Submission on self-harm and suicide by children

This submission relates to the first area of interest to the Commission: why children and young people self-harm. It is also relevant to the seventh area of interest in relation to refugee children and young people in detention.

This submission is based on what we learnt through my teenage daughter's experience.

Medication and genetic cytochrome enzymes

My daughter experienced anxiety and sleeplessness and this was diagnosed as a major depression. A psychiatrist prescribed anti-depressant (SSRI) medication. Later it was discovered that blood tests from that time indicated that she had a hyperthyroid condition (too much thyroxin being produced which causes symptoms of anxiety and sleeplessness), but this was not diagnosed for two years, by which time her thyroid gland had worn out and she was therefore suffering a hypothyroid condition (not enough thyroxin being produced). Meanwhile my daughter was wrongly treated for major depression.

Following the introduction of medication my daughter's condition deteriorated rapidly, as a consequence of which the psychiatrist increased the medication. Her condition then became very serious as she became compulsively self-harming. The psychiatrist added a further medication to help her sleep, and she continued to deteriorate quickly until she was admitted to hospital. As she went continually downhill that psychiatrist changed her medication to two different psychotropic medications, (an anti-depressant and an anti-psychotic), but her condition continued to deteriorate and she started making suicide attempts. She could no longer attend school. She had a serious incident of a syndrome called "Seratonin syndrome" which is caused by build-up of serotonin in the brain, which should have been an indication to the psychiatrist that the dose was wrong.

I became concerned that the medication was causing the deterioration because my daughter's condition became worse as the dosage was increased, but this was not accepted by the psychiatrist. He refused to allow trial withdrawal of the medication to see if that helped, and he introduced DOCS to her case to give consent to the continued administration of the medication. He then continued to increase the medication with dire results. Eventually I was told that she would have to live her whole life in hospital because she was so sick.

At the time, information was coming out in the USA and Europe that indicated that SSRI antidepressants could double the risk of suicide in young people and children under 25 years of age. Anti-depressants were not marketed for people under 18 by their manufacturers, so they were, and still are, routinely prescribed "off label".

It was and continues to be, common practise for hospital psychiatrists to prescribe anti-psychotic medication to overcome the activating side effects and sleeplessness caused by anti- depressant medication. Anti-psychotic medication is not recommended for people under 18, nor is it marketed for use in conditions other than psychosis. However the psychiatrist said that anti-psychotics have a sedative effect and that sleeping tablets are addictive, so they

use anti psychotics to assist sleep because they believe that anti-psychotics are not addictive. So the anti-psychotic medication is also routinely prescribed "off label" and for a condition for which they are not recommended by their manufacturers.

It became clear that the Therapeutic Goods Association is not aware of this routine use of anti-psychotics as sedatives for non-psychotic young people, although it appears to be standard practise amongst the small group of child psychiatrists in the state hospital system.

During this time I started researching what could be causing my daughter's mental state to so rapidly decline. Adverse findings suggesting that anti-depressants were causing an increase in suicidal and self-harming behaviour in teenagers and children were being published by health authorities abroad and this was mirroring my daughter's behaviour. When I put this to the psychiatrist he said that the USA's Federal Drug Authority and the European health authorities were wrong and would change their minds about the harm that they reported that anti-depressants were causing adolescents.

The FDA and the European authorities haven't changed their minds.

It was then that I found information about Pharmacogenetics, a branch of medicine in which pharmacology and genetics collaborate. Of particular relevance were the studies of the cytochrome enzymes and their role in the metabolisation of psychotropic medications and removal of medications from the body. The pharmaceutical companies' information about their products made reference to cytochrome enzyme systems, so I searched the internet to try to understand what that was about. As I learnt about it I became convinced that this may have had something to do with my daughter's rapid decline. Following genetic testing it was discovered that this was indeed the case.

Most psychotropic medications are metabolised, utilised and eliminated from the body by the cytochrome enzyme CYP2D6, and where that enzyme is poorly functioning then another enzyme, (in relation to medications the CYP2C9 enzyme) can perform some of the function. It is rare to have both of these enzymes of poor to non-existent function. The result of having poorly functioning enzymes is that the medications go quickly into overdose because the body cannot eliminate the medication. Such people should be either not given particular psychotropic medication at all, or should be given very low doses. They are termed "Poor Metabolisers" or "PM" in the scientific literature. This is my daughter's situation.

The opposite is the case for people with extremely efficiently functioning cytochrome enzymes as they eliminate the medication very quickly from their body, so need large doses. These are termed "Ultrarapid Metabolisers" or "UM". People who have average metabolising enzymes are termed Intermediate Metabolisers" or "IM". The other category is "Efficient Metaboliser" or "EM". This has nothing to do with body weight and can only be determined by a genetic test, however adverse reactions to medication should be an indicator that the cytochrome enzymes might not be able to metabolise a medication.

