

# NOT A SHRED OF EVIDENCE

Are scientists faking data on ADHD?

MEDICAL TREATMENT DECISIONS ARE NORMALLY BASED AROUND SCIENTIFIC PROOF BUT IN SWEDEN RESEARCHERS FACED WITH A LEGAL CHALLENGE, SHREDED THEIR OWN EVIDENCE. THE CASE INVOLVING INCREASING NUMBERS OF CHILDREN DIAGNOSED WITH NEUROPSYCHIATRIC DISORDERS LIKE ADHD QUESTIONS RESEARCH AND ITS FUNDING AND THE DIAGNOSIS AND SUBSEQUENT TREATMENT OF CHILDREN WITH STIMULANT DRUGS SUCH AS RITALIN, AS VIVIAN EDWARDS REPORTS

**W**hen Dr Leif Elinder returned to Sweden in 1995, after working in Whakatane Hospital and in Waikato Hospital's Child Development Unit, he became a community/schools paediatrician in Uppsala, a town with 200,000 inhabitants, 30,000 of them school children.

Elinder was concerned that Swedish doctors were labelling more and more children with ADHD (attention deficit/hyperactivity disorders). He did not consider asking questions of parents and teachers to be a valid procedure for diagnosing a supposedly hereditary brain dysfunction. An incorrect diagnosis could impact on a child's learning because of lowered expectations and affect their future job opportunities and earnings. Low intellectual test results could also lead to suggestions that special schools (Sarskolan) and classes were a child's best option.

Children attending special schooling with parents' consent had nearly doubled in two decades, but this varied greatly in different communities. Schools received four times the amount of money for each special needs child, and Skolverket (the National Education Agency) told Elinder that migrants were more likely to be classed as intellectually disabled and numbers of children with neuropsychiatric disorders were increasing.

In 1997, Elinder read a newspaper article signed by neuropsychiatrist Professor Christopher Gillberg and school doctor Sophie Ekman. Gillberg, a world authority on autism, headed Sweden's most influential group of child neuropsychiatrists and



was chief adviser to the National Board of Health and Welfare (Socialstyrelsen). Gillberg and Ekman claimed in their article that 10% of Swedish children had lifelong neuropsychiatric dysfunction needing a doctor's diagnosis. With 1,200,000 Swedish schoolchildren and 100 community school doctors, each school doctor could therefore be expected to have 1,200 children with a neurodiagnosis.

Elinder believes less than one percent of children qualified for such neuropsychiatric labelling. The frequent use of amphetamine drugs like Methylphenidate (Ritalin) as a first line of treatment was of concern. Ritalin a Class B drug was open to abuse and posed additional risks for children with growing brains.

Ritalin was being promoted in Swedish medical journals by the Gillberg group quoting American expert Dr Russell Barkley saying the drug was 'very effective and harmless.'

Barkley, research professor of psychiatry at New York's Upstate Medical University in Syracuse, claimed ADHD was due to a lifelong dopamine deficiency and that 80 percent of cases were incurable. Elinder, cautioned by his boss to look at recent research before speaking out publicly, says such a claim

was never proven. Stimulants sometimes brought about short-term behavioural improvements and temporarily reduced hyperactivity, poor attention and impulsivity, but they did not cure. They suppressed spontaneity, and sociability, enhanced obsessive-compulsive behaviours, isolated the child from outside influences and increased social withdrawal.

"Problem-solving and divergent thinking appear to be affected, and research studies on animals and humans suggests stimulants in a child's growing brain can permanently alter brain function."

Berkeley psychology Professor Nadine Lambert spent 30 years following up 500 ADHD children to their mid or late 20s. When her study findings showed that those treated with stimulants were twice as likely to develop smoking and cocaine habits than those not treated, her research was criticised and she found it more difficult to get access to research funding to continue this work.

After reviewing the literature Elinder presented a critical review at a November 1998 national doctors' conference (Svenska lakarstämman) in Gothenburg. A *60 Minutes* television presentation Bokstavsbarren ("The Labelled Children")

followed, but Gillberg refused to participate. Since then Elinder has suffered a string of untrue statements about himself, including a supposed affair with Gillberg's wife. His entire family, including his parents (aged in their 80s) received abusive letters.

Through a friend's advice he met University of Lund sociologist Assistant Professor Eva Karfve who later in 2000 publicly criticised the neuropsychiatric labelling of children in articles and a book.<sup>1</sup> They began supporting each other. The Gillberg group accused Karfve of her work being used by the Church of Scientology in its own arguments against stimulant drugs. However, neither she nor Elinder have no such connections.

