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To Rector Bo Samuelson
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I hereby apply to the rector to investigate whether good ethical standards of research (see SOU 1994:4) have been adhered to in the following research project.

During the 70s, the neuropsychiatrists C. Gillberg and P. Rasmussen in Gothenburg started a research project. Their aim was to investigate the prevalence of so-called neuropsychiatric disorders and also to document what would happen to the diagnosed children in the future. The disorders were sometimes called MBD, or DAMP or ADHD. The researchers regarded these disorders as inherited or neonatal brain defects—i.e. “specific neurodevelopmental problems” (1).

Following a questionnaire for the children in primary schools in Gothenburg, a number of 6–7 year old children were selected for an investigation. Of those investigated, 42 received the diagnosis MBD. (In the 80s, the researchers changed the MBD-label to DAMP [*Deficits in attention, motor control, and perception*].) The children were examined by a child psychiatrist, a child neurologist, a physiotherapist, and a psychologist. P. Rasmussen writes: “*The examinations of all children were later done at 10, 13, 16 and at the age of 22. The results have been summarized in four doctor’s theses and in about 40 publications in international and scientific journals and books*” (2). In all studies, based on the first study [at age 7] the researchers stress that the children were completely untreated. The researchers write: “*The results of the follow up of this group of children have been considered by us to reflect the natural outcome (without intervention) in DAMP*” (3). “*These children had received no intervention of any kind except what little had been offered as a consequence of parents demand*” (3). “*No medical or other specific treatment took place in the project*” (4).

At the 22 year follow up—completed 1993 and not published until year 2000—the following investigation procedures took place: “*A neuropsychiatric assessment, a brief neurodevelopmental examination, and a reading test*”. From the original 42 [MBD/DAMP diagnosed] children—fifteen years later [at age

22]—39 “children” [now young adults] turned up to be extensively examined—i.e. there was only a drop-out rate of 7 percent (3/42). Of these [39], 58 percent had a considerable psychosocial load with early retirement, criminality, drug abuse, and other psychiatric abnormalities (1). C. Gillberg and P. Rasmussen write: “*The young adults taking part in this study had not received systematic therapies according to current clinical praxis*” (1).

That such a socially troubled group without any reward—considering that they all were unaware of their diagnoses—voluntarily come and accept complicated neuropsychiatric assessments seems strange. As a comparison, in a simultaneous **treatment** study with 25 DAMP-diagnosed children, there was a drop-out rate of 68 percent. The researchers [including C. Gillberg] write: “*Unfortunately only 8 parents (32 %) were willing to let the child participate in this kind of comprehensive follow up*” (3).

With the support from the Gothenburg MBD/DAMP study, the Gillberg group—in the media, to the authorities, and to health organizations—warns of “a new threat to public health”. C. Gillberg writes that “*120 000 [Swedish] children have this diagnosis*”. “*The condition is either hereditary or arises through damage to the nervous system*”. “*The matter is about medical diagnoses, which only can be diagnosed/assessed by doctors*” (5). “*If you make an attempt to assess the background factors, about 50 percent would be hereditary and 30 percent [congenital] brain damage, with rather a high number of cases within both fields ... and 20 percent with an unclear background*”. “*Psychosocial factors do not seem, without a brain dysfunction involved, to be the underlying cause to the problem in DAMP*” (6).

Swedish DAMP research, information to authorities about sickness prevalence, and the distribution of resources and medical intervention programs for children with difficulties in school depend on the validity of the Gothenburg study.

The study can be questioned on the following points:

1. How is it possible to do this study without any intervention?
2. How is it possible to make statements about hereditary defects without a validated instrument for the diagnosis?
3. How is it possible to extrapolate the few reported findings of brain disorders to make these [reports] be valid for the diagnosis of DAMP in general?
4. How is it possible to compare severe MBD/DAMP with severe ADHD when the diagnostic criteria are so different? In the 80s, scientific society dismissed the MBD concept as not valid. The Gillberg group instead changed the name MBD to DAMP. Now, when the DAMP concept also

cannot be defended, the researchers say that DAMP is the same thing as ADHD + clumsiness. However, the independent (unbiased, neutral) investigator Tomas Ljungberg—appointed by the National Board of Social Welfare—protests against this and he writes: “In regard to possible neurobiological changes and, it is not scientifically defensible to discuss DAMP and ADHD together. The consequence of this is that DAMP and severe DAMP are something different to ADHD (Thomas Ljungberg, The National Board of Social Welfare, 2001-05-20, p. 16–18).

5. Is it scientifically defensible [justified, proper] to from a study of 42 untreated children to produce 4 doctor’s theses and 40 scientific articles?
6. Is it believable that in the group of **untreated** children the drop-out rate was only 7 percent (3/42 children) when the drop-out rate in the **treated** group was almost 10 times higher—i.e. 68 percent (17/25 children)?
7. Is it believable that the same doctors, who over 15 years examined the same children several times and still claim that they [during the follow up studies] all the time were unaware of their [original] diagnoses? (This is so unlikely that you must ask yourself, just for this reason, if other statements [by the Gillberg group] are not equally problematic)
8. How can the scientific community be persuaded that the children who were examined in 1978 were identical with the young adults who were examined in 1993, not being offered any treatment and yet willingly chose to participate in all the investigations? (7).

Sincerely yours,

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- (1) *C. Gillberg & P. Rasmussen*, *J Am Acad Child Adol Psych* 39:11 nov 2000, p. 1424–1430
- (2) *P. Rasmussen*, *Psykologtidningen* 4/2002, p. 10
- (3) *C. Gillberg*, *Europ Child and Adol Psych* vol 2, Issue 2, July 1993, p. 126
- (4) *P. Rasmussen*, *SvD*, Brännpunkt 2000-08-11
- (5) *C. Gillberg & S. Ekman*, *DN-debatt* 97-03-20
- (6) *C. Gillberg*, *Ett barn i varje klass: Om DAMP/MBD/ADHD*, Cura 1996, p. 134
- (7) A 15-year flowchart: Examined MBD/DAMP-children and drop-out rates

Flowchart

A fifteen year MBD/DAMP–study in Gothenburg during 1977/78–1993

Number of children born in 1971 5114 children
 Number of screened (by questionnaire) children in 1977 3448 children

Number of children	<i>Examined at age</i>					<i>Drop-outs after 15 years</i>
	7	10	13	16	22	
Severe MBD/DAMP	14	13	13	13	13	1
Moderate MBD/DAMP	28	27	24	26	26	2
Total MBD/DAMP	*42	40	37	39	*39	3
ADD/ADHD	12	12	10	11	11	1
MPD/DCD	7	6	5	6	5	2
Index groups (Summary)	61	58	52	56	55	6
Comparison group	51	48	44	45	46	5
TOTAL	112	106	96	101	101	11