on the costs of ADHD. The costs associated with significant ADHD sequelae such as substance abuse, for example, remain unknown (Pelham 2007), as do the

inherent and likely widespread costs involving parental stress and family dysfunction associated with the disorder.

However, even without including the above, the costs of ADHD are high and significant, particularly in relation to major chronic diseases and mental health disorders. In the United States, ADHD's total annual costs of US$42.5 billion are closely comparable to major depressive disorder (US$44 billion) and stroke (US$53.6 billion) (Pelham, Foster et al. 2007).

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Taking into account health, education, and justice-related costs from thirteen separate analyses, Pelham et al. determined the mean annual cost of illness of ADHD to be $14,576 per child in 2005 US dollars. Assuming a prevalence of 5%, this translates to US$42.5 billion. Using a prevalence of 4.5% for ADHD in British Columbia (MCFD 2003), there are roughly 42,000 British Columbian children with ADHD. If one assumes a conservative, per-person annual cost of C$10,000 per person with ADHD, the total costs to the BC government would be $420 million every year. Less conservative estimates would push this figure well beyond half a billion dollars per year.

Provincial Public Policy and Funding for ADHD

Responsibility for ADHD is divided among several government ministries in British Columbia. The Ministry of Health Services (MoHS) funds research, parent education, physicians' services and tertiary care for ADHD. BC Mental Health and Addiction Services (MH&A), an agency of the Provincial Health Services Authority, is responsible for the child and adolescent mental health and addiction programs, including BC Children's Hospital ADHD Clinic. However, it is the Ministry of Children and Family Development (MCFD) that is most responsible for children's mental health policy and ADHD. The MCFD funds and provides services primarily through interventional programs and community based inter-disciplinary mental health teams, intended to support patients transitioning from traditional physician and tertiary care.

Through these ministries, the government of British Columbia spends substantially more on mental health services compared to other Canadian provinces: 6.4% of total provincial health funding is spent on mental health, compared to the national average of 4.8% (Jacobs, Yim et al. 2008). In addition, the government has acknowledged that childhood is a critical time to prevent mental illness and now allocates 15% of child mental health resources towards prevention (McEwan, Waddell et al. 2007).

These are very positive steps. However, the division of ministerial responsibility has led to a fragmented strategic direction for ADHD and other children's mental health issues. To address this problem, an Inter-ministerial Child and Youth Mental Health Network was formed, which includes

representation from the ministries of health, education, children and family development and other relevant stakeholders. Its mandate is to "… facilitate inter-jurisdictional service coordination and planning for child and youth mental health service delivery" (Ministry of Children and Family Development 2008). However, meeting just four times per year, the network has been severely limited in its ability to deliver tangible outputs. To the extent that improvements in the access to and the quality of health care services for ADHD patients depend upon a coordinated effort across ministries, progress with the network is essential. For this reason, the BCMA recommends that the network be restructured to meet more frequently, supported with an adequate budget, and responsible for producing tangible outputs outlined in a publicly-available strategic plan.

Recommendation 1

The provincial government must restructure the Child and Youth Mental Health Network so that it meets more frequently, is supported with an adequate budget, and is responsible for producing tangible outputs outlined in a publicly-available strategic plan.

Even within the context of a strengthened Child and Youth Mental Health Network, it is possible that ADHD will remain a lower-priority mental illness. In 2003 the MCFD introduced a 5-year "Child and Youth Mental Health Plan for BC" (CYMH Plan). Its major emphasis was the delivery of community-based care and prevention and early intervention strategies (Ministry of Children and Family Development 2003). The plan was implemented in concert with a doubling of the budget for the Child and Youth Mental Health Services branch of the MCFD from $43 million to $87 million. ADHD was largely absent within the implementation of the CYMH Plan. Illness-specific interventions were instead focused on anxiety and depression – which a 2008 progress report mistakenly cited as the two most prevalent child psychiatric disorders[1] (Ministry of Children and Family Development 2008). Similarly, while the MoHS and MCFD have funded provincial strategic plans for anxiety, depression, suicide, fetal alcohol syndrome, substance abuse, and early psychosis, there is currently no specific strategic direction for ADHD (BC Ministry of Health Services 2008). Therefore, in addition to implementing changes to the Child and Youth Mental Health Network, the government must also work with stakeholders to create a new 5-year child mental health plan, including a strategic plan for delivery of services for patients with ADHD, no later than June 2009.