Elinder says unfounded guilt by association and slander enabled Gillberg to avoid debating the real issues of validity of diagnosis and risks of treating children with stimulants.

However, Elinder and Karfve's combined criticisms did result in the Gillberg group (in a document to Socialstyrelsen) reducing prevalence rates from 10% of children down to 2-5%.

In 2002, Elinder and Karfve found inconsistencies in the Gillberg group's research. Gillberg had diagnosed 42 children at age seven in 1978 with MBD (minimum brain dysfunction) according to his own criteria, yet parents were never given a diagnosis. Gillberg's wife Carina followed up the same children at 10 and 13 years for her doctoral thesis. The diagnosis was changed during the study from MBD to DAMP (deficiency in attention and motor perception), a new concept at the time pioneered by Gillberg. Lars Hellgren (now consultant psychiatrist to Socialstyrelsen) did his thesis, using the same children when aged 16, and Gillberg and his assistant colleague Peder Rasmussen followed them up at 22 years. By this time Gillberg was saying that DAMP was similar to ADHD.

Only three subjects dropped out, a low figure considering the study covered 15 years and that no children were actually treated. Yet Gillberg used this research to support his claim that DAMP/ADHD conditions affected 10% of children, potentially making them candidates for life-long stimulant treatment.

When Elinder and Karfve were refused access to the Gillberg group's raw data they took legal action. The civil court (Kammarrätten) gave them the right to inspect the research material but the Gillberg group refused. As a compromise Elinder and Karfve suggested an outside, independent investigation by the Scientific Council. Instead, the Gillberg group informally asked Ethics committee chairman Ove Lundgren to look at the material. Lundgren, given four hours to scrutinise 100,000 pages of research material filling 22 metres of shelf space told Gillberg that he could find nothing obviously

wrong, but pointed out it was impossible to examine all the information in that short time. The Gillberg group and Preses (President) Goran Bondjers, chief of the Sahlgrenska University Hospital in Gothenburg then made media announcements stating that the Gillberg group had been cleared by the Ethics committee.

Lundgren writing to the editor of *Dagens Medicin* (Medicine of Today) stated never in his professional life had he felt so exploited. The Ethics Committee never had freed the Gillberg group of scientific misconduct accusations.

By then Gillberg's wife and colleagues had shredded the group's research material rather than hand it over, citing patient confidentiality. The University reported this to the police. Gillberg, deemed innocent of the destruction, said he was devastated. However he renewed the employment contract for one 'shredder,' Kerstin Lamberg his project controller, and increased her salary. Gillberg himself continued to receive considerable research funds from the Scientific Council and from the State Inheritance Fund.

But he still had to face the scientific misconduct accusations in court, along with the University of Gothenburg, which provided protection, when it could have asked for names of Gillberg's study subjects to be de-identified, and a locksmith could have helped to access the research material.

In May 2005, Christopher Gillberg, Gunnar Svedberg (University Dean) and Arne Wittlov (University Board chairman, Scientific Council Board member and vice-president of Volvo) were indicted and put on trial at Gothenburg District Court.

Meanwhile the Gillberg group organised and circulated a petition among the medical profession supporting Gillberg's court obstruction. Two hundred and sixty-seven doctors signed the petition. Gillberg was in open conflict through the pages of *Dagens Medicin* with his university boss Professor of Paediatrics Birgitta Strandvik over the

petition. She told him it was not a good idea and could lead on to further crime.

Professor of child psychiatry, Per Anders Rydelius from the Karolinska Institute and Rolf Zetterstrom who was chief editor of *Acta Paediatrica* wrote an article in *Dagens Medicin*. They pointed out that the Gillberg group in order to prove their hypothesis repeatedly changed the diagnosis and information in their material. Study results and conclusions were therefore unreliable.

"Accessible articles (from the Gillberg group) reveal that those studied have been managed in an unscientific way – a conclusion which does not need strengthening by what could have been found in the destroyed research material".

