### Submission:

### **Productivity Commission Inquiry into Mental Health 2019**

### INTRODUCTION

I am a father of four and this submission outlines my eldest daughter's (adolescent) struggle with her mental health and a system that has failed to catch her when she has reached out, failed to recognise questionable presentations, and has significantly contributed to her decline. My wife and I are doing everything we can to cater for the impact this is having on our three younger children. As a Health Care Worker for over 20 years, I have witnessed the devastating consequences of many individuals with mental health issues (either as behaviourally disturbed, attempted suicide and completed suicides). However, as a Health Care Worker/father raising a family seemingly without issues, my view was always from one side of the fence. Now, I stare stranded from the other side of the fence. I'm at 'wits end' watching my daughter decline in institutions erected to protect and prevent harm. Institutions that are governed by 'Professionals' who purport to understand the intangible entity of mental health.



I'm no 'wordsmith' and this submission is lengthy with the occasional overlap for which I apologise. I wasn't sure how I was going to piece together what I felt needed to be said. I decided to adopt the SWISS CHEESE model to highlight major 'check points' (submission format outlined below) that my daughter has fallen or squeezed through in a system that at times is equipped to catch her and other times, there have been no nets. The ensuing result, an endless freefall into an abyss that's difficult to reach. I am my daughter's advocate and also for every other individual and their families that fall victim to this system driven by process. Instead, we should be striving for 1'anti-institutional,

democratic psychiatry' that places the 'suffering person and not his/her disorder at the centre'. We should be 'shifting from managed exclusion to social inclusion, affording the individual the same rights and standing of other citizens'.

### Submission format:

- INTRODUCTION
- ALONE AND NO AIR
- Major CHECK POINTS (that my daughter fell through):
  - 1. School Councillor: dismissed my daughter's cry for support/help (2016)
  - 2. Private Psychologist: labelling and referral (2017)
  - 3. Private Psychiatrist: admission/incarceration (2017)
  - 4. Child and Adolescent Mental Health Services (CAMHS): dismissed and abandoned (2018)
  - 5. Continuity of Care: rhetoric only (2018)
  - 6. Extended admissions: no to institutionalism (2018)
  - 7. Parental input: muzzled/trivialised
- Email sent to Mental Health Team, My Daughter, '12 Months On' (a father expressing his concerns), 2018.
- SUMMARY/CONCLUSION

To support the failings at these Major 'Check Points', I've utilised excerpts from a running log (diary) that I have scribed since my daughter's first visit to her Private Psychologist in 2017. I've made every effort to remove individual and institutional names.

Following 'Major Check Points (that my daughter fell through), I have included an email I sent to a Mental Health Team titled, '12 months on'. It summarises my daughter's distressing journey up until that time of writing the email. Per the Mental Health Team, it was an 'excellent summary' and broadly outlines the dilemma we as parents are facing and the trauma incarceration inflicts on our most vulnerable. This email is referenced in 'Major Check Point' number 7 (Parental input muzzled/trivialised).

My submission portrays my observations/experiences and that of my daughter's. It's in no way intended to undermine the incredible work performed and support offered by so many wonderful people (Health and Allied Health) involved in my daughter's care.

I have had to take significant time off work (have utilised a large portion of my accrued sick leave) and my wife has taken a year's leave without pay, so as we can afford our daughter every opportunity to support/care, manage flare ups, attend to appointments/meetings and reintegrate back into mainstream society (school, home, community). It's hard to know the cumulative consequence of this on our other three younger children but the impact on our family and the ripple effect has been immense.

The elected Premier Gladys Berejiklian pledged 88 million for every public school to fund one full-time counsellor or psychologist and one student support officer. The first 'Major Check Point' my daughter fell through was when she reached out to her School Counsellor (Clinical Psychologist). Unfortunately, my daughter's fears were dismissed. A safety net was put in place for exactly this purpose; to 'catch' the adolescent who was brave enough to seek help. Once rejected, emotions became further supressed, seeking help wasn't an option and the climb up that sheer cliff face was now a freefall.

Injecting large funds into various Mental Health arenas will serve little purpose if the philosophy is flawed, not uniform and the 'Check Points' (established/being constructed), are not robust or measurable. If the funds are just to serve a process or to fulfil political gain or to moderate perceived community expectations, then the current Mental Health dilemma will worsen, lives will be further compromised and suicide rates continued. If the philosophy is based on 'anti-institutional, democratic psychiatry' that places the 'suffering person and not his/her disorder at the centre', then changes (perhaps even radical) need to be made. The 'Check Points' mentioned above can all be related to matters outlined in the Productivity Commission's 'Terms of Reference' (23rd November 2018).