There are also studies which suggest that the cytochrome enzymes can affect the therapeutic response to psychotropic medication due to their presence in the brain:

> *…Drug metabolism by CYPs takes place primarily in the liver, but CYP enzymes are also found in many other tissues, including brain. It is predicted that local brain metabolism of centrally acting drugs at their site of action can influence their*

therapeutic efficacy independently of liver metabolism, and differences in brain levels of CYP enzymes can contribute to the observed interindividual variation in drug response…[1]

Unfortunately Pharmacogenetics is in its infancy in Australia (but is entering mainstream medicine abroad) and I had to give articles and information to my daughter's new psychiatrist and our GP so that they would understand what the genetic results showed. The new psychiatrist read the information and did some further research himself, then immediately started taking her off all of the medication, following which my daughter recovered slowly over the following three to four months after going through serious withdrawal syndrome. She had had more than three years on the medication by that time during which she had made numerous suicide attempts and constant self-harm, and had missed almost three years of high school as a result. However within weeks of stopping the medication she was sufficiently recovered to return to school.

She has never taken psychotropic medications since, has never returned to hospital, and her compulsive suicidal and self-harming behaviour stopped. It was clear that in her case the medication was the cause.

In Australia genetic tests are only available to test 3 of the cytochrome enzymes, CYP: 2C9, 2D6 and 2C19. The first two of those are the main enzymes which function to metabolise and remove psychotropic medications from the body. The genetic tests showed that my daughter has low to non-existent function in both her 2D6 and 2C9 cytochrome enzymes. This was compounded by the fact that the anti-depressants that she was prescribed had a further known effect of inhibiting the function of 2D6 enzyme. This means that within probably the first week of being medicated she had been unable to eliminate the medication from her body and would have been already in overdose, which was compounded during the years that she was administered these medications.

Therefore, not only did she have the effect of the anti-depressants which are reported by the health authorities to double of the risk of suicide in adolescents, but also my daughter was administered doses that far exceeded the dose that she could tolerate so the various medications were accumulating at very high levels in her body.

Now that we have had my daughter "genotyped", no well-informed doctor would ever administer these drugs to her.

However genotyping is not standard practise in Australia, and most doctors are unaware of the outcomes of pharmacogenetic studies in relation to cytochrome enzymes' role in metabolising medications. Therefore dosage adjustments are not tailored to the individual. Trial and error is the method of adjustment, which, given my daughter's case, is subjective and is clearly open to misjudgement when many symptoms of adverse reaction are mistaken for an illness, or psychosomatic symptoms when they cannot be explained (blame the patient).

Given that there is specific mention of cytochrome enzymes pathways in prescribers' information for each psychotropic medication, it is clear that most doctors are either not

[1] 2011 *CCNP Heinz Lehmann Award paper: Cytochrome P450–mediated drug metabolism in the brain*
Sharon Miksys, PhD and Rachel F. Tyndale, PhD http://www ncbi nlm nih.gov/pmc/articles/PMC3633708/

reading the prescribers' information or are clearly not curious about what it means. They continue to give one-size-fits-all dosages and I have heard of only rare cases in which patients have had their cytochrome enzymes tested in Australia as a doctor's initiative.

There are only a very small number of psychiatrists working in child psychiatry, and I understand that deviation from their standard practise leads to ostracism by this group. This is perhaps due to the fact that child psychiatry is in its infancy and the medications that they prescribe are both not tested on nor marketed for children or adolescents, so deviation from the small group's practises exposes the child psychiatrists to vulnerability.

However there are a few child psychiatrists in Australia who have become concerned about the adverse consequences of medicating children and have become outspoken about it despite the peer group pressure. It is reassuring that this is happening because the pharmacogenetic research indicates that the efficiency of cytochrome enzymes varies as a person ages. Some cytochrome enzymes become more efficient, some less. Therefore extrapolating the findings of pharmacological testing on adults to the possible effects on children and adolescents is speculation and experimentation.

Medicating children and adolescents should be approached with caution and child psychiatrists must start to follow cross-discipline research findings such as pharmacogenetics. There is a tendency in hospitals to have a demarcation between the roles of psychiatrists and the roles of pharamacologists, with psychiatrists delegating pharmacological issues to pharmacologists and not acquiring knowledge about this themselves. The same can be said of the delegation of knowledge of genetics to genetics committees within the hospitals. There needs to be cross fertilisation of the disciplines to ensure that advances in each discipline flow through to all disciplines of practitioners in child related medicine. This needs to be more than just various health professionals holding case meetings about each child.

This is a serious deficiency given that the much of the information about cytochrome enzymes has been available for more than 15 years. It is relevant not only to adolescents but also to adults who are "scheduled" and are therefore unable to choose to stop taking medications that they find intolerable, or who are in mandatory detention and are unable to decipher which symptoms are due to incarceration and which are due to adverse reaction to medication.

It has become apparent to me and my daughter that this information about cytochrome enzymes has been discovered by other people who have had similar reactions to psychotropic medication and became compulsively self-harming and suicidal. One case was similar to my daughter's case:

> *THE Victorian mother who launched an unprecedented lawsuit against her 16-year-old daughter's GP claiming her child became suicidal after being prescribed the anti-depressant drug Zoloft has reached a confidential legal settlement with the doctor…*
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> *…Ms Mulcahy's daughter attempted suicide five days after being prescribed Zoloft. Several other attempts followed. She spent five weeks at the Royal Children's Hospital adolescent psychiatric unit. Ms Mulcahy said her daughter was later diagnosed with*

a genetic defect that predisposed her to having an adverse reaction to the active ingredient in Zoloft. [2]

This is further reported:

Gene test may have prevented teenage suicide… Individual case studies are presented of people whose behaviour changed when taking antidepressants. Some became suicidal, some homicidal, some suffered both suicidal and homicidal tendencies. The article reveals that people taking antidepressants have very unique reactions to these drugs and a gene test may help determine those who should avoid taking certain antidepressants.