Three professors defended Gillberg in court for not handing

"GILLBERG'S WIFE AND COLLEAGUES HAD SHREDDED THE GROUP'S RESEARCH MATERIAL RATHER THAN HAND IT OVER, CITING PATIENT CONFIDENTIALITY. THE UNIVERSITY REPORTED THIS TO THE POLICE. GILLBERG, DEEMED INNOCENT OF THE DESTRUCTION, SAID HE WAS DEVASTATED. HOWEVER HE RENEWED THE EMPLOYMENT CONTRACT FOR ONE 'SHREDDER,' KERSTIN LAMBERG HIS PROJECT CONTROLLER, AND INCREASED HER SALARY"

over the research material. Elinder was witness for the prosecution, but in a courtroom filled with ADHD supporters his wife could not find a seat in the audience.

In June 2005, Gillberg was given a suspended sentence, two 50 unit fines<sup>2</sup> plus court costs. Svedberg, the University Dean received one 40 unit fine and costs, and Wittlov was found not guilty. Svedberg later resigned from the University to take up forestry company opportunities.

Another *60 Minutes* programme Uppdrag granskning (Time for Scrutiny) screened on National Swedish television. Rutter, Rydelius and Lundgren were interviewed, but again Gillberg refused to participate.

In March 2006 the Gillberg group appeared in court charged with destroying Government property, an offence that could warrant six months to two years prison. Carina Gillberg, Peder Rasmussen and Kerstin Lamberg each received suspended sentences and 50 means-related unit fines for having destroyed the research material.

Lamberg was already fundraising to pay Gillberg's fines for his court obstruction sentence, through the Autism (patients) society Riksforeningen Autism for which she is vice-chairman as well as through the Attention (patients) society Riksforbundet Attention. Participants at a recent neuropsychiatric child educational conference held in Lund were also asked to pay Gillberg's fines.

Lamberg's own salary was paid from research grants awarded to Gillberg from the State Inheritance Fund, and Elinder states that a substantial portion of Riksforbundets Attentions funding comes through drug company sponsorship.

"Eli Lilly, manufacturer of Strattera (Atomoxetine an alternative ADHD drug that Gillberg was trialing in a separate study) is one of the Attention Society's main contributors."

Gillberg has just organised and attended the second international Social Brain Conference called 'Mindroom' in Glasgow, Scotland. The conference patron was Queen Silvia of Sweden and important European psychiatrists participated.

Despite his conviction, Gillberg has kept his Gothenburg University position. The Scientific Council can not investigate him unless asked by the University.

But in a show of 'revenge tactics,' the University of Lund was persuaded to ask the Scientific Council to investigate Karfve and her book on the ADHD/Ritalin issue. The Scientific Council tried for over a year to get a panel together to scrutinise Karfve's written statements, during which period she was denied research funds. The investigation, just completed, has freed her of all charges and blame.

In Norway, Health Minister Sylvia Brustad stated on TV2 Channel 3 in March 2006 that the United Nations body for drug abuse is concerned. About 12,000 children in Norway (the highest number in Europe per head of population) receive daily stimulant drugs for ADHD.

Brustad announced an investigation into the practise of doctors 'labelling' children, and their connections with certain drug companies. ADHD diagnosis in Norway had been influenced by Gillberg's position as head adviser to the prestigious 'Children in Bergen' project, a post he now no longer holds. Having been convicted in Sweden he is also likely to lose his Royal Norwegian Scientific Council membership.



The Norwegians have taken a stand but in Sweden (the country that presents the Nobel prize) Gillberg carries on, supported by the State Inheritance Fund, and the University of Gothenburg, although he is no longer advisor to the National Board of Social Welfare.

The Scientific Council, set up to promote good quality research and deal with scientific misconduct has been paralysed. If it stops funding for other Gillberg research projects, then money previously invested will be wasted.

A project Gillberg started in 2003 for Eli Lilly, was expected to ease the way for the drug Strattera (Atomoxetine, previously promoted as an anti depressant) to be approved as an alternative non-stimulant ADHD treatment in Sweden. The trial on 40 adults was expected to last a year, but there are doubts it will ever be completed. Only half the patients enrolled, half of those never turned up and five experienced harmful effects. New overseas reports indicate serious side effects from Strattera can occur, for example, unexpected suicides, cardiac disorders and liver damage. In New Zealand, Pharmac received an application to fund Strattera but it has not been approved.

<sup>1</sup>'Hjärnsproken – DAMP och hotet mot fohkalsan' (Brainghosts - DAMP) ADHD) and the threat against Public Health) published Stockholm/Stenhagen 2,000 (Brutus Ostlings bokforlag Symposion AB

<sup>2</sup>One unit fine is approximately one day's salary minus tax. **INVESTIGATE**