I welcome Treasurer Frydenberg's request for the Productivity Commission to '...undertake an inquiry into the role of improving mental health...'

### **ALONE AND NO AIR**

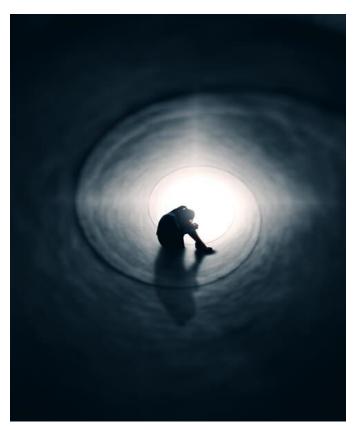
My daughter, spent almost all of 2018 incarcerated in Mental Health Facilities. I am absolutely shattered how it has come to this and the predicament my daughter now faces. In 2016, prior her 1<sup>st</sup> admission (2017), my daughter was actively participating in her academics, multiple co-curricular activities, managing her own bus/train transportation to and from school, attended work experience of her own volition, planning/discussing overseas student exchange trips. Now, she cannot leave a psychiatric ward without an escort.

**NO AIR** (see below) is a tool used by individuals with OCD (Obsessive Compulsive Disorder) to help them manage/lesson or eliminate these crippling behaviours. The concept of NO AIR is incorporated several times throughout this submission.

NO Avoidance NO Interacting NO Reassurance Seeking

An individual's OCD will forever hold them hostage so long as they continue to engage in rituals and not go places (**Avoid**), continue to **Interact** with those persistent negative/controlling thoughts and incessantly

seek **Reassurance** from others. To avoid Avoiding, requires tremendous courage as triggers and obsessive thoughts manifest from seemingly nothing. NO AIR can also be utilised by those suffering from



other forms of Anxiety (e.g. Generalised and Social), Depression and Mood disorders. In fact, NO AIR can be a simple tool that all individuals can utilise and benefit from.

The 'system' has played a significant role in assisting my daughter's Avoidance, Interaction and Reassurance Seeking. Her cry for help (long before her first admission) was ignored and her incarceration has done nothing but exacerbate her anxiety, depression, suicidal ideation, OCD and mood fluctuations. As a result of her 'extended admissions' of managed exclusion in Adolescent Mental Health Facilities (AMHFs), the claws of intuitionalism have dug in and are pulling on her ankles. We have been advised (as if it wasn't blatantly obvious), this typically results in deleterious consequences such increased avoidance of typical stressors, development of an arsenal of maladaptive behaviours, trauma and constant reassurance seeking (e.g. competition for Nurses). The crucial aspects of my daughter's recovery (i.e. illness, Developmental Arrest and

reintegration - school, home, etc), are more distant than ever.

**NOTE:** In order to deidentify and help differentiate between Adolescent Mental Health Facilities (AMHF), each facility is referenced as below:

Local AMHF: <sup>1</sup>AMHF
 Distant AMHF: <sup>2</sup>AMHF
 Alternate AMHF: <sup>3</sup>AMHF
 Different AMHF: <sup>4</sup>AMHF

### Major CHECK POINTS my daughter fell through

### 1. School Councillor: dismissed my daughter's cry for support/help (2016)



In 2016, my daughter took an active step in seeking help/advice from her School Counsellor (Clinical Psychologist). My daughter needed to make sense of the deluge of negative thoughts that were exhausting and afflicting her. The sense of numbness, failure, despair, frustration, low moods, guilt and fear were incapacitating. Despite this and the associated social stigma and existing prejudice engulfing mental health, my daughter showed tremendous courage and humility to seek help. Sadly, the School Counsellor dismissed my daughter's concerns. My daughter felt belittled, judged and rejected. Reluctance became her default in reaching out to another person; she retreated. The weight of depression began to smother my daughter as she metaphorically began to wave her arms; 'Not waving but Drowning' (poem by

Stevie Smith).



officer at a cost of \$88 million.

My daughter's path would be very different today had the School Counsellor not flogged her off. My daughter has an incredible capacity to mask the depths of her anguish. Unfortunately, she wasn't taken seriously on that pivotal 1<sup>st</sup> contact for help and as a result, fell through a small hole in a barrier that was put in place to catch her.

I think it's wonderful that the Premier Gladys Berejiklian during the NSW election campaign, announced that every public high school in NSW will get one full-time counsellor or psychologist and one student support

I pray these Counsellors are well trained, can let go of their own preconceptions, are able to articulate and empathise in a positive and genuine manner, provide support and nurture a child's development, steer through a child's concerns/fears and to never turn away a child that asks for help.



