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**Regarding a petition from Leif Elinder, dated 2002-04-08, reference no. H511493-02.**

*[Translation note: the first three pages mainly treat the history of MBD—Minimal Brain Dysfunction—and general considerations about the Gothenburg study; they are not translated here.]*

### **Scientific documentation and review**

The results from these studies thus have been summarized in four doctoral theses. All papers that the reports are based upon have been published in internationally well-recognized scientific journals. All the papers have of course been reviewed in detail by scientific opponents and scientific report committees and all papers have been approved. Added to what was included in the theses papers, several articles with results from the studies have also been published in Swedish as well as in foreign scientific journals. Some articles have been broad summaries and others have been based on original work. One example of the later is the report from the 22-year follow-up study.

In the year 2000, an investigation of [Medical Funded Research] MFR-supported research in Sweden was performed by a specially appointed international investigation committee. The statement [from this body] in regard to [the field of] child and adolescent psychiatry is cited here: “The group in Göteborg has pioneered the application of epidemiological and neuropsychiatric methods in child psychiatry in Scandinavia, and its track record over the last 20 years has rendered it one of the most renowned child psychiatry departments in Europe. It is particularly renowned in autism, ADHD, and in eating disorders, and has initiated productive collaborations with other first-rate researchers in other countries. The group has been enterprising in raising funds from other sources. Research into Child Psychiatry is less well developed at other centres in Sweden.”

## Regarding Elinder's critique

1. Elinder questions how it was possible to do the study "without any intervention".

At the time of the study, as has been said before, the knowledge of which type of treatment would benefit children with MBD was very insufficient. Ever since the beginning of the 40s in the U.S., people had been using stimulant medication [amphetamine] for children with these kinds of problems, mostly Methylphenidate (Ritalin), and good results were reported. Certain knowledge about educational principles had started to emerge. Basic guidelines were missing about the conditions in Sweden. Our study was regarded as a pioneer work, which might contribute to proposals about suitable steps [when encountering a child] with MBD, but only after long-term follow-up[studies] had been made.

We informed the parents about the results from our investigations, something we are certain has been of good use for many families. From the doctoral thesis [of Gillberg's wife, who was also his student] from phase 2 and 3 [age 10 and 13], you can see that the majority of the children who had participated in the study and who had neuropsychiatric problems have received important support from specialist teachers and sometimes also from being taught in smaller classes.

A treatment with stimulants was not possible during this period. Not before mid 90s did the Medical Product Agency start to approve restricted licenses for central stimulants, and even then only for children and adolescents. Participants in the study were by then already adults and therefore could not receive such treatment.

The children who participated in the study and who proved to have DAMP or DAMP-associated problems thus have not received any specific treatment within the framework of the study. But the parents have received help from us in regard to a basic analysis of the possible difficulties that children have had. Again we must point to the fact that the study had received complete approval from the National Board of Schools and from the Department of Social Welfare and that customary approvals from the research Ethics Committee had been given for the follow-up investigations.

2. Elinder's wording in regard to "hereditary defects" in this section we find difficult to understand. As far as we know the term "hereditary defects" has never been used by any of us. The only "validated diagnostic instrument" that we can think of in this situation is a cytogenetic analysis (chromosomal analysis) or a molecular genetic investigation. Any such tests or analysis were no part of the investigation.

We have concluded that it was much more common that close relatives of the children with DAMP themselves had (or have had) DAMP-associated difficulties and that this was in accordance with the experience from other studies with children with severe concentration/alertness problems.

3. This section too—regarding "brain disorders"—is so unclear in its formulation that we are forced to try to guess what Elinder is referring to. As far as we know, in no part in the study we have expressed anything about "brain disorders". In a partial study in regard to EEG examinations on a group of children, we have found that the basic electrical rhythm, as it is recorded by the EEG-investigation, on average shows somewhat lower frequency with children with DAMP compared with a control group. Regarding this finding we have clearly expressed that this finding cannot be used for a diagnostic purpose. We found that the children with DAMP somewhat more often, compared with the children in a control group, were more underweight at birth in regard to the length of pregnancy and that on average more children with DAMP have had febrile convulsions. Not even these findings have we extrapolated to "be valid for the diagnosis of DAMP in general".

4. We have not compared severe MBD/DAMP with severe ADHD. At the 22-year investigation we tried to see whether it was possible to apply ADHD criteria in accordance with the DSM system ["DSM" is the *Diagnostic and Statistical Manual of Mental Disorders*, which is a standard reference in psychiatry]. We showed that at the 7-year investigation, when the DSM criteria had not existed, we had registered various symptoms in such a way that this was possible. We did not "compare" these diagnoses, just shown that the majority of the children who had received the diagnosis DAMP at the age of seven also had fulfilled the criteria for ADHD. Children with DAMP have also problems with motor control and perception.

5. This question—whether it could be considered “scientifically justified” etc.—has above been answered under the heading “Scientific documentation and investigation” and in part 6. See below. Complaints in this matter do not in the first place fall upon us but rather onto the academic system as such.

6. Elinder chooses—in his criticism that we had a comparatively low drop-out rate—only a single figure [number] for the drop-out rate in just one of the groups at one investigation (at 22 years of age)—i.e. those 42 participants who originally had received the diagnosis MBD/DAMP. Elinder does not mention that in the study there were 3400 children and that 141 of those who participated in the more closely investigated material were included. The drop-out rate that Elinder mentions for just a subgroup with 42 participants is correct—i.e. 7% (3/42). The drop-out rate at the 22-year follow-up among those who had DAMP or any DAMP-associated diagnosis at seven years of age was 10% and in the control group the number was also 10%. The drop-out rate has thoroughly been explained in each phase of the study. Here it is important to mention that some participants have dropped out from a single or some or parts of the follow-up examinations and then later turned up again. These numbers which are mentioned above only come from the 22 year investigation. It cannot be considered valid that it falls upon us to defend the fact that so many of the young adults voluntarily have accepted to be examined at the follow-up investigations at 16 and 22 years of age. Researchers usually regard such a “coverage” a strength, and not as something to be discredited for.

The comparison with what Elinder calls “The treatment group”, where the drop-out rate (at 10 years of age) was very high, is irrelevant. This study was organized in another way and had nothing to do with the study Elinder is criticizing. Children, who in a accordance with a neuropsychiatric investigation were proven to have DAMP, were divided in groups and received various kind of treatment, however not by the research group, but by others, among them special teachers, who we did not control. Detailed information to parents about the child’s functional disorder and various types of support in the school were given in various combinations for different groups. However, the parents were disappointed in the way the school had performed its treatment procedures and the motivation to come back for a later follow-up thus was low.

7. Elinder has completely misunderstood the investigators “blindness” in regard to previous (investigation) results. At the first examination (Phase 1, when the children were 7) the researchers who examined the children did not know the results from the questionnaire, which was answered by the preschool teachers. At each follow-up, at ages 10, 13, 16, and 22, those who examined the children have not had any knowledge of the results from previous investigations. Not before all investigations and diagnostic considerations in one phase of the study had been finalized, we were allowed to compare with previous results. This is a basic, and an obvious, basic methodological rule. To emphasise this even more: neither Christopher Gillberg nor Peder Rasmussen had met the participants more than at the first phase. That we however have participated in putting the facts together from the various examinations is another thing.

8. As can be concluded from the heading “Scientific documentation”, the research community has already been convinced about the credibility of the above mentioned studies.

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