For example, a case study is given of Hannah Mulcahy. Her genetic makeup meant that when she took the drug Zoloft, it built up in her body until it caused a devastating effect. If she had had a gene test before being prescibed Zoloft, the doctor would have been made aware that this drug would not be metabolised normally by Hannah, and she could have avoided becoming suicidal.[3]

Also:

Selective Serotonin Reuptake Inhibitors, of which Zoloft and Prozac are the best known, are not approved for use in the treatment of depression in children or adolescents aged under 18 in Australia because they carry an elevated risk of suicidal thinking and self-harm.

The TGA told The Australian it is in the process of strengthening its SSRI warning to include 18 to 24-year-olds because of these same concerns in this age group.

"My daughter was stressed, had a hormone imbalance and had trouble sleeping so I took her to a doctor," Ms Mulcahy said.

"She was on Zoloft for four days then on the fifth, she had a complete mental breakdown."

…According to Ms Mulcahy, her daughter's condition deteriorated during her hospital admission and she continued to try to take her own life.

"The doctors ….absolutely refused to consider that she might be sick because of the so-called cure."

More than 224,000 scripts for SSRI antidepressants were issued "off-label" to children and teenagers last year, according to figures prepared exclusively for The Australian by the Department of Health and Ageing.[4]

The effects of cytochrome enzyme deficiency has been documented by other people, adults and children, who have had similar responses to anti-depressant medications. For instance a

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[2] *Mother settles landmark case over Zoloft* Julie-Anne Davies | October 27, 2008 http://www.theaustralian news.com.au...006785,00.html cited at

[3] *In Genes FX Health August 2010* http://www.genesfx.com.au/index.php?mact=News,cntnt01,detail,0&cntnt01articleid=26&cntnt01returnid=27

[4] *Antidepressant drug Zoloft made girl 'suicidal' — (The Australian) By Julie-Anne Davies March 20, 2008 http://www.ssristories.org/antidepressant-drug-zoloft-made-girl-suicidal-the-australian-2/*

woman named Rebekkah Beddoe wrote a book about her experiences of becoming self-harming and suicidal after taking anti-depressant medication, and recovering when she took herself off it, in a book called "*Dying for a Cure, a memoir of antidepressants, misdiagnosis and madness"*[5]. In a later magazine article a genetically based metabolising deficiency was mentioned as the cause of her adverse reactions.

Court reports give similar accounts of parents who believed that their children had been made self -harming and suicidal as a result of the administration of anti-depressant and psychotropic medications, a claim denied by the psychiatrists in the cases. The parents' claims were dismissed by the court.[6]

There is also a website with a very long list of articles about children and adolescents who have become suicidal or homicidal after being administered psychotropic medications by doctors. The site is:

http://ssristories.org/old/index1.php?p=suicides

Doctors should use extreme caution and only prescribe psychotropic medications to children and adolescents after doing genetic cytochrome testing, if at all, and only after trying other treatment strategies. Parents' surprise and alarm at their children's reaction to medication should serve as a useful indicator that a child is suffering adverse reaction to a medication, and not be dismissed due to Freudian psychological theorey.

Parents must be allowed to keep their right to refuse treatment with these medications. There has been no case recorded in which a court has found for the parents when they have objected to medication. The courts have always found for the doctors.

However doctors cannot be sure that they know better than the parents if they do not have information about the cytochrome enzyme status of the child they are medicating.

At present there are obvious problems in relation to medicating children and assessing the role of medications in self harm and suicide by children. There is no established testing of pharmaceuticals on children. There is only starting to be testing of pharmaceuticals according to genotypes (ie according to the function levels of cytochrome enzymes of test volunteers) or gender (pharmacogenetic studies have found that female and male hormones can have different influences in the function of cytochrome enzymes). Doctors and psychiatrists lack

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[5] *Random House publishers 2007*

[6] *In the Matter of Elizabeth* [2005] CLN 256 http://www.google.com.au/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CCgQFjAA&url=http%3A%2F%2Fwww.childrenscourt.lawlink.nsw.gov.au%2Fagdbasev7wr%2F_assets%2Fchildrenscourt%2Fm410051l716852%2Freelizabeth.doc&ei=IMqKU_WND47PlAXQyIC4Cw&usg=AFQjCNGBFNEIgo-8QzitI-vQCT2fzpwN6Q&bvm=bv.67720277,d.dGI;

Re Samantha [2007] CLN 782 http://www.google.com.au/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CCgQFjAA&url=http%3A%2F%2Fwww.childrenscourt.lawlink.nsw.gov.au%2Fagdbasev7wr%2F_assets%2Fchildrenscourt%2Fm410051l422001%2F2008%2520clnv%2520resamantha.doc&ei=QcmKU965D4zMkgXvrIHgDA&usg=AFQjCNHl_VifUbA3fCcdcMoFKBbQEGq6pQ&bvm=bv.67720277,d.dGI ;

*DoCS v Y [1999] NSWSC 644*http://www.lawlink nsw.gov.au/scjudgments/1999nswsc nsf/aef73009028d6777ca25673900081e8d/7290f691e4937c3fca25679f0007e5d6?OpenDocument

awareness and understanding of pharmacogenetics. Psychiatrists are relying solely on subjective observation and psychological theorey.

