Name

Address

Date

Re: Childs name, school and year group

Parental input re EHCP Assessment.

Dear ??,

To:The Special Educational Needs Dept

Re: childs name, School and Year group.

**Parental input re- Statutory Assessment for an EHCP.**

Dear Sir or Madam,

We are writing as the parents of the above child to request a statutory assessment of our son’s special educational needs under the 2011 Education Act. His school, private tutor, speech therapist, paediatricians (both locally and GOSH) and endocrinologist fully support our application.

Due to his extremely rare (additional chromosome) medical condition of 48XXYY he has complex global educational and medical needs.

 Research of his medical condition has proven that XXYY adults are significantly disadvantaged if early intervention and special educational support are not provided.

Childs name currently attends ?? school.

He has a diagnosis of **48XXYY syndrome**, a very rare chromosomal abnormality, (which causes learning difficulties). With underlying **Autistic Spectrum traits, Dyspraxia, Flat feet, Speech Disorder** clearly showing features of developmental verbal dyspraxia, **Joint hypermobility, Taurodontism, Behavioural difficulty,** **Radioulnar synotosis** (elbow bones are fused together), **Developmental delay and an Innocent heart murmur.**

Our reasons for applying for a statement are:

Due to his exceptionally rare condition no standard educational tool is available to guide us, or his school, in catering for him.

Even with the massive amount of intervention he has received and the huge level of support he currently gets, his progress is extremely slow and he is not achieving the levels we would expect of him in basic literacy and numeracy. Through research of his condition we are well aware that this will only continue to slow, as the curriculum becomes harder and more abstract.

During recent school testing he told me he had the questions read out to him as he “couldn’t do it” This shows that the low levels he is attaining are not true levels as he is being supported throughout his tests.

Through research of his medical condition and from the professionals that monitor Jack we have been made aware we will need an educational health care plan not only to support his learning now but also to ensure he can access the correct provision for his future. A n EHCP would enable us to choose his senior school in year 5, ensuring that he can be allocated a learning base with daily access to a main stream setting attached or a specific learning difficulties school. Up to date information shows that almost all 48XXYY cases of school age children in the UK attend these types of schools. Although secondary mainstream settings do differentiate work they are not able to differentiate it enough for XXYY abilities this coupled with the expectation of behaviour at secondary school would be too much for our son to cope with.

This will mean they can make the provision required to fully meet his

educational needs. They should also be understanding that as he has constantly changing complex global issues he must not be overloaded with the school curriculum and homework, and has a right to enjoy life outside of school too without being totally exhausted.

Another area for concern at transition is that due to the village location of his current school and the small class sizes he is unlikely to cope with the sensory overload of high numbers of pupils, noise levels and the fact that he doesn’t recognise anybody in a large secondary mainstream setting.

 We believe that a beneficial plan for his education and life skills can only be properly formulated with an EHCP and the help and guidance of his medical professionals. This multi-disciplinary approach will give our son the chance to have his needs met, implemented and evaluated on an annual basis. We are certain it will be the only way to ensure he performs to his full potential and most importantly remains happy in his school life.

**Current Situation**

 We believe, and the school is in agreement, that his needs are complex and his learning is sporadic and inconsistent. His tutor also reinforces this.

He attends a very small village school which has 102 pupils in total. His class has year 3 and 4 pupils, and consists of 31 children, his year group has 14 children. His class would normally have 2 or 3 qualified adults present at one time, one teacher, one SEN support teacher (who is specifically for another child with a statement, but often helps our son unofficially) and a teaching assistant. On top of this he is taken out to work in small groups or one to one. He is taken out on a daily basis for reading, numeracy,handwriting, speed tests etc.

He would not cope without this support.

??? school have been extremely supportive and have put lots of differentiation in place, However even with the high staff to student ratio his teachers have repeatedly expressed concern that they are unable to meet his educational needs in the current setting, with the current resources available i.e administering SALT, reading programmes, homework books, other areas.

We regularly experience difficulties getting him to school as he feigns illness, becomes argumentative, refuses to leave the house or get in the car, this often results in complete meltdown. He has also displayed this when going to a private tutor.

child’s name special educational needs are as follows:

* Difficulty with both expressive and receptive language
* Difficulty organising and ordering his ideas
* Difficulty with word retrieval
* Difficulty with processing verbal instructions
* Difficulty reading and comprehending
* Difficulty organising information
* Short attention span and is easily distracted
* Difficulty staying on task
* Interprets literally
* Doesn’t like to ask for help when needed
* Has difficulty working in large group settings
* Has impulsive behaviour including lying and stealing
* Needs extra help to understand another person’s perspective
* Difficulty understanding abstract ideas
* Finds it difficult to predict and anticipate events correctly
* Lacks self esteem & confidence
* Difficulties managing own behaviour
* Is socially vulnerable
* Mood instability
* Doesn’t manage well when plans are changed
* Worries when rules are broken
* Doesn’t get social cues and facial expressions in real life situations
* Has a lack of understanding of what is socially acceptable
* Doesn’t understand others feelings
* Difficulty understanding emotions
* Has confusion and fear of unexpected events
* Has significant sensory processing problems
* Has low muscle tone and suffers with severe tiredness
* Is very anxious and pessimistic
* Becomes upset and frightened very easily
* Is very strong minded and is difficult to persuade
* Becomes easily frustrated
* Unusual sleep pattern
* Meltdowns
* Doesn’t cope well in noisy environments
* He is unable to understand certain aspects of the school day without one-to-one support
* He comes home from school feeling totally exhausted and over stimulated and his behaviour then deteriorates due to his fatigue.
* Although we put much additional effort into helping him with his literacy and numeracy at home, (including up until recently) two sessions a week with a private tutor and school give all the support they can with current staff and resources, he is significantly behind his peers in **basic** literacy and numeracy.
* His private explained he has now reached a plateau in the level of understanding he can cope with and the work she was now trying to cover was beyond his capabilities this was resulting in severe behaviour issues, aggression and non compliance. She has also commented that he has the most complex and unusual combinations of learning and processing issues amongst all the special needs children she has ever taught.
* As the curriculum becomes more demanding research of 48XXYY shows that progress will slow right across all areas.
* Boys with XXYY syndrome have problems with Adaptive Functioning throughout their lives, and although some may have an IQ within normal range, they have difficulty accessing this IQ and translating it into social and life skills. As our son spends a large amount of time at school this becomes an important place for developing these skills, and to do this he needs constant support in all aspects of the school day and not just the academic parts.

The school day is very long, difficult and somewhat confusing for him he comes out absolutely exhausted and frustrated, this leads to him feeling either very emotional and argumentative (If you try to help or advise him in any way not just with homework, he takes this as criticism and goes into a complete angry meltdown this is very often followed by his form of total shutdown. He hides himself away and we find him asleep), or he wants constant reassurance and attention often acting very babyish.

**XXYY Syndrome and childs name.**

We are very lucky to have a relatively early diagnosis of 48XXYY. This will enable school, the Education Authority and Health services to act quickly in providing a comprehensive support strategy to best support and include him in a way he can understand and work with. It is well documented that early intervention has the most positive outcomes, not just for now but also ensuring his future is the best it can be thus enabling him to reach his full potential.

childs name was diagnosed with XXYY aged 5years 9 months, via a chromosome blood test ordered by Great Ormond Street geneticist Dr. Brain. We were referred to her through his paediatrician and speech and language therapist at the Nuffield Centre in London who had expressed concerns about his education, emotional & social behaviour and some physical difficulties.

childs name has two extra sex chromosomes in every cell, and this has been proven in recent research to cause specific medical problems; Developmental delay, learning disability across the spectrum, social interaction difficulties, Speech and language problems, behaviour outbursts and mood swings, intellectual impairment, ADHD symptoms, Autistic spectrum symptoms, lack of stamina, Heart irregularities, impotence, anxiety disorder, various mental health problems, significant dental problems, low muscle tone and flat feet. All of these symptoms are present in our son.

Due to the XXYY he will not have a normal puberty and will require testosterone treatment to make sure he develops into adulthood, this will be monitored from age 10 and will be administered anytime from this to his early teens, this will continue for the rest of his life to help prevent the problems associated with little or no testosterone, such as bone problems and extremely tall stature. This treatment often causes hand tremor and mood swings. This tremor increases with age, making handwriting become difficult.

 XXYY can cause heart and neurological conditions and all of these will continue to be monitored over time.

 Our son has undergone so many assessments, scan’s and various tests he is aware he is different and has 48XXYY, although he has not been told and would not at this stage be able to comprehend or understand all the implications it comes with, and the treatment he will have to go through. He does and will have to continue, to attend many appointments which do have a massive emotional impact upon him, he exhibits this in many ways including questions, frustration, anger and tears.

Boys with XXYY exhibit a very wide range in levels of learning disability and therefore one cannot fully predict how Jack will develop at school. However **all** **XXYY boys** **do** **encounter specific problems with reading and writing** and also meeting the behavioural expectations of the school setting. Jack tires very quickly mentally and has a short attention span so our concern is that as the intensity of work increases and without the right support he will slip back further, and increasingly lose confidence and interest, which will have a detrimental effect on his whole outlook and self belief.

Boys with XXYY are better visual learners and have problems processing auditory information. This is the case with childs name. He is prone to sensory overload and responds better to one-to-one or small group work due to his sensory processing difficulties. He has a strong visual memory and can talk in detail about past events.

XXYY boys often have social and behavioural difficulties and childs name shows this. He is a very anxious child who often feels insecure and lacks emotional judgement. He is also prone to extreme temper outbursts, aggression and emotional meltdowns. As we understand more about his condition we are managing this side of things well at the moment with the support of school, Parenting courses, behaviour management courses, friends and family. . We have access to the 48 XXYY Family Support Group UK (www.xxyy.co.uk) who work very closely with the Americans between them we are kept up-to-date with information about the condition and relevant research.

