



October 5, 2015

Maria Thorne  
Assistant Director of Mental Health Services  
London Borough of Redbridge  
C/o Transitions Department  
91 Ray Lodge Road  
Woodford Green  
Essex  
IG8 7 PG

Dear Ms. Thorne:

Re: Adam and Kane Orgel's Education Continuation

I am writing to you in support of Ms. Rachele Orgel's request to the LEA to place her two sons, Adam and Kane, at the residential Glasshouse College in Stourbridge, Birmingham, a special needs school where they will take an animal management course.

The XXYY Project is a global organization serving families of boys and men diagnosed with the rare condition 48, XXYY. We operate under the umbrella of AXYS, the world association for x & y chromosome variations such as Klinefelter Syndrome (XXY), Jacob Syndrome (XYY) and Trisomy X girls. The XXYY Project is the only organization serving XXYY families in the world and therefore we are the world experts on this condition. We serve dozens of families in the UK and have had frequent contact from our families about difficulties with obtaining appropriate educational and community supports in the UK system.

Ms. Orgel became a member of the XXYY Project on June 2, 2005, just months after the diagnosis of her sons, Adam and Kane. She has had constant contact with us since she joined our organization and has obtained all of the information available on XXYY Syndrome that can help her sons. She has attended events where we have sent our leading world physician on this condition to the UK as well. In fact, there is currently **only one physician** in the world who is an expert on XXYY, plus her team of psychologists, endocrinologists and therapists. They are located in the United States.

**In other words – there is no one in the UK who is qualified to do any kind of psychological assessments of Adam and Kane or provide any kind of help or treatment that could be more valuable than the knowledge that Ms. Orgel has about XXYY. Ms. Orgel therefore should be viewed as one of the UK's leading experts on XXYY Syndrome, and her insights and decisions about her boys should be considered the most relevant.**

AXYS (formerly known as Klinefelter Syndrome & Associates – KS&A), is a 501(c)(3) non-profit organization whose mission is to help individuals with one or more extra X and/or Y chromosomes and their families lead fuller and more productive lives.

Having one boy with XXYY in a family with two parents is extremely difficult and beyond the scope of understanding of most people. But Ms. Orgel is a single mother of twins with XXYY, an unimaginable position even for me. I have a 33 year old son with XXYY who still requires a great deal of care and support, which taxes my ability regularly in spite of the fact that I am the founder of the XXYY Project and know everything there is to know about these boys. The XXYY Project serves hundreds of XXYY families world-wide and I know all of them.

Adam and Kane were permanently excluded from their last residential school for behavior which was a manifestation of their disability. The fact that Ms. Orgel has had to deal with them at home for the last five months is unconscionable. The last school should have understood that the behavior they manifested was in fact due to their impulse control issues and poor judgment associated with their disability and they should have been accommodated. I have to wonder, if they had Down Syndrome, would they have been excluded or would the school have done more to help? Now that they have been excluded, they have nothing to do and nowhere to go and because the LEA has decided to exclude them from further education at the school in Birmingham, we have to wonder exactly what you expect them to do all day, while Ms. Orgel is at work?

The stories of adults with XXYY world-wide range from catastrophic to triumphant and those situations all depend on the level of support their families receive from local education authorities and community service providers. The less help the family receives, the more major the catastrophe, including wrongful imprisonment and life-long institutionalization against the will of the family in some countries. This includes the UK, where we currently have at least two adults with XXYY who have been taken from their families and placed in institutions permanently (at least one is against the will of the parents) and one who is constantly in trouble with the law because his mother (who is now deceased), had such a terrible time finding and obtaining supports for her son. All of these catastrophes could be avoided with the proper education and support of these young men.

Males with XXYY Syndrome are typically far behind their peers in social development. Adam and Kane are 19 years old, for example, but their social age is at least five years or more behind their peers. In other words, they are pre-teens in the bodies of adults. With time, they will grow to be more in line with their peers, or at least in the realm of behaving like the adults that they are. But they are not there yet and they need more time in school while their brains continue to develop so they can navigate the world more effectively and stay out of trouble. Together as twins, they feed off of one another, which for Ms. Orgel is an incredibly difficult thing to deal with, considering that she must work in order to support them and cannot attend to them at home 24 hours a day.

Males with XXYY also have a track record of “failure to launch” as some people would put it. In other words, they may have many skills while they are in school but once they leave school, they have great difficulty translating those skills to the workplace. The most successful of our adults with XXYY have been given more time in school, more training, more parental support, and more community support to be successful and stay out of trouble. We have some adults who

have their own businesses, went to college, went to school to learn to drive heavy machinery, work in factories and more. Yet, the vast majority of adults with XYY still depend heavily on their parents and the government and many are living in group homes or other supported living environments and working only part-time, often in a structured environment for people with disabilities. A great deal of this problem is due to the executive functioning problems in their brains. They are unable to organize, plan and execute things on their own. Some are able to gain more control over time as their brains completely develop, but they need more time and they need to be in supervised learning environments where these skills can be developed.