Therefore parents' objective observations should not be dismissed by the courts. It is time that psychiatry moved to a more science based approach utilising pharmacogenetics rather than adhering to fashions of psychological theorey which change from time to time and which vary between practitioners.

Records

I believe that official records must be kept of any court actions initiated against doctors in situations in which it is alleged that a child or adolescent has been harmed or killed due to adverse reaction to psychotropic drugs prescribed by that doctor, even if the case is settled or withdrawn without record against the doctor. The details of the doctor and the allegations must be recorded to enable research by academics and scientists, so that a clear picture of the extent of medication as a cause of self-harm and suicide in children and adolescents can be brought to light. There should be a searchable central database which includes these details.

In addition, hospitals and institutions keep internal reports of "incidents" within the hospital or institution. Where the reports concern children or adolescents who at the time of the incidents were prescribed psychotropic medications or were affected by them, the reports must be collated and made available to researchers in a central database.

Similarly hospitals and paramedics should collate records of all incidents which bring a child or adolescent who is medicated with psychotropic medication to a hospital, and these records should be made available to researchers on a central database.

Private doctors should also contribute their records of incidents involving their child and adolescent patients who are medicated with psychotropic medication to the database, and all of this should be made available for research on the database.

While reports of adverse reactions are supposed to be made to the Therapeutic Goods Association, this is not compulsory. In my daughter's case none of the very many incidents within the hospital were ever reported to the TGA, probably because the doctor did not regard them as adverse reactions to medication (despite the correlation of the most florid incidents with medication variations).

Reporting of all incidents involving children medicated with psychotropic medications must be compulsory even if the incident is not attributed to adverse reactions to the medication. This should also include incidents in schools.

It will be claimed that this would be too much paperwork, however the hospitals and institutions are already keeping records of incidents. It is only by collating the information in this way that records can show what the situation actually is and patterns may be found in relation to psychotropic medication and self-harm by children.

Cytochrome enzyme relevance to refugee children and young people in detention, and indigenous young people

Studies show that the manner in which cytochrome enzymes function varies according to which part of the world a person and their ancestors have come from. It is believed that cytochrome enzymes developed in animals so that the animals could eliminate toxins in their food. Plants developed defences to being eaten, usually toxins to discourage the animals. In turn the animals developed cytochrome enzymes to rid their bodies of the toxins and this allowed them to eat the plants. Thus, the studies show that people have different function in their cytochrome enzymes according to which part of the world they come from, due to their ancestors having evolved to cope with toxins in the available food in each region. For instance:

> *CYP2D6 is of great importance for the metabolism of clinically used drugs and about 20–25% of those are metabolised by this enzyme. …The polymorphism of the enzyme results in poor, intermediate, efficient or ultrarapid metabolisers (UMs) of CYP2D6 drugs. It is plausible that the UM genotype …is the outcome of selective dietary selection in certain populations in North East Africa. The UM phenotype affects 5.5% of the population in Western Europe.*
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> *… The polymorphism of CYP2D6 significantly affects the pharmacokinetics of about 50% of the drugs in clinical use, which are CYP2D6 substrates. The consequences of the polymorphism at ordinary drug doses can be either adverse drug reactions or no drug response…*
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> *… the genetics of the drug metabolising enzymes plays a critical role for understanding interindividual differences in drug response and adverse drug reactions…*
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> *… The action of CYP2D6 on substrates of potential activity in the brain would imply a functional phenotype on subjects, that is, poor metabolisers (PMs) lacking the enzyme. In fact, two studies have indicated a significant relationship between behaviour using psychological tests and the presence of CYP2D6…*
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> *…subjects with up to 12 extra CYP2D6 gene copies were identified. This turned out to be the first description of a stably amplified active gene in humans and the term ultrarapid metabolisers (UMs) was defined. Subsequent investigations of the frequencies in different populations revealed 30% in Ethiopians, 10% in Spaniards and 10% of the populations in Italy and Turkey, whereas UMs are uncommon (1–2%) in Northern Europe and essentially absent in Asia... In Ethiopians we found no individual homozygous for defect CYP2D6 genes but alleles containing 2, 3, 4 as well as 5 CYP2D6 gene copies. A similar situation was also seen among Saudi Arabians. Evaluation of the number of subjects carrying CYP2D6 gene duplications in Western Europe reveals that 5.5% of the Europeans carry more than two active CYP2D6 gene copies and are Ums…*
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> *…The most common allele in Asians (allele frequency of >50%) and thus perhaps the most common CYP2D6 allele in the world is CYP2D6*10 …Among Blacks CYP2D6*17 first described in 1996 is the major variant CYP2D6 allele. …*

