

**SUBMISSION BY HELEN & GRAHAM DAVIES TO THE HOUSE OF  
REPRESENTATIVES STANDING COMMITTEE ON EMPLOYMENT,  
EDUCATION AND WORKPLACE RELATIONS**

**INQUIRY INTO THE EDUCATION OF BOYS**

This submission seeks to bring to the Committee's attention Klinefelter's Syndrome. Klinefelter's Syndrome is a chromosome abnormality found mainly in males who seem to suffer the most from its effects. It means that the body does not produce enough testosterone to promote the normal growth of the testes and/or the penis. IF a diagnosis is made then the boy can have testosterone replacement much the same as a diabetic receives additional insulin. This certainly results in normal masculine body development than if the syndrome is left untreated.

Our son was diagnosed with Klinefelter Syndrome when he was 13yrs 2mths. The side effects of this random genetic disorder include poor gross motor co-ordination, delayed and poor language development which lead to learning difficulties, shyness and an inability to mix into a group.

Our son was teased and then bullied at school from the time he started preschool (mandatory from age 4 in the ACT) because he had a very poor vocabulary compared to his peers. Even four year olds can pick up on the sounds of common words being twisted around. At six he didn't have the ability to describe a carrot, he could not read, and was becoming disruptive in a group/class situation. Thanks to the help from CHADS, he had 1 year of speech therapy, hearing and sight tests and 1 year of a special "how to be in a group" session at the AIS gym school.

He was also receiving anger management counselling over several years from several counsellors, because the teasing and bullying at school was so extensive he could only cope by being violent. The school's remedy for his being bullied and retaliating was to isolate him during breaks. All this happened before his eighth birthday. The main teasing at this Government primary school was to call our son "Ken Doll and dumb giraffe" - they were the words he could tell us about. This ACT Government Primary School insisted that he was a capable student and should go on to 4<sup>th</sup> grade even though he could only read words like cat, dog and ran, but could not write or spell his full name without help.

We changed to another Government primary school, and, at our son's insistence, he repeated 3<sup>rd</sup> grade. Things improved for almost a year, then he became disruptive once more. A pattern emerged - he was a good boy all morning till after lunch, then in the afternoon he was emotional, had no attention span and eventually, by grade 6, violent. When his mother pointed out that there was obviously a pattern to his behaviour, she was

called a stupid interfering and overprotective parent by the school counsellor. At every stage we did exactly what the school wanted to be done but in return were patronised and had our opinions ignored.

In addition to more anger management courses, we did a “Parents as Tutors” course at the University of Canberra, used the Queanbeyan Primary Reading programme, and engaged a private tutor for reading and comprehension to help our son to keep up with his peers. At no time did our son share with anyone exactly what the teasing was. By the end of 6<sup>th</sup> grade we were consulting doctors about his behavioural problems and the school counsellor had suggested drug therapy be considered for Attention Deficit Disorder.

After he was rejected by two High schools because of his violent class behaviour, our son broke down and told his father exactly what he had put up with since he started school. Please, can you imagine the things young children can say to another if that child does not appear to be “normal”. All children go the toilet at lunch time, our son was noticed to be different from the other boys and was considered fair game.

Our family G.P. sent us to a Paediatrician who, after a number of tests that all came up negative, decided to try one last test. A chromosome test showed that, instead of having the normal number of chromosomes (46) our son has 47 chromosomes, the extra one being an additional X chromosome. As you know, girls have XX chromosomes and boys have XY. This is identified as Klinefelter Syndrome. The incidence of this syndrome is as high as 1:1000 males but most have not been identified. Since birth, our son has been examined by 4 paediatric specialists, 1 psychologist, 4 school counsellors and our family G.P. but not one of these highly trained people could give us an answer on his physical or behavioural problems. Yet even Centrelink did not require more the usual forms and a doctor’s letter to give our son a healthcare card and to provide a child disability allowance to help with extra education.

He started at a Government High School with a Year 4/5 reading level. By the November of Year 7 he had dropped to Year 3 level. The Government High School had promised that he would have full access to the Resource Centre to help him with literacy skills and any other learning problems. However, the ACT Education Department cut the funding for these centres and the school had to ration access to provide for the most needy students. The High School decided that to use the centre students must have an IQ of 70 and below, but our son is in the low 80’s. None of this information was in writing but given to us verbally in confidence.

In the community there are many young men who have low self esteem, literacy problems, behavioural problems, and we can not avoid wondering if many of these young men may have undiagnosed Klinefelter Syndrome. We know how relieved our son was to find out that there was a reason for his numerous problems and that something could be done to make him look like any other boy his age. In 18 months of testosterone treatment and a change to a small private school that has no restriction on its resource

centre he has gone from a very troubled and confused child to a confident and happy teenager. In 6 months out of the Government School system his literacy has gone from Year 3 to Year 7 thanks to the combined efforts of his new school, his tutor, himself and his family.

Please consider more general testing of boys at birth so that their parents can be given counselling on the problems of raising a boy with Klinefelter Syndrome. There is also a desperate need for educators to be made aware that there are more leaning difficulties than ADDF or Autism and that with a little assistance, encouragement and consideration boys with Klinefelter can be successfully taught. Interestingly our son has had no problems in his soccer team or scout troop, all the difficulties have been within the Government education system.

In addition, we all appreciate that humans cannot learn in an atmosphere that is threatening or violent. In our experience it is the natural tendency of a Klinefelter sufferer to lash out physically when bullied because without behavioural training and support he does not have the ability to express himself verbally or cope with his frustration. This encourages other children to join in the bullying and general Education Department policies are to punish both bully and victim if the victim resists in any way.

This would be fine if the victim doesn't already have all the negative attributes of Klinefelter Syndrome. Suddenly the child with a disability feels that he is being attacked by the very institution that is supposed to educate and protect him. This produces a downward spiral and almost total withdrawal from receiving an education, the teachers may see this as sullen resistance and the children take it as a sign that the disabled child is fair game for them to continue bullying.

(Helen Davies)

(Graham Davies)

4 Marsh Place, MELBA ACT 2615

E-mail: [marshrat@ozemail.com.au](mailto:marshrat@ozemail.com.au)