

Ethics Committee
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In his reply, dated October 14th, 2002, and forwarded to the Ethics Committee, Peder Rasmussen comments on my letter to Gothenburg University. Peder Rasmussen writes: *This kind of criticism/misunderstandings as proposed by Kärffe in this notification is usually dealt with inside the scientific community fairly easy by means of questioning the authors...* (p. 10).

I enclose as an annex the letter I sent February 19th, 2002, to among others Peder Rasmussen, as well as the letter I received from him (annex 1). In this the manners are the same as in the present commentary by Peder Rasmussen. Criticism is called misunderstanding, claims to critical examination are labeled defamation, and everything is presented with concepts like “campaign”, “persecution”, and “libel”. I am not aware that I ever expressed myself in an insulting way about any of the researchers in question and do not regard the tone with which the criticism is rejected as being in accordance with scientific customs.

As a social scientist, I consider it my duty to openly give an account of the apprehensions I entertain, in accordance with what is declared in The Government’s Official Report 1994:4, p. 55, where it is regarded as a sign of poor judgment and inappropriate behavior to not report a case that one judges to be an obvious instance of scientific misconduct.

My investigation started in 1999 with the ambition to study what could be regarded as a medicalization of the views on children in the kindergartens. To get fully informed about what was, among the kindergarten teachers, considered as “scientific evidence” supporting, for example, the DAMP diagnosis, I procured those scientific articles reporting what Rasmussen now calls “phase 1” of the Gothenburg study. The main authors of those articles were Christopher Gillberg and Peder Rasmussen, and the articles reported the outcome of the original MBD/DAMP investigations of 6-years-olds in 1977.

What I discovered in these articles was, from a methodological point of view, so remarkable that my interests came to focus on the standard of their research and, also, its popularity in the educational sphere. My book, “Hjärnspöken—DAMP och hotet mot folkhälsan” (2000), dealt with serious methodological errors. These errors can hardly be dismissed as “misunderstandings”—they were, in fact, known already within the psychiatric scientific community.

I want to stress the fact that, as a sociologist, I belong to a discipline that regularly occupies itself with population studies. My starting point has been the fact that prevalence estimates of, for instance, human activities, regardless of whether these activities are considered to be caused genetically or socially, must be conducted in similar ways and according to fixed rules. I have assumed that neuropsychiatric research follows these rules.

On no occasion has my interest focused on the moral standards of the scientists but, rather, on the scientific reports produced by the Gillberg group. In an extended review of the longitudinal study (“phases 2–5”), I have discovered serious self-contradictions and erroneous facts, enough to ask myself if there is misconduct and incompetence beyond the careless

mistakes. I have refrained from speculations as to the motives behind this, but felt more concerned about the social consequences of these poorly substantiated reports.

A good deal of the criticism that I have directed towards “phase 5” of the Gothenburg study—i.e. the investigation of participants in the index and the control groups at age 22—is not answered at all by Rasmussen. This applies also to the question about his own part in the investigation. As no neurological tests were made (except some “simple motor tests”, presumably conducted by some other doctor, and, besides, never reported), it is difficult for Rasmussen to claim co-authorship. According to Rasmussen’s letter, he and Christopher Gillberg themselves have conducted the compilation of data, a piece of work which, according to what is stated in the original article, was done with the assistance of eleven more persons (among them Rasmussen’s and Gillberg’s own children).

I will now comment on Rasmussen’s letter point by point.

“One single error in writing”

Rasmussen claims that what I have presented as contradictions in the reports by Carina Gillberg in, above all, the “phase 3” investigation [when the children were 13], is a simple matter of a mistaken digit, an error that had been noticed but regrettably not corrected.

But the mistake is more serious than that. In her dissertation from 1987, Carina Gillberg deplors that some children from “phase 2” did not participate in phase 3 because they had left Gothenburg. She writes:

“For the purpose of this follow-up I decided to see as many as possible of those cases who had moved to other parts of Sweden. This was in order to get as many children as possible to participate in the follow-up study, now that more parents were reluctant to let their children participate. Thus, only 4 children this time were excluded from the study because of having moved and these 4 children (1 boy in the ADD group and 2 boys and 1 girl in the Comparison group) had all moved back to their native countries.” (Gillberg 1987:21, my underlining.)

Regarding the same investigation, Carina Gillberg 1989 writes:

“The main reason for drop-out was that the child had moved, either to a place elsewhere in Sweden (seven children) or to his country of origin (four children). The parents of the other five children refused to let them take part in the study.” (Gillberg et al., 1989:15, my underlining.)

