

An e-mail from a family

Dear Kjeld Høgsbro

We just want to tell you that we are so sad about your report on ABA. We find your judgement of ABA prejudiced, and it fails to give a neutral, scientific evaluation of ABA. The negative sentiment towards ABA in Denmark might lead us to leave Denmark.

We will go to Norway where people dare take initiatives even if they cannot put up with any guarantee. (...) It is so difficult for us, as an 'autism stricken' family to hold on to optimism. (...) Everywhere you are confronted with negative prognoses and pessimism.

In the typical institutions the children are being locked in, gets a lousy treatment and the teachers ignore the existence of the parents. The children are 100% socially isolated.

Family NN

From the qualitative interviews

F: - Because if he gets turned loose, then 95% of the things he does are completely foolish, and that's what we find most depressing, when we don't have the resources to organise anything for him and we just sit and watch him run about and behave eccentrically. So then you feel bad and get unhappy, and on it goes. ABA gives us tools to get started on something, and the instant he completes a task, you can see how his energy picks up, and he cheers up, because he sees that there are some things that he can actually do...

M: - Yes, she has to... but I have racked my brains trying to figure out whether it's because I can't bring myself to make the effort, or because I don't have enough faith in her. But she gets very, very tired, and sometimes I can't even get her into her bath, because she's so tired. But it's a real dilemma when you're the parent of such a child, and once in a while I insist on having a normal life as well, which I couldn't do if I had to be her therapist here at home. She couldn't live with that, and neither could I.

How could we be sure?

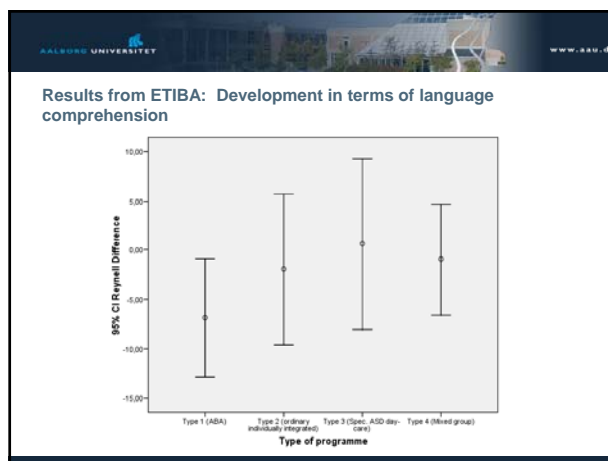
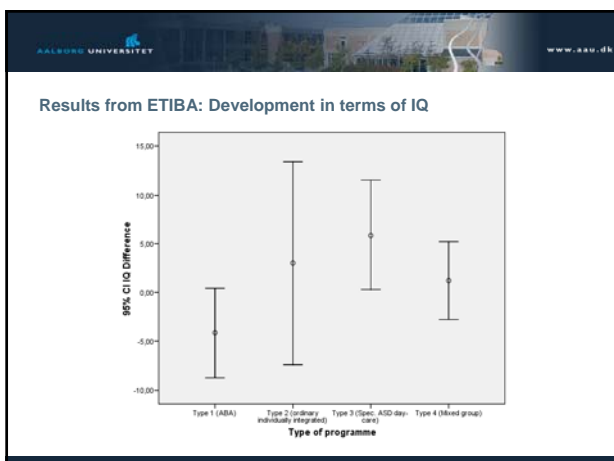
Are we the reason for taking away the miraculous training system that could help these children to be almost 'normal' for the rest of their lives.

