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The Gillberg affair: The reason that it has not been properly checked

The Gillberg affair is about research ethics and how medical research can be checked, writes Lars Nicklason, previously a journalist with *GU Journalen* [the monthly magazine of Gothenburg University].

There are many reasons why the general public has such great confidence in researchers. Unlike directors of big firms, government ministers, and union representatives, researchers live in a protected zone free from investigative journalists. Whether this depends on poor self-confidence, subservience, or pure lack of interest on the part of journalists is a matter that has not been settled yet.

It is, however, clear that researchers are not used to being investigated, apart from just being subject to public interest when presenting their results. Any journalist who feels otherwise must be aware that he is now entering a minefield, where people with lack of formal research education are not supposed to have access.

Part of the assignment of Gothenburg University's newspaper, *GU Journalen*, is to—in a journalistic way—investigate the background environment for good scientific education and research. Not doing so would be odd, considering that the universities put forward that they promote openness and teach critical thinking.

For two years' time, the GU newspaper has followed the controversy in regard to research material. The controversy deals with professor Christopher Gillberg's studies about DAMP. The sociologist from Lund Eva Kärfve and the pediatrician Leif Elinder suspect that these studies have not been performed in a correct way and therefore they have requested to see the raw data for the research.

A massacre of research material

The Gillberg group has consistently refused to hand over the research material—despite that they have lost three times in the Administrative Court of Appeal, and despite that they have encountered several failures in the Supreme Administrative Court, and despite that they have encountered two critical verdicts from the Parliamentary Ombudsmen. And now it is impossible [to scrutinize the material]. In a vast paper massacre in May 2004, three Gillberg employees destroyed nearly two decades' worth of state-financed research material.

The Gillberg affair is not only about the correctness in a 100 000 pages of extensive material, which (among other things) have rendered four doctors their doctoral theses and also has served as guidelines for the National Board of Health and Welfare about how to diagnose and manage so-called neuropsychiatric-labeled children (classified as brain dysfunctional). The question is much bigger than that. The question is about research ethics, research validity, and how medical research can be properly checked.

With *GU Journalen*, our way of putting forward straight questions in regard to Gillberg's refusal to show his material has caused harsh criticism. And it has not been entirely easy to pursue this question, as Gillberg has never accepted to be interviewed by us or to contact us. Instead, some close colleagues of Gillberg have taken on the task to be his defenders.

Through external pressures on our managers and on the university's management, the Gillberg group has, with mixed results, tried to strangle the newspaper's interest in this affair. But finally Christopher Gillberg and two of his employees have uncovered their mouths and reported me and the editor-in-chief of *GU Journalen*—Allan Eriksson—to the university rector for defamation and for deliberate harassment of Gillberg.

Gillberg has all the time claimed that patient secrecy was the main reason the he could not submit the material [for an investigation]. This is very well nice and honorable. But this argument contradicts a fundamental Swedish law (*Offentlighetsprincipen*—the principle of openness) and also contradicts good research ethical standards, which state that all scientific research must be made available for scrutiny.

Moreover both Kärfve and Elinder, who are not interested in personal details, but rather the research method, were under legal obligations to keep the material under strict secrecy. If they were to break this secrecy, they would receive severe penalties. These are obvious legal facts.

Nevertheless the Gillberg group has launched media horror stories to the Swedish press. “The controversy is all about deep personal details that quickly will become public”, Gillberg's colleague Peder Rasmussen put forward in *Göteborgs-Posten* on 02 March, 2003.

A common misunderstanding is also that Gillberg is supposed to have been acquitted by Gothenburg University's Ethics Committee. “Not only once but twice”, writes *GT* [a Gothenburg newspaper] in an article (08 July, 2004). When the mistakes were pointed out to the writer of the article, she only says that we have different opinions in regard to this question. In this affair, there is no difference between facts and opinion. It is impossible to ask critical questions in this nasty affair or even to make a report about obvious facts without being classified as a member of an evil “campaign”, which is being conducted against Gillberg.

It is not only *GU Journalen* who has received this label, but also the magazine *Dagens Forskning* [a popular science magazine].

The statement that Gillberg has been exonerated by the University's Ethics Committee is incorrect. Strict proof of a research fraud has certainly not been found, but the Ethics Committee's chairmen, Ove Lundgren, has pointed out in a letter that his four-hours long investigation was not sufficient [to exonerate the researchers] and that a more extensive investigation was needed, to be carried out by an external expert.

In Sweden only the Swedish Research Council (SRC) can make such an independent external review. This, however, requires that Gothenburg University's rector submit an application to the SRC to do so. For some reason that has not been done. This has happened despite the fact that the Swedish Research Council and many others (among others, Leif Elinder and Eva Kärfve) have asked for such a solution, which should have satisfied all parties.

Instead, in the media, a picture has been painted that the Gillberg affair is very complex and twisted and that the affair is very difficult to understand. Yes, the affair is certainly difficult to understand, but for quite other reasons. There is nothing wrong with our current laws that govern scientific research.

Experts of ethics

This is the opinion of several ethics experts that *GU Journalen* has spoken to. Björn Thomasson, the Swedish Research Council's ethics expert says, "the problem is that Gillberg has given promises, which he has no right to give. You cannot promise that the material will never be checked by someone outside the research group. He [Gillberg] has gone too far".

This picture is also confirmed by the university's own administrators, who prefer not to deal with this matter any longer. Even the university's legal representatives withdrew after the Administrative Court of Appeal's first verdict, as they felt that it was meaningless to pursue this question further.

New experts

The material must be made available [for scrutiny]. But Gothenburg University refused and instead engaged a new expert—a former head of the Administrative Court of Appeal—Nils O. Wentz, who was also the father of one of Gillberg's close colleagues. This has been kept secret.

Instead the Gillberg group repeats its permanent mantra about a slander campaign perpetuated by [a band of] litigious doctrinaires, revenge-inclined doctors, and a few odd journalists. The last boost into this band is the Director of the National Board of Health and Welfare, Kjell Asplund. According to Gillberg, Asplund deliberately lied to discredit him when he, with reference to a faulty preliminary investigation, fired Gillberg from his position as a scientific advisor to the National Board of Health and Welfare. This was a top story in *Göteborgs-Posten* on 04 November, 2004.

The media picture of Gillberg is often the one that he is painting himself: he is the hero, with the moral right on his side, fighting for the weak against the authorities.

Why the corps of journalists do not challenge this portrayal is hard to understand. Would he have been a top manager in the business community or politician who had devoted himself to court defiance, doubtless he would have been exposed to many impertinent questions.

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