To sum up: What is at stake is not one single erroneous digit, easily corrected, but two versions, each excluding the other, of the same event. If I understand Rasmussen correctly he is in favor of the first version. If this be the case, new problems are encountered when attending “phase 4”, the investigation made three years later. In that report it is stated that all children (except one) were examined at a nursing centre in Gothenburg. While the previous investigation, when the children were at age 13, demanded extensive traveling around the country to reach all participants, the investigation three years later could be carried out much

more effectively when the children appeared in Gothenburg. I find it very hard to understand this readiness on the part of the teenagers and their parents to take part, particularly on an occasion that late, in a study from which they did not benefit.

The low drop-out rate

Of the 112 children who were chosen for the follow-up studies, 96 children were examined personally by the doctors in “phase 2”, 96 children in “phase 3”, 101 children in “phase 4”, and 101 (now) adults in “phase 5”. [Phases 2, 3, 4, and 5 occurred when the participants were aged 10, 13, 16, and 22.] The attrition has not just been low, it has decreased during the years.

I do not know any other example of a population-based longitudinal study—regardless of what has been examined—where such a low attrition rate has been reported.

Rasmussen gives an explanation: *Kärfve obviously cannot imagine that persons with the kind of problem as suffered by our participants may feel motivated to partake in an investigation of this kind without getting any treatment. Many with DAMP and equal problems benefit from getting their troubles investigated and analyzed.* (p. 7.)

As I see it, Rasmussen, in an attempt to explain an abstruse eagerness to help on the part of the participants, creates new problems concerning the reliability of the whole study. In the report from “phase 5”, Rasmussen and Gillberg wrote: “Three child and adolescent psychiatrists were involved in these interviews, which were performed blind to the original study diagnostic group status of the individuals (who were themselves unaware of the diagnoses assigned)” (Gillberg & Rasmussen 2000:1426, my underlining). This fact has been stressed since the beginning. It has been maintained as certifying that the study presented a natural course. But Rasmussen now challenges the statement he has given earlier. In his reply he writes (on p. 2) concerning the original examinations at age 7: *The results, though not in diagnostic terms, were presented to the parents.*

A presentation of results, no matter how vague, must imply that parents, whose children have been engaged in a DAMP investigation, easily could understand what their children were supposed to suffer from.

How big is the base population?

In almost every follow-up study, the fact is emphasized that from the original study (“phase 1”), 141 children were chosen for further examination. Of these children, 29 were excluded and were never to partake in the longitudinal study including “phases 2–5”. The reason for this was that three of children were mentally retarded and the remaining 26 did not have problems qualifying them for a diagnosis, in spite of the fact that problems were indicated in the nursery school inquiry.

When it comes to “phases 2–5”—the actual longitudinal study—it has to be one way or the other: either this “29 group” belongs to the base population or it does not. As I understand the design of the study, the “29 group” did participate in the original study, as the aim was to establish the prevalence rate for the child population as a whole. The presence of the group

was then necessary for statistical reasons. It is then excluded from the remaining follow-up study, since the group is irrelevant in this context.

The base population in “phases 2–5” is, then, 112 children. “In the end, a total of 112 children were left for follow-up studies” (Gillberg & Rasmussen 2000:1425). It must be so, since the attrition rates presented is calculated on this number. Were the population 141 children, the attrition rates in all follow-up studies comes close to 30 %, instead of 10%.

Now Rasmussen is introducing a hitherto unknown investigation. On page 5 he writes: “Our aim has been, in every follow-up study, to examine all participants from phase 1” (my underlining). This includes the 29 children earlier said to be excluded, because just above these lines, Rasmussen writes:

“26 children had problems according to the nursery school inquiry but attained no diagnosis when examined—the ‘pre-school questionnaire group’ (psq). The participants in the psq-group and those mentally retarded have been examined in the follow-up studies in the same way as other participants, but the results of these groups have not been reported in the articles published, as the question at issue was children with DAMP, not mentally retarded children or children in the psq-group” (my underlining). Rasmussen continues: “Above the 101 participants accounted for in the present study [phase 5], 20 more persons from the ‘psq group’ and two persons from the mentally retarded group were examined. The results from these two latter groups are not presented in the article and have not yet been published.” (page 7).

When now, at the eleventh hour, two new groups are presented, I would like to point out:

1. In the presentations of phases 2–5, it is emphasized that this group is excluded.
2. It is difficult to find the reason for these investigations. How are results from longitudinal studies concerning a remnant group of three mentally retarded children planned to be made use of scientifically? The same goes for the 26 healthy children: are these forming an extra comparison group beside the ordinary one? How did the researchers motivate the parents to make their children take part in running physical, psychological, and psychiatric tests?
3. It is hard to imagine in what kind of journal—as well as under what headline—the publishing of a report like this would be possible.