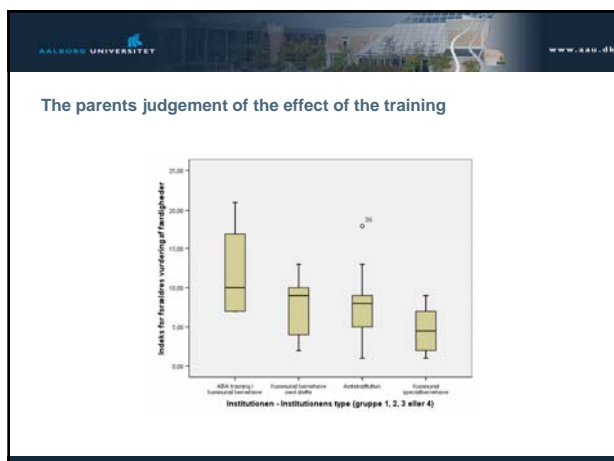
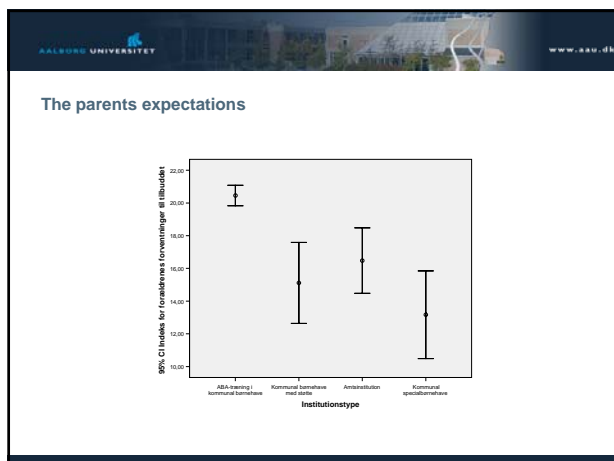
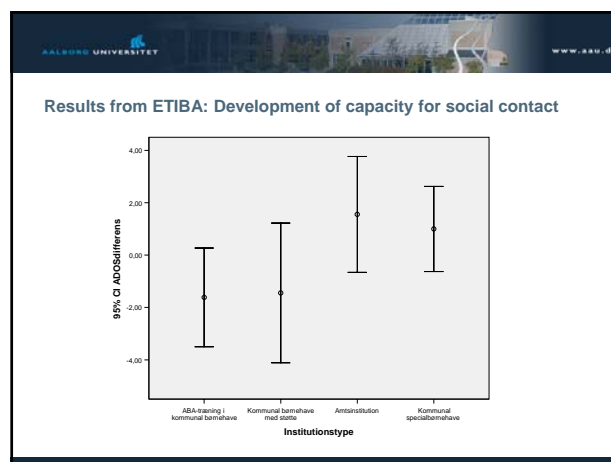
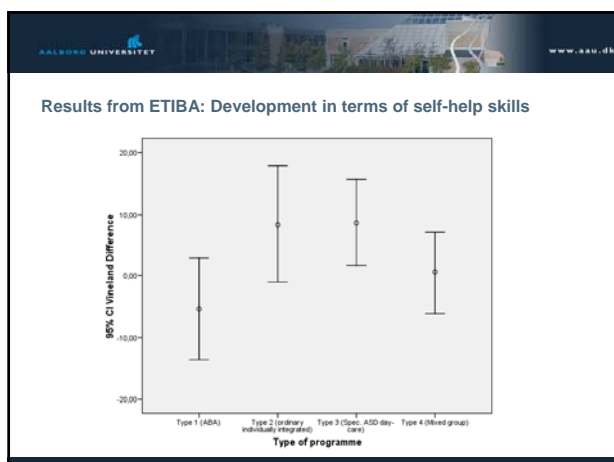
Are we the reason for rescuing these children from being deprived of any self-confidence due to ambitious parents and a wrong theory.

Should we recommend that they tried once more to implement the ABA-concept in a better organisational setting.

Would it be 'fair' to offer another extraordinary public grant to develop the ABA concept when any other concept could need that extension too?

We were stressed by our own ambivalence, the authority of our decisions and the pressure from strong actors in the political field.





- ### Potential sources of error
- Psychological tests do not explain everything. They are reduced representations of useful competences. Questions of ecological validity.
 - But ABA recognised them as the prime source for judgement of personal development.
 - Vineland Questionnaire is tested to be a rather robust prediction of future competences.
 - Vineland should have a rather high level of ecological validity.
 - Psychological tests might be influenced by prejudices of the people who conduct them.
 - But we made a statistical analysis of this effect and could not find any influence.
 - Data could be wrong due to improper transference to SPSS-data system.
 - But we have examined these procedures over and over again.

Potential sources of error

- The statistical tests could be inadequately chosen and the results could be misinterpreted.
 - But we did use four different tests and the differences were small.
 - The interpretation was made by experienced researchers.
- The evaluation design could be wrong
 - In this case we did not have any better alternative.
 - Alternative designs have alternative sources of error.

