

Cynulliad Cenedlaethol Cymru | National Assembly for Wales
Y Pwyllgor Plant, Pobl Ifanc ac Addysg | Children, Young People and Education
Committee

Ymchwiliad i Gwella Iechyd Emosiynol ac Iechyd Meddwl Plant a Phobl Ifanc |
Inquiry into The Emotional and Mental Health of Children and Young People
EMH 01

Ymateb gan: Unigolyn

Response from: Individual

XX

History

XXXX was removed from biological parents at birth (no drugs or alcohol involved), placed with a foster family for a year before being adopted by us in July 2011.

At this time he was awaiting a Ruth Griffiths Assessment in XXXX, but XXXX knew nothing of such assessment or anything similar - so nothing was done - **an opportunity missed.**

At this time XXXX wasn't sitting unaided or crawling - so we were aware of his delay in development. Birth mum had special educational needs and birth father had a low IQ.

As soon as he came to us, he flourished, within a week he was sitting unaided and within 2 weeks he was crawling.

It took a few months but he was soon walking. (Lack of crawling time may have contributed to balance and core strength issues).

He was around 8 month late hitting his 2 year target, but nobody was overly concerned and the health visitor didn't know who to refer him to for the tremor in his arms and lack of hand control.

In May 2014 (at nearly 4 yrs old) we realized that XXXXXX had enlarged tonsils and adenoids as he was frequently waking in the night, Screaming, gasping for breath with oxygen levels dropping as low as 88% - so his temper and heavy handedness was put down to tiredness.

Tonsils and adenoids removed in Oct 2014, and then we said it may take a while for him to forget the learned behaviors. (Would this be classed as Early Years Trauma?)

Main issues are seen in school:

Been on School Action Plus since January 2015 - with very little progress.

Very anxious in school which results in him hitting, pinching, biting, kicking other children, lack of concentration, not learning in the class environment (about 2 years behind now),

anxious when within a large group or when asked to recall information (colours, letters, numbers) everything he's learnt so far, we've taught him at home on a 1-2-1 basis.

He struggles with change of routine or people and if things don't go the way he expects, his reaction is very dramatic and outbursts are more frequent. He finds it hard to understand why other children don't always do what he wants them to do and struggles with free / unstructured times. Struggles to see the effect his behavior has on other children – unable to control his impulses, if he wants to be at the front of a crowd then he'll be so focused on what he wants that he'll barge people out of the way. On several occasions he's bitten children when hugging them when being excited or when a limb is in front of his face, when support is offered for balancing when getting dressed or getting off a bus, but he can't explain why he does these naughty things, sometimes it's like he has no recollection of them happening – he just can't control his impulses.

ISCAN Panel

School referred his case to this panel which resulted in appointments with: Physio who referred him to pediatric due to trembling in arms and leg Consultant Community Paediatrician XXXX for tremor but he just confirmed no Cerebral Palsy and discharged him.

I requested GP to refer him for ADHD / ASD assessment – GP didn't know who to refer to??

Months later I received a rejection letter from the ISCAN panel

Mild OCD Tendencies:

Once he's been taught something one way, we're unable to change it (very stuck in his ways) so progress is difficult as you build in change to things learnt.

He closes all the doors in the house, won't get out of his bed until we go in the room.

Doesn't like dirty sticky hands, (food has to be removed, doesn't like playing with finger paints and glue).

We have to sing the same songs before going to sleep.

He has to smell everything.

Recent findings

While looking into strategies to help XXXX with his anxiety I came across information that stated if birth mother was stressed / anxious during pregnancy this could have an effect on the development of the unborn child. As XXXX was his birth mother's 5th pregnancy (concealed), with the 3 older children taken into care and a 4th pregnancy (which was also concealed) was a still born at her home, I think it would be fair to say that birth mum was under a great deal of stress / anxiety about her 5th pregnancy to conceal it again.

Once I had made that link, the information I read started to be very familiar:

Premature birth – Yes

Low birth weight - Yes

Behavior problems being apparent from the age of 4 – Yes

Problems with motor skills – Yes

Problems with Anxiety – Yes

Lack of concentration – Yes

Behavior problems (ADHA tendencies) – Yes

Plus lots more!!!!!!!

But making this link hasn't helped us in getting him any help!!!

Requests for Help

Application to Educational Psychologist – Rejected “Not a priority” use helpline for strategies.(School implemented all suggested strategies)

Application for Addition Learning Support – Rejected Contact Teacher's Advisory Service.

