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Swedish doctor prosecuted for refusal to hand over patient data

From Wikinews - January 18, 2005

Stockholm - A well-known Swedish doctor and researcher at Gothenburg University has been prosecuted, together with the Vice-Chancellor and the President of the University Council, for failing to hand over sensitive data on patients to outside critics.

The *Parliamentary Ombudsman*, an official appointed by the Parliament, decided to press charges against Professor Christopher Gillberg, MD, Professor Gunnar Svedberg, (Vice-Chancellor) and Arne Wittlöv (President), for failing to comply with a court order from February 2003.

The court had ordered Gillberg and his colleagues to hand over sensitive data on patients and their relatives to two critics of their research: Eva Kärfve, a sociologist, and Leif Elinder, a pediatrician. The basis for the court's decision was the section of the Swedish constitution relating to freedom of the press. Since the university was a public body, it was obliged to turn over any documents to any citizen upon request unless the document was protected by a specific paragraph in the *Secrecy Law*.

The university argued that the material should be protected by a paragraph referring to the confidentiality of information about patients. The courts decided, however, that they could hand over the data (about 70 shelf feet of documents) if they specified a proviso that would preserve confidentiality. The university was thus ordered to first write a proviso (set of conditions) for Kärfve and Elinder and then hand over the data.

Gillberg and the other members of the research group refused to comply. They referred to the promise they had given to the participants in their studies that all the data would be kept completely confidential. They also argued that the data was particularly sensitive since the research concerned psychological and psychiatric disorders among children, and that it was impossible to anonymize the data beyond possible identification. When they had pursued all legal avenues without success, someone apparently destroyed the documents in May 2004.

The Gillberg group received considerable support from other medical researchers and from their university. They felt that important clinical research could be jeopardized unless complete confidentiality could be promised to the patients.

Eva Kärfve stated that she was happy with the prosecution and that it would "strengthen the protection of research in Sweden."

Convenor's message

Dear A4 member,

Here we are starting another year. The media is full of disaster and catastrophe.

Thanks to the activities of A4 members, A4 is meeting with the health minister as soon as parliament resumes in 2005. The meeting is just a first step. But it is a step and it results from A4 members talking with and writing to their politicians. We are starting to get things moving.

Recently, A4 was invited to send representative to a national forum on employment issues for people with a disability. I want to see this as a sign that autism is recognised as important in policy; and perhaps that all our efforts are starting to pay off.

Simon Baron-Cohen, author of the elaborate Mindblindness or "absent theory of mind in autism" hypothesis, has another hypothesis about autism. He suggests investigating whether autism is due to too much testosterone, probably in very early development. As yet I have not seen an explanation of why the male to female ratio apparently drops as the diagnosis rate rises.

For A4, 2005 will be a good year if everyone increases their understanding of people who experience the autism spectrum. Understanding leads inevitably to more appropriate environments and to better use of available effort, capacity and resources. In some cases, better understanding leads to increasing support and improved equity.

Regards
Bob Buckley
Convenor

State News Queensland

The Queensland Government has released a consultation paper to help stimulate community comment on proposed improvements to services for people with a disability.

The Minister for Communities, Disability Services and Seniors Warren Pitt, said the consultation paper 'Have your say: On improving disability services in Queensland' would provide valuable feedback to the Government.

"Responses may be lodged the traditional way through a written response to the consultation paper, by attending facilitated sessions, through a phone-in, or by participating online at www.getinvolved.qld.gov.au," he said.

Mr Pitt said the newly appointed Disability Council of Queensland and the 10 Regional Disability Councils would also play a key role in helping regional Queenslanders access and participate in the consultation.

"The new Regional Disability Council members who have been appointed have diverse skills and are respected for their views and their ability to engage with their community," he said.

"One of the first challenges in their roles will be helping shape the consultation process on these issues for their regional communities."

The consultation period would remain open until 15 April 2005.

To request a consultation paper, call the Department of Communities on 1800 102 225 or DIAL the Disability Information and Awareness Line on 1800 177 120. Hard copies [are now available].

The document is also available from www.communities.qld.gov.au. Alternative formats are available on request.

Queensland parents call for help

Rex Warren, an A4 member from Gladstone Qld, sent us a distressing story from the Courier Mail (see "Custody grab breaks parents' hearts", 10/1/2005, http://www.thecouriermail.news.com.au/common/story_page/0,5936,11894429%5E952,00.html). He says:

"It would help immensely to vent your anger and disgust on mass to shake up the Queensland government right now.

There's a feedback link at the bottom of the story where you can post your comment online."

