

Parents are urged to sign Gillberg's protest letter

Information, urgent request, or pressure?

Parents and children who have been included in ADHD-research in Gothenburg have got completed formulated protest letters to sign. The letters come from the researchers and are meant to be returned to Christopher Gillberg.

Stamped reply envelopes have been enclosed.

People who sign [the letters] are sending the message that they refuse to accept the decision of the Administrative Court of Appeal that gives sociologist Eva Kärfve and the paediatrician Leif Elinder the right to check the research material. In the letters exists among other things the following wording: "I accept under no circumstances that these facts will be given out to the two named persons".

It was during the spring 2003 that parents and children (now 32 years old) who participated in the Gothenburg study had been contacted by telephone and then got the protest letter by post. Enclosed was also a copy of a letter that the Attention Society and the Autism Society sent to the [Gothenburg] University board at the start of March.

The researchers telephoned

"I was called by a woman who said that her name was Anna Gillberg and that she participated when I and my child participated in the study in the end of the 1970s", says a parent, whose children also have received the preprinted letter. "She told me that the information would be sent by post and that there was something for me to sign—if I wanted to do so".

Carina Gillberg [wife of Christopher Gillberg] was one of the doctors who researched for the study from the beginning. She did not want to reply to any questions [for this story], but there is no doubt that the researchers are the senders [of the letters], since no other person has access to names [of the study subjects] and their records.

One of the issues that Carina Gillberg was asked about was how they [i.e. the researchers] looked upon the risk that the letters would intimidate the addressees. For example, in view of the wording in the letter from the [Attention and Autism] Societies, that they are deeply worried about the consequences the verdict of the Administrative Court can have for those individuals who participated in the study.

Another question was if you [Carina] are aware that your wording of the letters can be regarded as pressure. In the survey, there exist of course many parents and children with gratitude and respect for the doctors in the group of researchers.

A third issue is about the Gillberg group's hope that despite the verdict of the administrative court, they will get away without having to submit the research material [for investigation]. But if the court's decision remains, this hope can be a gamble of concern for those involved—this is definitely is a risk.

The incorrect view that a investigation [by Elinder and Kärffe] means that everyone—journalist, and anyone—will be able to see the material is widespread. A 32-year-old man who participated in the study recently made a comment on [Swedish] television channel 4 where he warned the public that “your worst enemy would get access to this sensitive information”. In *Göteborgs-Posten* [a major Swedish newspaper], Christopher Gillberg has compared an investigation with throwing out AIDS medical records on the street [“What would you say if you had AIDS and your doctor threw your medical records out on the street?”].

No, the initiative of the group of researchers does not seem to be meant to calm nervous parents and children. Another key question is what is needed to calm the research group, which seems to be noticeably tormented by the situation.

What you know for sure, without having their replies, is that the Gillberg group wants to activate a lobby group and that the letter campaign has taken place without the knowledge of the university board. “This [letter campaign] I know nothing about”, says the [university rector] Samuelsson, who did not want to comment further on the topic before talking to close employees and legal advisers.

MarieLouise Samuelsson
Dagens Forskning
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