The base population, one more time.

I have stressed how the authors, Christopher Gillberg and Carina Gillberg, in a report published in Rothenberger (1990), obviously been lacking in respect for scientific methods. (This critique is summarized in annex 3 in my request to Gothenburg University.) In this report the base population in phases 2–4 is erroneously presented as consisting of 141 children. In the statistical tables—in reality based on 112 children or fewer—the authors have presented “numbers” in accordance with the larger base population (141 children).

Rasmussen comments on this: “Readers acquainted with these kinds of reports understand that numbers on top of the tables, as Kärffve pointed at, mirror the original quantity of participants.” (page 9).

If we examine 50 children out of a group of 100 and present the results in a statistical table, the “numbers” should be 50, not 100. This is an elementary statistical rule, which is known to readers of these kind of reports. I assume that the Gillberg Group also knows this rule, as I have nowhere else met with any fault of this kind in their other reports.

To sum up: There are no obvious reasons to let two groups of children, excluded from the longitudinal study, suddenly reappear as examined “in the same way as other participants”. Regardless of the motives behind this new information, it is unserviceable as a pretext for the erroneous presentations of statistical tables in Gillberg & Gillberg (1990).

The identity of the examining physicians, and knowledge about diagnostic affiliation.

A recurrent theme in the answers from Rasmussen is that I have not understood which doctors did what examination.

Well, this is a part of my critique. In his answer of February 28th, 2002, Rasmussen writes: “It is shown in the reports which doctors have carried out the different examinations.” This is not the case, and neither is the statement a few lines further below correct. There Rasmussen writes: “The doctors doing the follow-up studies were blind to which diagnostic group or control group the children belonged.” The identities of the doctors are, in fact, as obscure as those of the participants, and none of the doctors are identified by name in the reports. The authors claim that this is the case. That is not the same thing.

Through all the investigations it is difficult—and sometimes impossible—to understand which doctors did what examinations. Rasmussen now writes that in “phase 5” the examinations were carried out by three other doctors, while he and Christopher Gillberg only compiled data. On the very first page of this report the authors give their thanks to those who assisted them in collecting and compiling data: Gunilla Carlström, Andriette Bågenholm, Gunilla Campenhausen, I. Carina Gillberg, Ingela Enerskog, Andreas Gillberg, Nanna Gillberg, Lars Hellgren, Magnus Rasmussen, Thomas Rasmussen, and Ulla Welin. This assistance (which includes the authors own children) is hard to understand when comparing to the picture of the work plan now presented by Rasmussen. No one is mentioned to have assisted with the examinations, but eleven persons are mentioned as participating in data collecting and compilation, a work Gillberg and Rasmussen in their reply now claim they carried out themselves.

Besides, Rasmussen writes on page 4: “Christopher Gillberg and Peder Rasmussen personally examined all the children in phase 1. They are the only ones in the research group who have had knowledge about group affiliations and diagnoses.” But this cannot be true. The original diagnoses were made by three child psychiatrists. “My warm thanks are due to my colleague and friend, Dr. Gunilla Carlström, who interviewed all the mothers, performed the inter-rater reliability study with me and took part in the global diagnostic procedure” (Gillberg 1983:4, my underlining).

Now Rasmussen writes that in the study fifteen years later, “phase 5”, three child psychiatrists took part, and one of these had participated in “phase 1”. This must refer to Gunilla Carlström. Rasmussen’s statement that not one of the examining doctors knew the children’s

diagnoses is thus erroneous, since Carlström had the same knowledge as Gillberg and himself. And Gillberg and Rasmussen obviously regarded themselves as too well-informed to handle the material before it was made anonymous. Why Gunilla Carlström should be regarded as “blind” remains a mystery.

It is also stated that one of the examining doctors had seen the participants six years earlier. It is difficult to understand who this “one” may be. Mentioned are Andriette Bågenholm, Carina Gillberg, and Lars Hellgren, all of them investigators in “phase 4”. The latter two have also made their doctoral dissertations within the frame of the longitudinal study and must, as I see it, at least at some point in their lives have had intimate knowledge of the children examined and their diagnoses.

As appears from Rasmussen’s reply, the situation of blindness is even more complicated by the fact that the participant children were more or less conscious of their diagnoses and able to discuss [with the doctors] their social and psychological problems in neuropsychiatric terms. If this is true, the Gothenburg study does not describe the natural courses of the disorders.

To sum up: In spite of the mysterious anonymization of the participant doctors in the study, it is obvious that one of them made the original diagnoses 1977, and that two of the others made their doctoral dissertations on the study. The participants’ ignorance as to their own diagnoses is put in question by Rasmussen himself.