The 'Read Feedback' section of Courier Mail's website (see <http://www.thecouriermail.news.com.au/sectionindex2/0,5935,Feedback%5Efeedback%5ETEXT,00.html> and use your web-browser to search for 'custody grab') shows some of the public responses. One affected parents wrote:

I am heartened to see so many letters condemning the State Government for the way that they are treating my family. Take this opportunity to move the government to make an overdue change please write to Minister Pitt. There are many families in our position or soon will be. By this time next week I fear that we will have lost our son. Help us.

You could also send a copy of your comments to Hon Warren Pitt MP, Minister for Communities, Disability Services and CandDS@ministerial.qld.gov.au (fax 07 3210 2186) and to Hon Shane Knuth MP, Shadow Minister for Communities and Disabilities, charter.towers.clermont@parliament.qld.gov.au (fax 07 4787 3919).

Here is my comment, sent to the Courier Mail and the Queensland politicians...

So the Queensland government is determined to repeat mistakes it made with the stolen generation, this time with children who develop major behavioural challenges related to their untreated autism.

Children with autism have a clinical condition that requires clinical attention. Last year the ABC 7:30 Report showed children with autism do not get the treatment they need. Tearing children from their families makes it worse.

Far better outcomes at much reduced overall cost will result if ever the government provides treatment for their autism and supports their families.

Currently Government agencies, that demonstrate profoundly ignorant misinformed and prejudiced views of autism, decide the government will separate children with autism from their families. Instead governments should develop partnerships with parents to provide for these children; and for adults who are severely or profoundly disabled by autism. Governments would do far better if they improved significantly their understanding of autism and their knowledge of how to improve outcomes for those it affects.

A further embarrassment for the nation is that complaints through Australian legal systems do not work. The Australian legal system protects its own processes (that are utterly inappropriate in such matters), governments and government agencies ahead of children's rights, especially the rights of children with autism.

The Queensland Government released its "consultation paper" (see <http://www.communities.qld.gov.au/community/disabilityconsultation>). Please have your say through this channel as well. Government should be left in no doubt about what we want.

Bob Buckley, 15/1/2005

ACT Consultation Paper

A Therapy ACT webpage (see <http://www.dhcs.act.gov.au/TherapyACT/AutismConsultPaper.htm>) contains a "consultation paper" on Autism Assessment that says "The consultation period is from 21st December 2004 to 31st January 2005". The paper recommends "that the Autism Association of ACT, ... , be consulted on the implementation of this proposal and invited to provide input". As yet, Therapy ACT has not contacted the ACT Autism Association. The predecessors of Therapy ACT, CHADS and parts of The Disability Program, had particularly poor track records in community consultation.

Therapy ACT's consultation paper says "the proposed model provides a program based on intensive family support and parent training for families". Further reading of the paper reveals Therapy ACT and the ACT government use "intensive" to mean...

"... 4 parent information sessions and 4 group-play sessions, with parents attending with their child and being coached in implementing aspects from the parent information session."

"There will also be a home visit each week (by the Psychologist, Speech Pathologist or Occupational therapist) which will help to integrate the learning from training sessions into the home environment. The program will also include a time for planning and administration and (possibly) a further half-day for social skill groups, or education outreach training or consultation etc for childcare staff."

Clearly, the proposal does not address the intensive treatment needs of most children with autism. The proposal seeks to further burden families with explicit responsibility for meeting their children's clinical needs. The ACT health system does not ask that families supervise and deliver cancer treatment or major surgery when their child needs it. The ACT government should not separate children with autism out to be treated this way.

People in the ACT can send their comments about Therapy ACT's proposal to therapyact@act.gov.au and copies to Mr John Hargreaves MLA, the Minister, (hargreaves@act.gov.au) and Mrs Jacqui Burke MLA, the shadow minister (burke@parliament.act.gov.au).

Please note the urgency as the deadline is 31st January. You can send an anonymous comment via Bob Buckley (convenor@a4.org.au) or the ACT Autism Association; who will pass on comments they receive to the ACT government.

Northern Territory

The Australia Day story **Surgeon captures 'Australian spirit'** (SMH, 26/1/2005, <http://www.smh.com.au/news/National/To-make-a-difference--the-spirit-of-who-we-are/2005/01/25/1106415597814.html>) says:

Senior Australian of the Year is Antonio Milhinhos, of Winnellie in the Northern Territory. He migrated from Portugal and opened a fish and chip shop before developing a retail-wholesale distribution business, but it is his philanthropy that is special. He gave the entire stock of his supermarket to support the families displaced by Cyclone Tracy in 1974, and since then has donated to the RSPCA, the Farmhand drought relief appeal, guide dog organisations, autism sufferers and their families and now the tsunami victims. "Australia has been very kind to me," he said.