### 2. Private Psychologist: labelling and referral (2017)

- 1) How accurate are modern assessment tools?
  - i. **Anxiety and depression** were diagnosed by my daughter's private Psychologist (2017) & confirmed by her private Psychiatrist (2017)
    - As per my daughter's Psychologist assessments (utilising various anxiety/depression scales):
      - Per Multidimentional Anxiety Scale for Children 2<sup>nd</sup> edn (MASC-2): my daughter was experiencing 'clinically significant' levels of anxiety
      - Per Children's Depression Index 2<sup>nd</sup> edn (CDI-2): all parameters reported 'clinically significant' levels of depression
      - Per the "Obsessions and Compulsions" component, T-score was 73: A T-score of 65
        or above is considered clinically significant.
- 2) Search the Internet and you can easily find a plethora of information to self-diagnose, to self-label, to find a box that you can squeeze into, to correlate those aching and relentless signs & symptoms in order to find a solution to fix it or end it.
  - I. My daughter was desperately searching for something she can fit into, something she can relate to, something that would make sense of those unrelenting despairing thoughts. Struggling to be heard and understood, she just wanted to stop the hopelessness, alleviate the fear and just make the pain go away.
  - II. My daughter had looked into sites like Beyond Blue and the Black Dog Institute and validated her depression via 'Depression Self-Tests' (similar to e.g. Table 1 below). When you factor into this, the catastrophic negative impact the Internet has via various other platforms (such as social media, blogs, youtube, etc), the link to increased suicide rates in teenagers shouldn't come as a surprise.
    - o How helpful are sites dedicated to mental health?
      - Vulnerable kids label themselves with an illness based on their interpretations of information acquired, their experience and their signs/symptoms.
      - Taking that susceptibility and self-diagnosis into account, when my daughter was assessed by her Psychologist utilising 'Multidimensional' Anxiety/Depression scales for children, she had already practiced many times via the Internet and was always going to register in the 'clinical significant' range.
        - I. In reality how accurate are these assessment tools?
        - II. My daughter is validating her illness via the internet and her Psychologist is endorsing her own validations.
- 3) My daughter had contacted Suicide Hot line many times (I was made aware following visits to her Psychologist's) and at times, waited for `15-20 mins.
  - ii. Who is manning the phones?
  - iii. What experience have they got?
  - iv. What are their qualifications?
  - v. What are their benchmarks for escalation?
  - vi. Waiting times are discouraging and detrimental.
  - vii. Are they actually helpful?
  - b. Psychologist referred my daughter to a Psychiatrist:
    - i. My stereotypical view of a Psychiatrist, is that they dish out medication and I have a healthy scepticism about the effectiveness of psychotropic medication.
- 4) This labelling of the intangible entity known as mental health, has continued throughout my daughter's journey (treatment/admissions). Mental Health Professionals are basing their views (diagnosis) on experience, understanding/interpretations of the Diagnostic and Statistical Manual of Mental Disorders (5<sup>th</sup> edition), observations and their intrinsically perceived perceptions. There has certainly been a demonstrated subjective bias that's by far outweighed objectivity. This I'll try to

describe via a simple analogy re fractured hand: The initial consult (by a Doctor at an Emergency Department), has identified the individual has a clearly displaced fracture of a bone in their right hand (say metacarpal), which has been confirmed by X-rays and assessment (discoloration, swelling, pain, unable to facilitate specific movements, etc). The individual's arm is placed in a temporary cast and referred to an Orthopaedic clinic for review. The Orthopaedic Specialist after reviewing the Emergency Department discharge summary and the X-ray states it's not fractured; the Orthopod doesn't perform an assessment (the hand remains immobile in a temporary cast), questions whether it's their right hand and not their left and even questions whether the X-ray belongs to them. The Orthopod's consult with the patient lasted < 1min. Sounds absurd? Welcome to the world of Mental Health. This subjective approach into an entity that isn't tangible, has had a sizeable impact on my daughter! A Lovely Psychiatrist stated to me in reference to my daughter: 'Psychiatry isn't an exact science.' This crippling effect is best described (in greater detail), under Major Check Point, Child and Adolescent Mental Health Services (CAMHS): dismissed and abandoned. One aspect describes the first meeting my daughter had with the local CAMHS Psychiatrist post her 1st admission (7 weeks) at a local AMHF. The CAMHS Psychiatrist having met my daughter for the first time, after only ½ an hour questioned her medication regime (even discontinued one medicine), the dosing, and her diagnosis. After walking out of that meeting, my daughter asked me: 'What's wrong with dad? Seven weeks admission at the local 1AMHF, just came undone. A defining moment.

### TABPLE 1

Per the Black Dog Institute Website (Under depression – Depression Self Test)

Over the past two weeks how often have you been bothered by any of the following problems?