[1] While anxiety is the most prevalent disorder, ADHD is actually the second most prevalent, and depression is fourth. See Waddell et al., 2007.

Recommendation 2

The provincial government should work with stakeholders to ensure that any new child mental health plan includes a strategic plan for the delivery of services specifically for patients with ADHD.

One consequence of the lack of strategic direction has been the reduction in services offered to patients with ADHD through the province's sole centre for ADHD diagnosis and treatment initiation at BC Children's Hospital (the ADHD Clinic):

- In 2004, $150,000 was allocated to the Clinic as part of a three-year pilot project to help meet the burgeoning need for adult ADHD assessment and treatment. The demand proved so high that the clinic's waitlist rapidly lengthened to 14 months. Although the pilot continued beyond the 3-year term (it was agreed that ethically, adults who had been referred and accepted prior to the end of the three-year term should be provided an assessment and offered group therapy), new referrals and requests for re-evaluation were not accepted. Today, the PHSA offers no similar service for adults with ADHD or follow-up for the children who graduate from the ADHD clinic at age 18.
- In 2006, each division of child and youth psychiatric care administered by the PHSA, except for the ADHD clinic, included in the MH&A business plan a proposal for additional funding from the government. By 2008, funding for 2.3 full-time equivalent employees at the ADHD clinic ended, despite evidence of very high ongoing demand for the clinic's services. Data from 2004-2005, for example, indicated that of all ambulatory clinics, ADHD received the highest number of referrals (643), had the highest number of patients on the waitlist (78), and had the second longest wait-time at 3.5 months (MH&A 2006).

To guarantee that the needs of all ADHD patients are met, the government must provide services for adults with ADHD and follow-up for children who graduate from the ADHD clinic at age 18. This can be done by either expanding the mandate of the clinic to encompass children, youth, and adult patients, or by offering similar services for adults in another setting. In either case, funding for these services should be increased to ensure a maximum waitlist of three months for ADHD patients, regardless of age.

Recommendation 3

The provincial government must provide services for adults with ADHD and follow-up services for children who graduate from the ADHD clinic at age 18.

Recommendation 4

Funding for ADHD services should be increased to guarantee waitlists of less than three months for all ADHD patients.

Traditionally, there have been many financial disincentives to physicians wishing to provide optimal care for ADHD patients, in large part because diagnosing ADHD is a lengthy process. A Health Canada Survey indicated that an average of 69 minutes of assessment and 47 minutes of administration are required to diagnose ADHD (HealthCanada 1999). Recently, however, steps have been taken to improve compensation. Changes to the BCMA Fee Guide allow general practitioners to bill four $100 "mental health planning fees" per patient per year, and four $50-$65 follow-up fees (BCMA 2007). For a pediatrician, a $344 "complex behavioural" fee can be billed for a detailed battery of assessments and exams. These fee changes are an important first step in decreasing financial barriers to optimal care (BCMA 2008).

While a significant improvement, these new fees do not address the disincentive for physicians to communicate with schools. Ideally, prior to diagnosis, a physician would speak with a teacher. Then, after initiating treatment, the physician would be in close communication with the child's teacher to ensure the correct dosage is being used, and to monitor side-effects (Leslie and Wolraich 2007). This practice is evidenced to help improve outcomes over standard care (MTA Cooperative Group 1999). Yet in reality this does not happen, as busy physicians are not compensated for such a time-consuming practice. Ultimately, assessment and treatment of ADHD in private primary care practices is poorly remunerated because it is a time-intensive activity associated with considerable indirect care and poor compliance. A billing fee for consulting with third parties, such as teachers, should be added to the BCMA Fee Guide to encourage optimal coordination with teachers in the diagnosis and management of ADHD. Such a fee would be similar to the current patient management conference fee for psychiatrists.

Recommendation 5

A billing fee for consulting with third parties, such as teachers, should be added to the BCMA Fee Guide to encourage optimal coordination with teachers in the diagnosis and management of ADHD.

Quality of Care

In a 2005 survey of British Columbians with mental health needs, 76.3% indicated that 'acceptability of services' was the greatest impediment to care (MHECCU 2005). However, patients with ADHD, their families, and their physicians face additional challenges beyond those experienced by patients with other mental illnesses, including a lack of national guidelines on the treatment of ADHD, inadequate public coverage of ADHD medications, and poor coordination among providers of care for ADHD patients.