> *…… Similarly, we have proposed that such a selection has occurred for alleles carrying multiple active CYP2D6 genes in North East Africa. The basis for this selection would be the capability of the CYP2D6 enzyme to detoxify alkaloids, thereby increasing the availability of potential food among carriers of multiple CYP2D6gene copies. This would be very beneficial for survival under periods of starvation when only a fraction of the population in this region reaches maturity. …the manner that constituents in the Ethiopian food, presumably alkaloids, inhibit the CYP2D6 activity and that such components could indeed be a trigger for genetic selection. We propose that the Ethiopian population expanded about 10 000–20 000 years ago to such an extent that food exhibited an important constraint. During periods of starvation, a selection pressure has occurred favouring survival of subjects being able to detoxify plant toxins at a higher extent, increasing the number of plants being able to provide useful food … it can be speculated that the substrate specificity of this form of the enzyme is beneficial for the metabolism of certain plant products. …*[7]

The cytochrome enzymes which evolved to metabolise plants are used by the body to metabolise medications:

> *They enable humans to metabolize plant toxins and related toxic substances before the substances enter the systemic circulation and cause cell damage. Since many drugs are derived from botanical compounds and may resemble plant toxins, they are metabolized by these enzymes and at times by other biotransformation processes...*[8]

Many child and young asylum seeker detainees are administered anti-depressant or other psychotropic medication (which are metabolised by the 2D6 cytochrome enzyme). Given the differences in cytochrome enzyme function in people from different parts of the world and the fact that Australian medicine is dished out in a one-size-fits- all manner (usually based on a person's weight and age), it is clear that a number of the detainees would be suffering from either overdose due to being Poor Metabolisers (PM), or would be receiving no benefit due to being Ultra-rapid Metabolisers (UM).

Until genetic testing is done to determine the level of function of young detainees' cytochrome enzymes 2D6 and 2C9, the possibility cannot be discounted that their self-harm and suicidal behaviour is related in some part to the psychotropic medications that they have been administered.

The same possibility of adverse drug reaction due to the individual cytochrome function is also relevant to indigenous children and adolescents who are prescribed anti-depressant or psychotropic medications, as it is obvious that their ancestors would have been eating food

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[7] From *Genetic polymorphisms of cytochrome P450 2D6 (CYP2D6): clinical consequences, evolutionary aspects and functional diversity* M Ingelman-Sundberg ,The Pharmacogenomics Journal (2005) 5, 6–13. doi:10.1038/sj.tpj.6500285 Published online 19 October 2004; http://www.nature.com/tpj/journal/v5/n1/full/6500285a html#bib5
My note: Each cytochrome enzyme has two alleles, one inherited from each parent, and it is the efficiency of each of these alleles that determines the overall level of ability of the enzyme to function. Alleles have been given various numbers so a genetic result will show the number of both inherited alleles in the enzyme. If one allele is has good function it will overcome a poorly functioning second allele. However my daughter has inherited two poorly functioning alleles on both her 2D6 and her 2C9 enzyme, a situation which is rare.

[8] *Overview of Drug Interactions Modulated by Cytochrome P450* Charles H. Brown, M.S. Pharm. Associate Professor of Clinical Pharmacy,Purdue University, School of Pharmacy and Pharmacal Sciences,Department of Pharmacy Practice, West Lafayette, IN
http://www.uspharmacist.com/oldformat.asp?url=newlook/files/Feat/druginteractions.cfm&pub_id=8&article_id=704

that has very different properties to food eaten for centuries by Europeans. Therefore indigenous people's cytochrome enzymes would have evolved to acquire the capacity to metabolise different toxins.

Therefore adverse reactions due to cytochrome enzyme deficiency may contribute to the suicidal or self-harming behaviour of indigenous youth who are taking anti-depressants or other psychotropic medications.

Recommendations

Records should be kept of all self-harming and suicide by asylum seeker and indigenous children and adolescents who are receiving psychotropic medications in order to establish whether medication is a contributing cause of self-harm.

Ideally each patient and detainee should have the functional ability of their cytochrome enzymes tested before any medication is prescribed. It costs a few hundred dollars to set up an assay to test each cytochrome enzyme, and it is made more cost effective if the enzymes of a number of individuals can be tested in the same assay. It is therefore cost effective to test each enzyme of a number of individuals at the same time.

In knowing a person's cytochrome enzyme sufficiency before prescribing medication, the costs associated with adverse reactions to medications can be avoided.

However if this is considered too costly, I suggest that cytochrome testing be carried out on representative samples of residents of remote indigenous communities to establish the efficiency of the dominant cytochrome enzyme alleles (the two inherited components of the cytochrome enzymes) in the genetic pool of each remote community. In this way precaution could be taken in prescribing not only psychotropic medication but all medications which are known to use the enzyme pathways of the currently testable cytochrome enzymes (currently CYP2D6, CYP2C9, and CYP C19.)

As the literature samples show, there have been cytochrome tests conducted to profile the dominant cytochrome status of various racial groups around the world. It is time that the same was done for our indigenous community to assist in focusing on the possible causes of self-harm and suicide amongst our indigenous youth.

All people in mandatory detention in any type of facility should have their cytochrome enzyme status determined prior to any medication being prescribed for them.

