

Submission
No 195

**INQUIRY INTO THE PROVISION OF EDUCATION TO
STUDENTS WITH A DISABILITY OR SPECIAL NEEDS**

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Submission from:
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**Re: THE PROVISION OF EDUCATION TO STUDENTS WITH A DISABILITY OR
SPECIAL NEEDS**

Dear Committee Member,

Our response to the above mentioned inquiry comes not just from the professional viewpoint, BUT also from a personal position.

Our concern with the education system deals with its lack of provision and understanding of the progressive illnesses, in particular, genetic neuromuscular disorders such as **MITOCHONDRIAL DISEASES**. Although this group of illnesses was once thought to be rare (approx 1:20000), latest research now suggests that the incidence is in the realm of 1:200-250. Of this incidence, the majority affected are children, and USA statistics show that 1 in 4000 live births will be a child developing a mitochondrial disorder before the age of 10 years. Unfortunately we are **way behind** in the statistical analysis of this illness in our country, as it is relatively “new“ (first diagnosed in 1988), it is extremely difficult to diagnose, and because of the difficulties and expense in setting up a national registry to collect data for the illness.

Mitochondrial disease is just one of the many sinister progressive disorders which also includes a vast number of other genetic disorders such as, muscular dystrophies, lysosomal storage disorders, cystic fibrosis, and a number of the lesser known metabolic disorders.

Our experience in the education system for children with disabilities/special needs, has been via the misfortune of our eldest child, Kara (DOB: 3/3/99) having one of the mitochondrial diseases called **MELAS** (**M**itochondrial **E**ncephalopathy **L**actic Acidosis **S**troke/Stroke-like symptoms). She first began to have difficulties at age 3yr, which slowly progressed till her first MELAS (stroke) attack at age 8yr on the 5/3/2007, when she was in Year 2 and the diagnosis was finally made. Between the age of 3 and 8, Kara was considered “normal”. She overcame her extremely poor fine and gross motor skills (percentile bands of 0-4% in performance), poor exercise tolerance and balance, and her attention deficit/poor concentration by her own simple hard work and determination, to the point where she was in the top reading and maths groups at the time of her first attack. The symptoms she was experiencing were the hallmarks of mitochondrial disease but it had not been picked up at the time, as the medical profession as a whole is still in the infancy stage of understanding and diagnosing this illness.

Kara's relatively good performance at school up to the time of her first attack also made the urgency and necessity for a teacher's aid progress slower than it should have. As her first IQ test was approx 55, she qualified for no help. However by the end of 2007, less than 9 months later, Kara had had 4 strokes (MELAS attacks) in total so her performance had greatly decreased. **BUT**, education policy was that she was **not** allowed to be reassessed because one year had not elapsed since her last test. Even when her reassessment the next year showed her IQ now 35, she still did not qualify for any aid but a special needs school was suggested. This may be an appropriate step where the schooling for the child is long term, and hence uprooting them and settling them into a new school is worth the effort. However, when the child's prognosis is in terms of years, and their school education much less than that, allowing them to stay the remainder of their schooling life where they are already established amongst friends and teachers who know them, is much more appropriate and less disruptive. ALSO, there is a major disruption to the child and our lives as we would have another school to attend, and therefore add another hour to our day. We are extremely lucky to have an understanding school principal who also saw the ridiculousness of changing schools.

The nature of MELAS and many other of the mitochondrial illnesses, is that they affect multiple organs and systems. Kara's needs were many, but without being able to fulfil the criteria of any of the already pre-existing disability groups, we then had jump through the many hoops to gain aid by being presented as a "special case".

Kara's problem list included,

- 1; **Decreasing cognitive function** – due to the general progressive nature of the illness, and accelerated by the stepwise decline with each MELAS attack (stroke). The education system however provides no assessment that keeps up with the rate of its progressive nature.
- 2; **Dementia** – progressive and very similar in nature to the multi-infarct dementia presenting in elderly patients after many strokes. Again the education system is not geared towards this "old person" problem.
- 3; **Increasing deafness** – she started with a hearing loss of about 5% in 2007 to progress to 40% in 2009. Now requiring hearing aids.
- 4; **Increasing blindness** – most of Kara's initial strokes were in the visual cortex causing an ever increasing cortical blindness. Therefore the subsequent loss in her peripheral vision is not taken into account in any educational visual testing because the central vision is intact.
- 5; **Decreasing fine and gross motor skills** – resembles the appearance of mild cerebral palsy due in part to her cerebellar atrophy which was present from the beginning on an MRI scan in 2007, and compounded by the 10-15 strokes since.
- 6; **Fatigue and increasing exercise intolerance** – the hallmark of all mitochondrial diseases and more self limiting than a child with a depressive illness.
- 7; **Poor concentration and attention deficit** – another common presentation in children with mitochondrial disease. They tend to be dreamy rather than hyperactive so the children are well tolerated and not disruptive in the classroom, but still have the same learning difficulties.
- 8; **Frequent hospitalisations** – missing as much school work if not more than say a child with leukaemia, yet catch up was instigated by Kara's own motivation after school and on weekends. No provision or aid was given at school for catching up, and it wasn't possible at hospital during Kara's attacks because of her altered mental state.

However, despite Kara's list of fairly rapidly progressive disabilities and special needs, it still took a staggering **two and a half years** to get a teacher's aid for Kara. Not to mention we are still waiting for her wheelchair after nearly a year. The aid which was so urgently needed in the initial 2 years, finally arrived when Kara was down to only 4-6hrs of schooling per week (down from 16hrs/week earlier in the year of 2009).

The school principal and teachers at Yowie Bay Public School have been marvellous and incredibly supportive, but the school counsellor seemed to be more of a detriment to the process. Most of this was probably due her being bound by a system that DID NOT allow for a progressive illness. The counsellor found it difficult to be allowed by the education system to reassess Kara more regularly and to find a set of criteria that she fulfilled to receive assistance. Kara was eventually presented as a special needs case **and that response took nearly a year!**

Where a child has a special needs school/class locally and is aware of their diagnosis before starting Kindergarten, then that would be the best solution. **However**, when the child is already established at a school and their prognosis is limited to years, taking them away from this environment would be extremely disruptive in a number of ways.

1; **Loss of support** – in already established friendships of students and their families who also importantly live locally.

2; **Loss of security** – the child and the family already face an insecure future and to change schools to re-establish new relationships with staff and students and their families simply adds to their insecurities.

3; **Loss of routine and time** – usually there are other children in the same family attending that school also, so an extra school adds to the family's workload.

Therefore in summary, the provision to children with disabilities and special needs in our education system needs to be revised in the particular area of **PROGRESSIVE ILLNESSES**. These progressive illnesses need to have their own criteria stated, *need to be differentiated from those disabilities that are "stable"*, and then need to be further differentiated into,

A) **Rapidly Progressive** – prognosis in terms of years, and,

B) **Slowly Progressive** – prognosis in terms of decades

Then the priority of the allocation of aid can be given appropriately whilst it is still **relevant** to the child. It may be said that for these children education is not a priority, but when you have personally gone through the situation and can see how important it is for the child to feel as close to "normal" for as long as possible, whilst maintaining school friendships, then you may change your mind!!

Yours sincerely,
Dr Karen Crawley and Mr Craig Crawley