The process of diagnosing ADHD can be difficult since there is no definitive diagnostic test. Canadian surveys indicate that 70% of physicians believe there are too few properly qualified diagnosticians for ADHD and that physicians in general are not well informed about standard

diagnostic criteria (HealthCanada 1999). Indeed, the peer-reviewed literature demonstrates that highly variant diagnostic practices exist (Chan, Hopkins et al. 2005). The prospect of long-term psychoactive medication hinging on variant diagnostic practices is a significant problem.

Research suggests that while there is no evidence of the rampant over-diagnosis some fear, misdiagnoses do occur, as do 'missed' diagnoses (Goldman, Genel et al. 1998). In an effort to improve diagnostic practices, in 2001 the American Academy of Pediatrics implemented official guidelines for the assessment and diagnosis of ADHD, and offered ADHD training to all physicians. In conjunction with the guidelines, in primary care offices across America, the AAP implemented what is referred to as a 'diagnostic toolkit' which standardized the method of gathering diagnostic information and the DSM assessment checklists to be used in diagnosis (Leslie, Weckerly et al. 2004).

In Canada, no guidelines have been officially endorsed by the medical professional associations. National experts in ADHD (e.g., Canadian ADD Resource Alliance) have developed consensus guidelines and a 'diagnostic toolkit', but they have not been acknowledged as the national standard of care (Edmunds 2008). Therefore, the BCMA calls upon health professional associations for pediatrics, child psychiatry, psychiatry, neurology, and family practice to endorse CADDRA's ADHD practice guidelines or review, amend and then endorse revised CADDRA guidelines. In concert with the guidelines, a diagnostic toolkit for ADHD should be implemented in primary care offices across British Columbia. Such a toolkit might include, for example, standardized teacher and parent DSM-based assessment sheets; standardized sequence and method for distributing and gathering assessments and booking a series of appointments; and a clear delineation of available community resources and referral process, perhaps in collaboration with the developing Community Health and Resource Directory (CHARD) (Brown and DeSandoli 2008).

Recommendation 6

Medical professional associations for pediatrics, child psychiatry, psychiatry, neurology, and family practice should endorse the Canadian Attention Deficit Disorder Resource Alliance (CADDRA) ADHD practice guidelines; or review, amend, and then endorse revised CADDRA guidelines. Such guidelines should be accompanied by the implementation, in primary care offices across British Columbia, of a 'diagnostic toolkit' for ADHD.

Simply writing a prescription for ADHD is woefully insufficient care, and practice guidelines universally acknowledge that treatment of ADHD with medication must be accompanied by psychoeducation about the disorder, appropriate environmental accommodations, and behavioural intervention. Prescription of medication without additional support has been shown to be associated with poor compliance, persistence and community-based outcomes (MTA 1999). Within a year, almost 50% of parents discontinue their children's medication (Firestone 1982).

One factor influencing non-compliance is pills that must be taken multiple times per day. Research demonstrates that "once daily" formulations improve compliance by 32% (Swanson 2003). Currently, MSP covers short- and intermediate acting ADHD stimulant medication (4-6 hour or 6-8 hour effectiveness) that must be taken two or three times daily, forcing children to experience bursts of symptom rebound as the medication wears off. They must also take the pill at school, which necessitates coordinating supervision and may lead to stigmatization and embarrassment. Missing a dose equates to losing an afternoon of focused learning. Medications that can be taken once daily, with efficacy comparable to those requiring more frequent dosing, exist but are not covered by BC PharmaCare (i.e., long-acting medications with 12-24 hour effectiveness). These once daily formulas are typically 25% more expensive. However, the most expensive covered short-acting medication – dexedrine spansule – is actually more expensive than the least expensive long-acting medication, Biphentin.[2] Saskatchewan, Ontario, and Quebec have already approved coverage or restricted access to long-acting ADHD medication, as have Australia and other countries around the world.

Recommendation 7

PharmaCare should expand coverage for long-acting ADHD medication in order to facilitate compliance, minimize stigma and prevent missed opportunities for focused learning.

In Canada, according to research performed by the World Federation for Mental Health, from the first point of contact with a physician it takes 1.59 years to receive treatment for ADHD (World Federation for Mental Health 2004). In the US, it takes an average of one year. Such a wait time must be taken seriously, given children's rapid development and the consequences of falling behind academically.