As suggested in the previous section, records should be kept of all cases initiated against doctors or hospitals as a result of injury or death of indigenous or detained children and adolescents in which the administration of psychotropic medication is present, even if the case is settled without record against the doctor. All incidents in relation to such children should also me recorded. This would be informative of some of the serious consequences of self-harm or suicide resulting from psychotropic medication given to detained and indigenous children and adolescents. Hospitals' records of incidents in hospital, and resulting in arrival at hospital, involving indigenous and detained children and adolescents medicated with psychotropic medications should also be collated in the database in order to have the material needed to research and gain an overview of the extent of this problem.

Institutionalised disempowerment

While she was hospitalised, the adverse effects of the psychotropic medications were compounded by a complete disempowerment of my daughter by the hospital staff and doctors and I consider that this exacerbated the nightmare and hopelessness that she was living. She had been a child who had always been curious and sweet natured, and who was very well behaved. She was loved and praised by many people. Her academic and athletic aptitude was recognised and rewarded.

However on entering the hospital she was treated as a naughty person who was not trusted nor allowed any freedom, sunshine or exercise. She was cut off from her friends and school, and the psychiatrist and the staff implemented Freudian principles based on the child's problems being due to the mother. I was accused variously of being too controlling, or of being not strict enough, acting as a friend instead of a parent to my child and not setting sufficient boundaries. My daughter's academic success and scholarship were held as evidence that I was too pushy and my daughter was encouraged not to study. I was told there was no need for her to return to school (she was in Year 9). My daughter was told that I was the cause of her psychiatric problems and while she thought that we had a good relationship she was told that she was wrong.

At times she was locked in a small isolation ward by herself for weeks on end (without being scheduled...it was not a scheduling hospital) with only a bare mattress on the floor and no belongings, being observed 24 hours a day by male and female staff, with no privacy, no fresh air or exercise or sunshine. DOCs (now Family and Community Services) approved this because I had had my parental right to consent or refuse my daughter's medical treatment removed. Therefore I could do nothing to stop it and my daughter knew this.

As a result of all this my daughter was not only maddened by the medication she also completely lost her sense of self, and all of her reference points for her self-identity were removed. She was encouraged not to see me (as a single mother with an only child this was extraordinary, given how close we had been).

I was also disempowered, because one Freudian theorey that the psychiatrist mentioned was that a controlling mother must never be allowed to succeed in her attempts to control. Therefore my observations and suggestions that the treatment was wrong were dismissed, and it was made clear that the psychiatrists regarded me as a greater problem the more I tried to work out why my daughter's health had taken such a sudden change and was deteriorating so fast.

It is clear from the reported court cases mentioned above that this is was not an unusual situation, nor is the psychiatrists' use of the Community Services Department to enforce compliance with the pharmaceutical regimen when parents suggest that the treatment is causing harm.

Given the disempowerment and loss of identity that my daughter and I both experienced in this institutionalised setting I consider that institutionalisation, especially when no end is perceivable, would contribute to self-harming behaviour whether or not psychotropic medications were administered, but the combination of the two is unbearable.

In addition, the Family and Community Services slots in tandem with the hospital, seamlessly removing a parent's power to decide medical treatment for their child, as they did in my daughter's case. DOCs was suddenly there, complete strangers, telling my overmedicated, identity-lost 14 year old daughter that her mother would no longer be making decisions about her treatment but they would. My daughter, who had always tried to do the right thing all her life, was now surrounded by people in positions of absolute authority within the hospital, telling her that her mother was wrong for her and that they were now in charge of her, and that she was naughty for trying to harm herself.

This disempowerment by DOCS and the medical system has been reported to have happened in many cases of parents who have objected to all types of medical treatment, see for instance the article *Bitter Pills* at: http://www.smh.com.au/lifestyle/bitter-pills-20121008-277yj.html

Much of the Community Services action is not scrutinised. There is a stigma attached to intervention by Community Services and a general perception by the public that there must be something wrong for them to intervene. Families in which parental powers are removed are taken by surprise by the swiftness and lack of consultation with which the Community Services operate. Notices are given at times that make finding representation difficult, and there appears to be a smooth interlocking of the medical system and the Community Services. Given the stigma of the Community Services intervention there is shame attached to telling people what has happened, but in my case I was lucky enough to have seriously outraged friends who assisted in every way they could.

In the case of my daughter the Community Services were used as a means to overcome the fact that her psychiatrist was not working in a scheduling hospital. A scheduling outcome was achieved by disempowering the child and the parents in relation to consent to treatment by having that power transferred to DOCS. DOCSs appeared to act at the behest and on direction from the psychiatrists. The Children's Court was part of this operation and thus the hospital bypassed the need to have a magistrate's hearing in the hospital in which the child can participate and be heard.

The Children's Court is a closed court and so there is also a lack of scrutiny of the court. The small number of regular practitioners play alternate roles in the cases that come before the court, sometimes acting for the department of Community Services, at other times acting for the child or the parents. At all times the practitioners appear comfortable with the apparent conflict of interest in acting in an adversarial roles to the department from which each of them derived a third of their income when they take their turn to act for the department.

Given the very small number of psychiatrists who work in child psychiatry, they are also regular and familiar attendants at the Children's Court and appear comfortable and familiar with the other regular actors. Any new lawyers entering this closed world on behalf of the parents are subjected to eye rolling and sniggering attitudes by the coterie of regular Childrens Court lawyers. This has the effect of being a very disempowering situation for the parents.

