



# ADHD – diagnostics and treatment, organization of the health care and patient involvement

YELLOW REPORT | A SYSTEMATIC REVIEW

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## Executive summary

Attention deficit hyperactivity disorder (ADHD) is a condition that is not usually classified as a disease, but as a disability with childhood onset. The core symptoms are difficulties with attention, impulsivity and hyperactivity. The condition typically involves significant impairments that can persist into adulthood. The prevalence of ADHD among school children is estimated to be 3 to 10 per cent depending on how the diagnosis is applied. Approximately 3 to 4 per cent of the adult population is estimated to have ADHD.

### Purpose

Here we summarize the main conclusions from a comprehensive systematic literature review published only in Swedish: ADHD – diagnostik och behandling, vårdens organisation och patientens delaktighet. This report comprehensively examines the scientific evidence regarding the diagnosis and treatment of ADHD for both children and adults. It assesses the reliability of diagnostic tools, as well as the effectiveness and side effects of both pharmacological and non-pharmacological treatments. It examines how the treatment of ADHD should be managed by the health care system. The report also addresses the social and ethical aspects of ADHD treatment and diagnosis, including patient empowerment issues.

### Conclusions

- ▶ **Current data suggests that the diagnosis, treatment and monitoring of ADHD should continue to be handled by specialists.** Studies are needed to determine how health care and society's efforts should be organised and coordinated to best help those with ADHD. The diagnostic instruments used to diagnose ADHD also need to be better studied. It is also important that drug treatment is monitored in order to control the effects and side effects, and to minimise the risk of the drugs being distributed outside the patient group. Taken together, this indicates that diagnosis,

treatment, and monitoring of ADHD should remain within specialist care.

- ▶ **Many different non-pharmacological interventions and treatments are currently in use, but our understanding of their benefits, risks, and costs need improvement.** Of the 30 different non-pharmacological methods for treating ADHD identified in this report, we were unable to find sufficient scientific evidence to assess the efficacy of any. Cognitive behavioural therapy may be effective when provided as an adjuvant therapy to adults with ADHD who have persistent symptoms despite drug treatment. However, even this must be confirmed by independent studies.
- ▶ **Both methylphenidate and atomoxetine relieve ADHD symptoms during short-term treatment (3 weeks to 6 months) of children and adults with ADHD** (Moderately strong scientific evidence ⊕⊕⊕○). Due to a lack of studies assessing long term effects, it was not possible to assess the effects of prolonged treatment (>6 months). The same applies to assessing whether the risk of substance abuse in adulthood is effected in individuals who have been treated with central nervous system stimulants as a child. There was also insufficient evidence to determine the efficacy of drug treatments for individuals with any form of addiction.
- ▶ Common side effects during short-term treatment with atomoxetine that have been documented in clinical trials include nausea and loss of appetite. For children, weight loss and pulse rate increase are also common side effects. For adults, dry mouth and erectile dysfunction are common side effects. The primary side effect of methylphenidate is loss of appetite. Abdominal pain is a typical side effect for children. Common side effects for adults in-

clude loss of appetite, nausea, dry mouth, sleep disorders, headaches, and weight loss (Limited scientific evidence, ⊕⊕○○).

- ▶ Schools and health care providers should work to empower individuals with ADHD and their families, as well as help them develop better social support. Although there is no available research indicating how this can be best achieved, we know that the families of children with ADHD as well as adults with ADHD feel alienated and largely lack sufficient social support. It was also documented that the parents<sup>1</sup> of children with ADHD feel dependent on healthcare providers, while having misgivings about treatment options, and feeling frustrated over poor service and lack of influence over their situation.
- ▶ Both parents<sup>1</sup> and school staff feel they are insufficiently informed about ADHD, which could affect their attitudes and limit their ability to influence the situation in a meaningful way. Medicating children with ADHD leads to mixed feelings of both relief and doubts among parents<sup>1</sup>. Both adults with ADHD and parents<sup>1</sup> of children with ADHD feel that medication alone is not sufficient, even if the medication is effective.

## Knowledge gaps

Within the scope of this review, a large number of knowledge gaps have been identified. Here are some of the most important:

- None of the diagnostic instruments used in Sweden today are sufficiently studied.
- There is a lack of available evidence regarding the efficacy and side effects of non-pharmacological treatments for ADHD. This also applies to various types of combination therapies.
- The long-term effects and side effects of ADHD drugs have not been sufficiently studied.
- It is unknown how health care and society's efforts should be managed to most effectively help people with ADHD.
- How individuals with ADHD perceive their overall care has not been researched for any patient group: including children, adults and the elderly. The gender aspects of ADHD are largely unexplored.

<sup>1</sup> Most studies only included data from the mother's perspective when reporting parental outcomes.

## Ethical and social aspects

- People with ADHD are a vulnerable group, in many cases with limited autonomy. They risk impaired function in terms of social interaction, education and professional life, and thereby social exclusion. An early diagnosis creates opportunities for individualised support and treatment, which may reduce the risk of problems later in life.
- Treatment with central nervous system stimulants is controversial. Many people ask themselves if administering central nervous system stimulants to children, adolescents and adults with ADHD may eventually lead to addiction, and whether the treatment can be helpful for those also suffering from an alcohol or drug addiction. This group, which also includes people within the criminal justice system, belongs to the most marginalised and difficult to treat in our society. There is also a risk of illegal distribution of prescription central nervous system stimulants. The scientific basis for answering these questions is insufficient.

### Project group

#### Diagnosics and treatment

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#### Organisation of the health care

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SBU: Nasim Farrokhnia (project director may 2010–november 2010), Agneta Pettersson (project director november 2010–october 2012), Maria Ahlberg, Derya Akcan, Thomas Davidson, Sofia Tranæus.

#### Patient involvement

Experts: Bengt Mattson (chair), Rurik Löfmark, Svenny Kopp (until 2011-07-23), Lennart Lundin

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