Hierarchy of Evidence in Meta-Analysis

Level 1: Randomised controlled trials (with concealed allocation)
 Level 2: Quasi-experimental studies (using matching)
 Level 3: Before-and-after comparisons
 Level 4: Cross sectional, random sample studies
 Level 5: Process evaluation, formative studies and action research
 Level 6: Qualitative case study and ethnographic research
 Level 7: Descriptive guides and examples of good practice
 Level 8: Professional and expert opinion
 Level 9: User opinion

Gains and losses linked to the quasiekperimental design

Conditions	Losses	Gains
The children might have got qualified training before they start.	No baseline Differences in distance to the beginning of the training	The sample represents children in different phases of personal development
It is impossible to order children into a program the parents does not believe in.	No randomisation The parental background is different.	The evaluation shows the results when parents have made an informed choice
The authorities are interested in an evaluation of both organisational principles and training methods	No controlled comparison of different training methods under equal conditions.	A comparison of two methods when implemented into the decided organisational setting.
The 'typical eclectic' program is by essence a group of different programs for different levels of disability	No comparison of a single controlled ABA training with a single controlled 'typical' training program.	A comparison of 14 different cases of ABA training with 40 cases of 'typical' training programs.

Reliability in accordance with the evidence hierarchy

- It is a quasi-experimental setup: The children in the ABA training can be compared with the children in the typical training. They are equal with respect to IQ, language comprehension, self-help skills and social contact.
- Measures are based on internationally recognised tests and statistical methods.

Validity that goes beyond the evidence hierarchy

- Real-life study/Realistic Evaluation. The evaluation includes effects of public assesment and referral to different ordinary programs
- The qualitative methods shows how different programs are perceived by parents and professionals
- The design gives a survey of issues and methods linked to the ordinary program
- The Qualitative interviews and questionnaires illuminate conflicts that might stem from differences between
 - training concepts
 - theoretical approaches
 - ethical and cultural premisses
- Comparing data from standardised tests and questionnaires illuminates the difference between tested quality and perceived quality.

The career family situation

M: When I had [B] – the first year- I had come to the point of my career where I thought I should apply for an executive position. But completely.. I'll never hold an executive position. And I can't change my job because no one is looking for part time employment, so I'm tied to the same job. Career wise my ambitions have been completely changed. It has had a major impact on the ambitions I had for my life.

M: - There have been some situations where it really crossed the line for us to do training, because some demands were made of him that actually made him start to cry, and that wasn't particularly fun. It's not that great to sit there and see your child being all upset that he's supposed to just keep his hands down, and hold them a certain way. That's why I said 'no more,' that we wouldn't do it; they simply had to accept that he sat with his hands up by his mouth... he was so unhappy.

The psychological strain on the teachers

	Antal	Procent (%)
,00	4	33,3
1,00	6	50,0
2,00	1	8,3
4,00	1	8,3
Total	12	100,0

	Antal	Procent (%)
,00	6	85,7
1,00	1	14,3
Total	7	100,0

	Antal	Procent (%)
,00	15	83,3
1,00	3	16,7
Total	18	100,0

	Antal	Procent (%)
,00	9	75,0
1,00	3	25,0
Total	12	100,0

How do we deal with the ambiguities?

The stress hypothesis

- The double carrier family situation.
- A high level of exchange of teachers in the ABA program.
- Great expectations to the results of the ABA program.
- ABA training ambitions override the child's resistance.

The reduced stimulus hypothesis

- The children in the ABA program are isolated from peers.
- The children in the ABA program are formally brought together with typical children. They do not necessarily have any contact with these children.
- ABA teachers are isolated from colleagues.
- The ABA program missed a strategic plan for the involvement of typical children and the ordinary institution that housed the program

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How do we deal with the ambiguities?

The point is

- We have to be able to explain the results
- We are responsible for the political conclusion that follows our judgement
- Our research intervene in theoretical conflicts as well as conflicts between user groups
- Our research is supposed to make a decision about what is myth and what is reality
- The political discourse about 'facts' and 'truth' is different from a scientific discourse dealing with 'probability' and 'evidence'.
- There are no clear cut line between research results, the interpretation of these results and the political decisions.

And in the end – being researchers

We do not want to cheat anyone

Especially we do not want to cheat ourselves!

(The basic ethical prescription according to Lars-Henrik Schmidt)

But there is no specific method that gives us any guarantee

This is the end