The closed nature of Children's Court proceedings has led to 'disturbing'[9] practices in the Children's Court. In *Wilson v Department of Human Services – Re Anna*[10] Palmer J expressed concern about a failure to ensure procedural fairness, stating:

> *'[a]s a result of what appeared to be a rather quick and "in club" discussion between the Bench and Bar Table, an interim care order was made. The most important person in the courtroom at that time – the mother [who was unrepresented and] whose child had been taken from her at birth two days ago – was ignored.'*[11]

He observed that solicitors who appear regularly in the Children's Court could be perceived as 'enjoy[ing] a relationship with the Judge which [i]s something more than merely professional'.[12] He pointed to a further instance of concerning conduct:

> *Mr Chapman routinely began his cross examination with the salutation "Good morning, Ms Wilson… He was met with a stony silence. How could Ms Wilson or Mrs Wilson greet politely the man who was avowedly intent on taking Anna away from them by destroying their evidence? A witness in their position would inevitably feel it to be the most odious hypocrisy to be compelled to return the salutation with a polite "Good morning, Mr Chapman"… Mr Chapman, of course, noted the rebuff and, on occasion, directed a meaningful look at the Bench…the impression which could well have been conveyed to Ms Wilson and Mrs Wilson was that, even before Mr Chapman had begun his cross examination, he had already unfairly scored a point against them because he had put them in the position in which he could say – eloquently, by a look, not even a word – "You see what rude and unpleasant people we are dealing with here, your Honour".*[13]

The reference to an 'in club' alludes to concerns about the limited pool of legal representatives that appear regularly in the Children's Court. It is like a game of musical chairs: they all seem to take turns representing the Department and the child. It's hard to believe that solicitors representing the child would challenge anything sought by the Department given they are regularly instructed by the same DoCS officers. There is a report that another parent whose children were taken on medical grounds was told to engage her own lawyers because 'local lawyers all sucked from the same government teat, all lunched together and rarely did a good job'.[14] These observations are echoed in the case law. For example, in two separate cases involving parental objection to a similar treatment regime in a particular hospital, the same solicitor acted for the child in one case and for the Department in the other.[15]

The closed nature of care proceedings is compounded by a failure to publish the vast majority of Children's Court decisions in any forum accessible by the public, meaning that decisions

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[9] *Wilson v Department of Human Services – Re Anna* [2010] NSWSC 1489, [4].

[10] [2010] NSWSC 1489.

[11] Ibid, [104].

[12] Ibid, [108].

[13] Ibid, [109]-[110].

[14] Bitter Pills, above n 1.

[15] *In the Matter of Elizabeth* [2005] CLN 256, [2], [16]; *Re Samantha* [2007] CLN 782, [1].

cannot subject to public or academic scrutiny. Furthermore, it has been reported that of the 600 submissions made to the 2008 Inquiry, many of them critical of FACS, only 47 were made public,[16] supposedly in the interests of ensuring the protection of the identities of children in out-of-home care.[17] The non-publication provisions have been described as

> '*shackl[ing]…innocent parents whose children have been removed from their care…[who] could not speak out and take their cases to the court of public opinion.*'[18]

Brereton J's commented in relation to an application for the Supreme Court to be closed in the exercise of its parens patriae jurisdiction:[19]

> *In my view, great caution is required before determining that proceedings, even of this type, should be conducted in closed court. It is one thing to make an order…prohibiting the publication or disclosure of any information that would tend to reveal the identity of a party or a child, but it is quite another to order that the proceedings be conducted effectively in secret. The issues which typically arise in this type of case…are generally of significant public interest, not merely out of curiosity but because all parents and the community as a whole have deep and abiding interest in the welfare of children. Proceedings such as these have a significant informative and educative function. It is important that what the Court does in this field be open to public knowledge, information and scrutiny. Proceedings in the Family Court of Australia – in which there is a large amount of litigation concerning the welfare, custody and guardianship of children – are not heard in closed court… There may no doubt be some cases in which that course is appropriate, but ordinarily sufficient protection of the child will be achieved by a non-publication order of the type to which I have referred.*[20]

FACS has been criticised for the manner in which it presents evidence about parents in cases, including deliberately omitting facts that were favourable to the parents. Case law reveals numerous instances in which FACS caseworkers have put forward on unsubstantiated allegations. For example, when an 11-year-old was taken to the local 'in pain with a swollen belly':

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[16] Caroline Overington, 'Child welfare inquiry turned into farce by official secrecy' *The Australian*, 28 August 2008 < http://www.theaustralian.com.au/news/child-welfare-inquiry-made-into-farce/story-e6frg6o6-1111117321592>.

[17] Frank Ainsworth and Patricia Hansen, 'Confidentiality in Child Protection Cases: Who Benefits?' (2010) 35 (3) *Children Australia* 11, 14; James Wood, 'Report of the Special Commission of Inquiry into Child Protection Services in NSW' (November 2008), 6.

[18] Heather Stewart, 'Secrecy Rules Surrounding Children May Be Concealing Injustice' *The Australian*, 25 April 2009 < http://www.theaustralian.com.au/news/secrecy-rules-may-conceal-injustice/story-e6frg6no-1225703254855>.