An organisation called Unique Rare Chromosome Disorders has information on XXYY boys in education. Many start out in mainstream with one-to-one support where needed. Very few remain in mainstream secondary and generally if they do they need a dedicated resource teacher. Most boys attend second education in special schools or learning centres.

Childs name is a boy who is inquisitive, loving, excitable and interested in life and the world around him. He sees, hears, feels, smells and tastes the world differently from the rest of us. He is immature for his age, and socially vulnerable. He will play alongside other children (often younger than himself) hoping they will include him. He will not initiate friendships and when he does get one they are generally short lived as he tends to “lock on”, he likes it all to be on his terms and for him to be in control. He can’t understand why they don’t want to be with him all the time. This then results in him getting on their nerves and them pushing him away and name calling or ignoring him. This has happened many times and leaves him feeling angry, upset and bereft.

Our son is desperate to be liked and be sociable. He has tried and given up many activities, the only hobbies he has stuck with are horse riding with “Riding for the Disabled” where he has progressed to his level two certificate, and motorcross. Interestingly both of these are where he is in control and neither of these entail him interacting with others, but this does show that with the right support and understanding he can flourish and achieve.

Childs name has many different traits and diagnoses’ and we are keen to see what the Private Educational Psychologist and Private speech and language Therapists assessments show. We have these booked for ??. We believe that they will give us a better global picture of his specific areas of concern. The reports we have from the local authority educational psychologist and SALT show he is well below the level of his peers and in the area of “major concern” however they are not specific enough and do not highlight in enough detail his levels of understanding and how this impacts upon his education. He is already being monitored by GOSH clinical psychologist and our local educational psychologist as well as local speech and language and they will continue to see him regularly.

We would like you to take into account the many professionals who work with our son and fully support our application for an EHCP they have even suggested  **that an** **EHCP should be considered”** on their reports), alongside this we should like you to consider the low scores he attained from his last speech and language assessment when making your decision.

We are a member of the 48XXYY Family Support Group UK and are in touch with many other families in the UK with 48XXYY boys. All of which have an EHCP from their local authorities, and only one remains in mainstream schooling. As far as we are aware no other boys with 48XXYY live in our LEA. As the condition and its impact on education and daily life skills is proven to progress with age and research shows that living independently with this condition is very rare we think it only fair that you consider our son’s future needs as well as his present ones and give us the opportunity via an EHCP to get his needs met for the whole of his education. This will ensure we can apply to the schools & colleges that will best meet his needs. By ensuring this we will not waste any of his precious educational time fighting to get him what he is rightly entitled to, and we will avoid causing him unnecessary stress and confusion (which would have a massive detrimental effect on his confidence, self esteem, wellbeing and his future).

As explained Our son has a very complex condition which manifests in many ways it is inconsistent and will always be constantly changing. It will become more severe as he ages and research shows he will need constant support. It is very difficult to explain this and all his needs in one letter, but we have enclosed reports from some of the intervention he has received so far to prove his needs. Alongside this we have enclosed medical research upon how 48XXYY affects individuals daily life skills, education and behaviour.

 This is not a problem to be solved, but a situation to be managed. Childs name is going to have a lot to deal with medically during the next few years and with the help and support of experienced people, who can maximise his strengths and support him in his difficulties, we can ensure he enjoys his education and time at school, giving him full access to the curriculum. This will help ensure he benefits from a positive experience, enabling him to reach his full potential, whilst building him a secure platform from which to face his future.

Yours sincerely,

Your Name

Professional papers included:

XXYY Syndrome - Dr. Nicole Tartaglia, MD. 12 pages

Understanding and modifying the behaviour of boys with XXYY – Karen RileyPhD

We have also included reports listed below from professionals working with our son

from Great Ormond Street Endocrinologist Dr.Caroline Brain.

from Great Ormond Street Geneticist Dr.Maria Bitner-Glindzicz FRCP,PHD

from Local Speech and language Therapist – Helen Rowe showing percentile scores of 1 and 2.

Letter from Local paediatrician Dr.Karpagm Swaminathan.

Letter from school supporting this application.

Samples of school and homework in literacy.

Reports due to us in the near future which will be forwarded to you:

 from Anna Worthington SpLD special tutor, BA Hons, Primary PGCE, Dip. – April 2012

 from Local paediatrician Dr.Karpagm Swaminathan. – April 2012

 from GOSH Endocrinologist Dr.Brain - April/ May 2012

 from Celia W Claughton BA (Hons), PGCE, MEA Ed Psych,C Psychol. – June 2012

 from Janet O’Keefe B.Sc (Hons) in Speech Therapy, Master Practitioner of Neuro Linguistic Programming - May 2012