In the United States and Canada, teens with XYY Syndrome receive special education services until they are 21 years old. From the age that Adam and Kane currently are, until age 21, the schools provide further education and a lot of assistance in helping the individuals to learn skills such as money management and other social skills development. They have job coaches who help them to develop job skills and follow them at work to ensure that they are successful in the workplace. From there, Vocational Rehabilitation and community services take over to provide further education and support to help them to reach their goals. In Adam and Kane's situation, the school that Ms. Orgel has selected for them is an ideal situation where they can learn an extremely valuable trade and still have the kind of supervision that is going to be necessary for them for many years to come.

Furthermore, many males with XYY are unable to drive cars because they have many medical problems, impulse control issues and extreme lack of judgment. Adam and Kane cannot be expected to drive themselves to appointments with psychologists or to attend community programs on their own. They need to be driven there and supervised. They will forget all of their appointments and will be distracted. Ms. Orgel simply cannot quit her job in order to keep them busy by driving them around to appointments that cannot help them anyway.

Therefore, the "option" that has been suggested to Ms. Orgel that Adam and Kane see more psychologists and behavioralists instead of providing them with further education and a supported living environment is completely and utterly wrong, irresponsible and potentially disastrous not only for Ms. Orgel and the boys but for the UK government as well. While psychologists and psychiatrists might be part of a team approach to assist an XYY family in some way, there is no known behavior therapy that works for males with XYY. Most psychologists tell us they have no idea how to help our families in a very concrete way. We know as well that in the UK, medications are used less frequently and even if they were used more, finding the right medications would be a trial and error endeavor that may not necessarily produce the desired result. What does work is continued education, community support services and experience while the boys continue to mature.

Adam and Kane should be provided the opportunity to learn a skill that could translate into meaningful work, in a supported environment that understands people with disabilities like the school in Birmingham that Ms. Orgel has selected. Any "option" that would require the boys to get somewhere on their own, be home alone for extended periods of time, blend them completely into a typical population of people or force Ms. Orgel to stop working to support them will not work. Even after they complete their studies in Birmingham, Adam and Kane may still need a

supported living environment of some kind. But if they have meaningful work to do and a safe environment in which to live, they could do fairly well, at least in the realm of how it works for males with XYY Syndrome.

My 33 year old son received special education services until he was 21 years old. Although he has been unable to work and unable to drive a car due to his own issues with behavior, he does live independently. He receives community supports and we manage his money. He lives in a condominium that I purchased for him. His only income is government support. The supports he did receive were woefully inadequate, did not take into account his maturity level and he did not learn a trade of any kind. He did, however, benefit greatly from his extended period of time in public school, which did teach him independent living skills. When he was a teenager, he was in a great deal of trouble with the law and had numerous psychiatric hospitalizations. His behavior issues were far more significant than Adam and Kane's issues. He overcame all of it and while he is not living a dream life, he is independent and even with the extreme behavioral issues he had in the past, he has not been in trouble since that time.

Without further education and supports, the UK government is going to find that Adam and Kane will become much more costly and difficult to serve in the future. They will become completely dependent on government support and services and they will get into a lot of trouble. This is how it works with XYY, world-wide. Sending them to the school in Birmingham is their very best hope and their mother is 100% correct about that. In fact, they never should have been excluded from the last school, which has caused extreme disruption in their lives and horrible stress on their mother. The LEA needs to listen to Ms. Orgel, because the LEA has no understanding of XYY Syndrome or what she faces in the future. While the LEA may think it knows what is best for these boys, it is obvious it does not. What you are doing to them is basically throwing them out to a life devoid of any meaning, without skills but with behavioral issues that cannot be fixed by psychologists. They will not be equipped to deal with the world when their mother can no longer care for them, either. The fact that you have told Ms. Orgel that Adam and Kane cannot benefit from further education is, in our view, completely irresponsible and belies the fact that you do not understand XYY like Ms. Orgel and we do.

We urge you to take the appropriate actions to move Adam and Kane to the school in Birmingham immediately and to make certain they stay there until their education there is complete.

If you have any further questions about XYY Syndrome, contact me directly at 303-400-3456 or by email at [support@xyysyndrome.org](mailto:support@xyysyndrome.org).

Sincerely,



Renée Beauregard  
Founder, XYY Project