[19] The parens patriae jurisdiction is an inherent jurisdiction of the Equity Division of the Supreme Court: *DoCS v Y* [1999] NSWSC 644, [85]-[86]. It enables the Court can make orders with respect to the protection and welfare of children, including orders for medical treatment when there are issues of consent: *DoCS v Y* [1999] NSWSC 644 [98]-[103]. Similar proceedings in relation to medical treatment also occur in the Family Court: see for example, *Department of Health and Community Services v J W B & S M B (Marion's case)* (1992) 175 CLR 218. Brereton J's comments regarding the parens patriae jurisdiction and Family Court are relevant because of the similar nature of issues dealt with in the Children's Court.

[20] *Re Jules* [2008] NSWSC 1193, [24]-[25].

> *The doctor said she was pregnant and notified DoCS. The parents didn't believe it for a moment and Sarah was subsequently diagnosed with cancer. The family doctor told the social worker that the family belonged to a religious group that frowned upon modern medicine. They did not. They were non-denominational Christians and held no such views, but the profile stuck…Everybody involved with the case was told about the family's weirdo religious beliefs. Nobody bothered to check if it was true…*

Unsupported allegations were also made by FACS in Re Georgia and Luke (No 2). In this case, the Children's Court had accepted evidence put forward about a couple's '*history of mental health issues'* and '*domestic violence'* and made an order placing children in out of home care. However, in a Supreme Court decision, Palmer J ordered the immediate return of the children, stating:

> *There is not the slightest evidence before this Court of a "history of mental health issues", whatever that vague phrase is intended to mean…The Court will not countenance the removal of a child from his or her parents on evidence of this type…The officer refers to "the history of domestic violence" between the parents. Again, although this is a highly emotive phrase, there is no evidence of any particularity at all of any domestic violence. I repeat the remarks I have made above: children are not to be taken from their parents on the basis of vague and prejudicial "evidence" such as this.*

Palmer J's scathing judgment in Re Georgia and Luke (No 2) identified '*a serious abuse by certain DOCS officers of the Department's power to take children into custody under the Act*' and '*an intransigent refusal to acknowledge a mistake, regardless of the consequences to the children*'. Relevantly, the conduct of FACS' legal representative in these proceedings was described as '*cavilling*'. Similarly, the Senior Chief Magistrate has drawn attention to inappropriate and unprofessional behaviour on the part of FACS and the '*occasional need for the Court…to…warn and cajole DoCS to lift its game'*[21].

It would appear that FACS consistently fails to exhibit fair and transparent standards, leading the Wood Inquiry to conclude that FACS' conduct falls below the standards of conduct required of it as government department. [22]

Given the manner with which FACS conducts proceedings, it is of concern that FACS has successfully applied to the Supreme Court in its parens patriae jurisdiction for the indefinite preventative detention of children in their care in secure residential facilities where they have exhibited violent, self-harming and/or anti-social behaviour: see, for example, Director-General, Department of Community Services; Re Thomas (2009) 41 Fam LR 220, Re Helen [2010] NSWSC 1560, Re Tracey (2011) 80 NSWLR 261, Director General, Department of Family and Community Services; Re Vernon [2011] NSWSC 1222.

This indefinite detention power must be reviewed. Unsatisfactory reasons for indefinitely detaining children and adolescents can only lead to despair and self- harm by the young

[21] Wood, above n 27, 414.

[22] Ibid, 498. For this reason, the Inquiry called for the development of guidelines for FACS based on the Code of Conduct for the Office of the Department of Public Prosecutions: ibid, 541.

people detained. FACS has not demonstrated the conduct, judgement nor ability that would make safe any indefinite detention based on their recommendation.

The legal and welfare systems in place must be made more accountable and open to scrutiny if those subjected to them are to have confidence that they will receive fair treatment. Injustice, failure to be heard or respected and hopelessness can lead to self-harm and suicide.

Cultures within institutions which foster disempowerment of children and adolescents must be remodelled and alternative models found that will give children and adolescents detained there a positive sense of self and of control of their situation, with contact reference points in their lives which are outside the institution. As far as possible they should be allowed to maintain their normal ties beyond the institution. Indefinite detention must not be allowed because adolescents and children need hope otherwise there is a real chance of self-harm and suicide.

Institutions involved in child and adolescent health and welfare need to be made more accessible and accountable in order to prevent misuse of power. The closed proceedings of the Children's court need to be opened to public and academic scrutiny in order to engender confidence in the process for children and adolescents involved in proceedings before the court, and a reconsideration of the power to detain children and adolescents indefinitely should be undertaken to avoid the worst despair and excess of institutional disempowerment.

Luckily we managed to escape the system in a manner I will not explain here. My daughter stopped all medication, slowly recovered except for injury sustained in hospital, went back to school and completed university.

I have run out of time to provide further references for the pharmacogenetic information today. If the Commission would like further information about this I am happy to forward further articles.

I strongly believe that this is a science which must be utilised to prevent self-harm and suicide by children caused by adverse reactions to psychotropic medications, especially in detention centres and hospitals.

I wish to remain anonymous.

Thank you for the opportunity to make a submission.