Teacher's Advisory Service observed XXXX in class, verbally suggested “Comm IT” and “Time to Talk etc.” school has implemented with small steps of progress, just less time in busy classroom

Application to CAHMS – Rejected due to separation from birth parents – not priority.

Application for Statutory Assessment – Rejected but instructed an Educational Psychologist to do an observation and suggest strategies.

Ed Psych: Observed and recommended strategies – very limited progress, advised to resubmit application for Statutory Assessment, which we did.

Speech & Language Assessment completed – showed his development is below average for his age, and upon observation and assessment in school, they confirmed he is below average on a 1-2-1 basis, so would definitely struggle in main stream school environment they would've requested for school to introduce Time to Talk and Comit techniques which they are already doing.

Final report stated:

- XXXX is not able to access the curriculum unless he is given a high level of adult support (School can only provide 10 mins a day!!)
- He does not attend to adult instruction
- He becomes easily distracted and distracts others
- Physically shakes when anxious and cannot continue an activity when in this state at school
- Delay of over a year in the Renfrew Action Picture Test
- Unable to function within a busy classroom setting
- Responded well when working on a 1-2-1 basis in school holidays
- They support our Application for Statutory Assessment
- Previous report submitted states he has Auditory Memory Difficulties

They also sent the report to the Primary Mental Health Team as a referral – but after 10 months of hearing nothing I rang around and managed to force an appointment only to be told that our case was too complex for Primary Care!!!!!!

After Adoption Psychology Team

As we weren't getting anywhere with the Educational dept, the After Adoption Team agreed to complete a Vineland 2 Assessment

Which stated XXXX was showing to be Low or Below Average for his adapted behavior, gave a few suggestions on how to deal with XXXX then discharged us.

Overall Level of Adaptive Functioning

The adaptive behaviour composite standard score is based on all of the items in every domain, and so it is statistically the most dependable estimate of adaptive functioning. Brendan's score was between 66 and 76 with a 95% confidence interval, this confidence level suggests that the chances are good that Brendan's true Adaptive Composite is within this range. This score classifies his general adaptive

functioning as between 'Low' and 'Below Average', he scores higher than approximately 3% of children his age.

The following table of the Vineland-II results shows the areas in which Brendan is performing above average, average or below average compared with the 'national norm group'. The age equivalent for each skill sub domain is shown in brackets in the format Years:Months. The contents of this table will be discussed below.

	Percentile Rank	Low	Below Average	Average	Above Average	High
Communication	2	✓				
Listening and Understanding			✓ (2:5)			
Talking			✓ (3:7)			
Reading and Writing		✓ (4:5)				
Daily Living	4		✓			
Caring for self			✓ (3:7)			
Caring for the home			✓ (2:8)			
Living in the community			✓ (4:2)			
Social Skills and Relationships	6		✓			
Relating to others				✓ (4:7) (Strength)		
Playing and Using Leisure Time			✓ (3:10)			
Adapting / Coping skills		✓ (1:11) (Weakness)				
Physical Activity	10		✓			
Using large muscles / Gross Motor Skills				✓ (5:11)		
Using small muscles / Fine Motor Skills			✓ (4:10)			

2nd Application for Statutory Assessment - was successful, proposed 5 hours additional support a week, school and parent fed back that wasn't sufficient, panel agreed to provide 10 hours a week - which starts in Sept 2017. So each morning he will have 1-2-1 support for literacy and maths and then in the afternoons he will be in his class unsupported - which means he will be anxious and disruptive as he'll be unable to access curriculum as stated in the Speech & Language Report above.

I now have to go back to GP to discuss getting another referral for ADHD / ASD as our case is too complex for the Primary mental Health Team and I had my hopes on them being able to help us!!!! But I feel I'm back at the beginning again with the GP!!!

All I can say is, it's very confusing and frustrating when Health and Education don't work together and as a parent nobody is able to tell me where to go for help!!

As you can see we've been to the ISCAN panel twice (second time I had no input - GP done it)

Rejected from CAHMS

Rejected by Additional Learning Support

Refused by Education Psychologist – only for a piece of work to be sanctioned after Statutory Assessment application – we had to apply for Statutory Assessment twice.

Now the Primary Mental Health Team say our case is too complex for them!!!!

We've been pushed from pillar to post, told numerous time that there's no funding.

This is a total waste of everyone's time while everyday my Son is struggling in an environment without adequate support – nobody seems to care!!