Letters to the Editor/A4

Thank you for the update. You have raised an issue which I have always found very frustrating. Whenever I have sought help for my son, I have been offered seminars and workshops to attend. This does not help my son and I find it infuriating. The autism association finds it very easy to put on workshops but fails to advocate for services for the

person with the disability. The government pretends to help by funding these useless programs for parents as parents are easier to handle than young people with autism.

Keep up the good work.
Margaret Nicholson

Hi everyone,

This is the website for the DVD: ***BEING RESPONSIVE: You and Your Child with Autism***

<http://www.uq.edu.au/sbs/index.html?page=19836&pid=167>

<http://www.uq.edu.au/sbs/index.html?page=20560&pid=19836>

Early intervention for young children with autism or social and communication impairments must be a high priority. Research has demonstrated that outcomes for these children are improved when intervention commences at an early age. This is why researchers at The University of Queensland developed the program BEING RESPONSIVE: You and Your Child with Autism.

The program is available on DVD and is intended for use by parents, carers, therapists and others interested in improving their communicative interactions with young children that have autism or social and communication impairments. The program was developed from research conducted as part of the [Stronger Families and ASD Research Project](#).

Research Team

[Dr Deb Keen](#)

[Dr Michelle Braithwaite](#)

[Dr Sylvia Rodger](#)

[Dr Anne Jobling](#)

About the DVD - contains downloadable Activity Sheets, Resources and ordering information.

BEING RESPONSIVE: You and Your Child with Autism is an interactive DVD that provides information and instructions on how to use techniques that increase opportunities for social interaction in everyday situations. During the video component of the DVD, four families who participated in the program talk about the techniques they used with their child and demonstrate how these helped to improve everyday interactions. Members of the research team provide additional information and tips about how to enhance communication and social interaction.

To provide opportunities to adapt the techniques for each child and family situation, a series of Activity Sheets are included on the DVD and are also available to download from this site. Each activity relates to a particular section of the DVD video and provides the viewer with practical ways to put into practice the ideas and techniques covered in the DVD video.

Our Support Group has invited the Research Team to present their DVD to a group of medical practitioners (general & specialist) along with Allied Health professionals, local service providers and educators.

A few Speechies saw the Team at a Conference at the end of 2004 and took the idea back to their local Disability Services Therapy Team to discuss facilitating a Parent Group locally. I really hope they do implement this with parents in their caseload.

Our Support Group have purchased a copy of the DVD and will loan it out from our lending library. However we hope that the professionals involved at the diagnostic and assessment end of things will be helpful in letting parents know about this DVD, perhaps even loaning them a copy or helping us purchase more copies for loan.

Cheers,
Helen Steinhardt - Qld

Help with advocacy

If you need advice or help with advocacy for yourself or your child, the federal Health webpage, <http://www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-contacts-orgs-advocacy.htm-copy7> lists disability advocacy services in each state. If you use these services, please tell us how it went.

A4 Contacts

Update team (newsletter)
edit@a4.org.au

A4 Convenor, Bob Buckley
convenor@a4.org.au

Treasurer (donations)
treasurer@a4.org.au

Profile

This months profile is on Geraldine Robertson, who is an active member of A4 (Steering Committee). Geraldine is one of two people that have been chosen to represent A4 at the national forum on employment issues for people with a disability.

NAME: Geraldine Robertson.

BORN: South Africa.

LIVES: Beautiful west coast of Tasmania.

FAMILY: 3 adult offspring and 1 lively grandson.

LIKES LISTENING: No, I don't. I would rather talk.

LIKES READING: Eclectic but I don't like gory bits.

LIKES RELAXING: Savant abilities here.

LIKES EATING: I have a black belt in cooking. I specialize in Cordon Noir, ie everything burns, so I like to eat food cooked by other people.

LIKES: Broadband internet connections, hardware stores and small children.

DISLIKES: Dial up connections, cosmetics and supermarkets.

IDEAL WEEKEND: Camping at an isolated beach alone. Luckily I live in the ideal spot for that.

LAST HOLIDAY: This one. Christchurch, New Zealand.

NEXT HOLIDAY: Probably Melbourne with my grandson at Easter.

Editors Notes

Our feature article this month is a newspaper article from overseas about Professor Christopher Gillberg, MD. This is classed as 'World news', and as such has no relevance to anything happening in Australia, except to question just how confidential 'confidential' means in University studies taking place in our country.