Understandably, this is greatly frustrating to physicians who feel that they are forced to over rely on medication rather than refer patients and families to parent training, proper psycho-education, or other appropriate expert consultation when needed. Similarly, some patients feel that physicians are not sufficiently informed about alternative resources and treatment options. The failure to coordinate comprehensive care inevitably leads to patient frustration, lack of treatment, and noncompliance.

Acknowledging the important role for community-based care in managing ADHD, MCFD's 2003 Mental Health Plan stated:

> "ADHD is best managed in community settings by multidisciplinary child and youth mental health teams where possible, working together with families, schools, family physicians, and others in the community as needed" (Ministry of Children and Family Development 2003).

[2] Based on July 9, 2008 prices in Vancouver.

Nonetheless, other mental health disorders such as psychosis, anxiety, and depression often supersede ADHD. Many Health Authority mental health teams do not consider ADHD as part of their mandate. The common misconception that there is little to offer children and families with ADHD beyond medication also prevents effective community-based care. Ironically, the service designed to improve transitions from physician services and coordinate access to care is not itself accessible. In order to improve access to services for ADHD patients and foster the kind of collaborative care arrangements necessary to provide optimal care, both the MoHS and MCFD should train specialized ADHD clinicians for mental health teams and provide BC families access to community services to complement treatment by physicians.

Recommendation 8

In order to improve access to services for ADHD patients and foster the kind of collaborative care arrangements necessary to provide optimal care, both the Ministry of Health and Ministry of Children and Family Development should train specialized ADHD clinicians for mental health teams and provide BC families access to community services to complement treatment by physicians.

Conclusion

When Olympic swimmer Michael Phelps was in the fifth grade, his mother and physician discussed whether he might have ADHD. A string of disciplinary issues at school and his inability to concentrate led them to consider that his problems went beyond those of an ordinary, high-energy child. At age nine, he began taking Ritalin. Two years later, again after having consulted their family physician, Michael's mother agreed to take him off the medication. The stigma of going to the school nurse's office to take a pill at lunch was too great, and Michael had asked to stop taking them. By that time, Michael's talents were becoming obvious to his swimming coach, and plans were being laid for his participation in the Olympics.

Michael's condition was correctly diagnosed, treated, and managed by a physician and his family such that they removed whatever barriers it might have placed before his potential successes. While few BC children and adults with ADHD will excel as far in their field as Phelps has in his, all should expect that they, too, will be able to access the health care services necessary to manage their condition. BC has already taken several positive steps, including, for example, increasing funding for mental health services and the creating of the Child and Youth Mental Health Network. By continuing down this path and giving ADHD the kind of attention currently devoted to other mental health issues, we will enable many British Columbians to realize their fullest potential.

LIST OF RECOMMENDATIONS

1. **The provincial government must restructure the Child and Youth Mental Health Network so that it meets more frequently, is supported with an adequate budget, and is responsible for producing tangible outputs outlined in a publicly-available strategic plan.**

2. **The provincial government should work with stakeholders to ensure that any new child mental health plan includes a strategic plan for the delivery of services specifically for patients with ADHD.**

3. **The provincial government must provide services for adults with ADHD and follow-up services for children who graduate from the ADHD clinic at age 18.**

4. **Funding for ADHD services should be increased to guarantee waitlists of less than three months for all ADHD patients.**

5. **A billing fee for consulting with third parties, such as teachers, should be added to the BCMA Fee Guide to encourage optimal coordination with teachers in the diagnosis and management of ADHD.**

6. **Medical professional associations for pediatrics, child psychiatry, psychiatry, neurology, and family practice should endorse the Canadian Attention Deficit Disorder Resource Alliance (CADDRA) ADHD practice guidelines; or review, amend, and then endorse revised CADDRA guidelines. Such guidelines should be accompanied by the implementation, in primary care offices across British Columbia, of a 'diagnostic toolkit' for ADHD.**

7. **PharmaCare should expand coverage for long-acting ADHD medication in order to facilitate compliance, minimize stigma and prevent missed opportunities for focused learning.**

8. **In order to improve access to services for ADHD patients and foster the kind of collaborative care arrangements necessary to provide optimal care, both the Ministry of Health and Ministry of Children and Family Development should train specialized ADHD clinicians for mental health teams and provide BC families access to community services to complement treatment by physicians.**

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