The question about blindness is not answered.

The increasing number of illiterates

In “phase 4” it is stated that two out of eleven boys with “severe DAMP” cannot read or write. In “phase 5” the number has increased to three.

Rasmussen explains this strange fact in two ways:

- (a) “... only 12 of the 13 participants in the group ‘severe DAMP’ are the same in both occasions.”
- (b) “[it is] ... not possible to make comparisons between reading and writing abilities at the different occasions, since these aspects have been examined in different ways.”

The latter argument is not very strong. It is hard to imagine a research team that prides itself with measuring small-bore differences in attention and concentration, does not use strict methods when examining a deficiency, which every normal literate person can discover. (This kind of defense is brought forth when it comes to “antisocial personality disorder” as well, and seems equally illogical then. The intrinsic concept of a longitudinal study must be the possibility of making tolerably-comparable investigations.)

Statement (a) is more interesting. The group “severe DAMP” contains 12 boys. One of these boys is missing in phases 2, 3, and 4. In the reports from phases 2 and 3, he is described as placed in an institution, and his parents are said to oppose his participation. We can be sure he is not in phase 4, because there are already two illiterate boys. The boy placed in an institution must be illiterate too; otherwise he would not enlarge this group by entering in phase 5.

As there are only 12 boys who theoretically belong to the group “severe DAMP”, the boy from the institution must have entered in phase 5, while a literate boy disappeared.

Conclusion: This explanation that the boy from the institution—whose family resisted participants during fifteen years—suddenly at age 22 reappears, and in spite of his total inability to read and write chooses to endure the rather extensive examinations, is not fully trustworthy. An impartial scrutiny of the participants should strengthen Rasmussen’s statement and ward off any suspicion that you instead have chosen to examine some of the persons in (the excluded) mentally-retarded group.

Depression as a variable for “poor outcome”

“We have simply presented what we did find”, Rasmussen claims apropos my suggestion that it is scientifically dishonest to exclude a variable like depression when performing the analysis. Rasmussen here does not seem to comprehend the difference between presentation and interpretation.

If one wants to judge life quality (or whatever one chooses) of a sample of individuals, criteria must be formulated beforehand. These criteria must then stay valid, independent of the results.

Gillberg and Rasmussen did choose, in the context of psychiatric health, to judge one disorder or “sub-threshold” symptoms of two disorders as tantamount to “poor outcome”. Very well. But when analyzing the results of the psychiatric investigations (made by other doctors), they found that depression [originally considered one disorder] was as common among the controls as among the DAMP participants. Rasmussen then makes this amazing comment:

Since we found out that depression, according to those measuring methods we used, had been very common among both the index groups and the controls, there was hardly any reason for keeping depression as a criteria for “poor outcome” (page 8).

The correct conclusion to be drawn must be that (1) depression remains a criteria for “poor outcome” and (2) the authors did not find any correlation between DAMP and depression.

To sum up: It is not allowed to cut out a variable because the results were not the wished for. Rasmussen seems not to be aware of this, and he does not acknowledge that this might be “elimination of scientific findings which contradicts the preferred theory or hypothesis”, which is regarded as scientific misconduct according to the Government’s Official Report 1999:4.

By eliminating the variable of depression, the final results of the investigation are distorted. The actual finding is that there is no association whatsoever between the diagnosis of DAMP and depression. The fact that the Gothenburg group keeps this a constant secret in their communication with authorities and the public strengthens the suspicions of scientific misconduct.

Finally

I would like to point to the fact that Rasmussen's reply in no way settles any anxieties. In an attempt to extenuate, Rasmussen rather creates a space for new contradictions, thus adding more complications to the picture of the Gothenburg study.

The introduction of a new "silent" group of 29 participants, which was not presented in the study as such, is such a complication. The statement given by Rasmussen that the participants returned every three years during fifteen years time in order to "investigate and map out their problems" introduces two new problems: first, this is not in accordance with prior statements that the participants did not know about their diagnoses; second, the knowledge of the participants brings the blindness of the examining doctors into question.

To strengthen the reliability of the Gothenburg study—and thus justify its use as a base for important decisions in society—the following points must be considered by an independent party. This investigation must attend to issues that make it possible to confirm that

1. all participants in phase 5 actually have been examined,
2. these people came from the original base population of 112 individuals (and were not erroneously fetched from, for instance, the "psq" or "mentally retarded" groups),

and that

3. the examining doctors get identified so that their blindness can be evaluated,
4. it is confirmed that the participants were unaware of their own diagnoses.

I would appreciate it if these comments were added to my original letter from June 25th, 2002.

Lund, 9th of December, 2002.

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