Questions	Not	true	Slightly true	Moderately true	Very true
Little interest or pleasure in doing things	$\circ$	Not	0	0	0
Little interest of pleasure in doing tilings	true		Slightly true	Moderately true	Very true
Feeling down, depressed or hopeless	$\circ$	Not	0	0	0
realing down, depressed or hopeless	true		Slightly true	Moderately true	Very true
Trouble falling or staying asleep or sleeping too much	$\circ$	Not	0	0	0
	true	NOL	Slightly true	Moderately true	Very true
Feeling tired or having little energy	$\circ$	Not	0	0	0
	true		Slightly true	Moderately true	Very true
Poor appetite or overeating	$\circ$	Not	0	0	$\circ$
. co. appoint of crostaining	true		Slightly true	Moderately true	Very true
Feeling bad about yourself – that you are a failure or have let yourself or your family	$\circ$	Not	0	0	0
down	true		Slightly true	Moderately true	Very true
rouble concentrating on things, such as reading the newspaper or watching television	$\circ$	Not	0	0	$\circ$
	true		Slightly true	Moderately true	Very true
Moving or speaking so slowly that other people could have noticed. Or the opposite –	$\circ$	Not	0	0	$\circ$
being so fidgety or restless that you have been moving around a lot more than u	true		Slightly true	Moderately true	Very true
Thoughts that you would be better off dead, or of hurting yourself	$\circ$	Not	0	0	0
Thoughto that you would be better on dead, or or hurting yoursen	true		Slightly true	Moderately true	Very

### 3. Private Psychiatrist: admission/incarceration (2017):

a. My daughter's Psychiatrist advised at her first appointment, that Psychotropic medication will improve her cognitive state and therefore her capacity to articulate. The Psychiatrist referenced a generic '3 pronged' approach to benchmark her treatment:

- 1. Psychotherapy
- 2. Medication
- 3. Parental Consultation
- b. After our first visit with the Psychiatrist (2017), we (parents) wanted to explore our options. My daughter and I visited a second adolescent Psychiatrist who was disinterested and dismissive (despite currently treating my daughter's cousin, which raised the question of a familial connection). My daughter would not engage with the second Psychiatrist so we opted for the first because she was able to at least, communicate (rather pivotal) with the Psychiatrist.
- c. Early in my daughter's therapy with her private Psychiatrist, I inquired whether my daughter had a 'plan'. The Psychiatrist quickly defended the need not to disclose any information due to confidentiality. I persisted in my inquiry and added as parents, 'HER SAFETY IS OUR NUMBER ONE CONCERN; it'll be a good idea to advise if she has a plan and what her plan is, so we can be on the lookout, prepared and vigilant.' Per the Psychiatrist, 'she wants to throw herself in front on a bus.' Right!! My daughter was catching a bus and a train to/from school.
  - i. After ~ 6 months of getting to 'know my daughter', my daughter's private Psychiatrist already managing elevated risks, became very concerned for her wellbeing and strongly advised admission into an Adolescent Mental Health Facility (AMHF) because:
    - 1. 'I cannot guarantee her safety'
    - 2. 'Her Safety is at significant Risk'
    - 3. 'It'll only be a short admission (one to two weeks)'
    - 4. 'They'll manage medications with respect to diagnosis (i.e. correct medication/dosing, compliance, effect, etc)'
  - ii. In the meantime:
    - I vividly recall sitting in my daughter's Psychiatrist's office contemplating the suggestion that admission was the best option. Just the thought of admission for my daughter made me feel ill. I mulled on the cohort that my daughter will mix with; their influences on her; the devastation of social isolation; the violation of her innocence; incarceration; the road to institutionalism.....
- d. My daughter's Psychiatrist is a specialist in Psychological medicine who was advocating for admission; advocating for managed exclusion; advocating for institutionalism. In the construct of NSW Mental Health, the Psychiatrist had no other safe option. The Psychiatrist was well aware of the pitfalls of admission: i.e. the impending isolation, the implications of incarceration, the resultant developmental arrest, the dependence on carers, acquisition of maladaptive behaviours, trauma, loss of resilience, exacerbation of existing fears and creation of new ones, the habitual dependence/reassurance seeking, continued/strengthened avoidance, obsessive interactions with negative thoughts made worse by poorly stimulated ward environments but offered no other option.
  - i. If it was feasible, my wife and I were more than willing to take care of our daughter with community-based support if available. The advice remained categorical and stern: 'Her safety I cannot guarantee; her safety is at significant risk; they'll manage her medication (i.e. administer medication/dosing that best suites her in a controlled setting) and have her sorted swiftly'.
  - ii. Who cross checks a Mental Health Professional's decision making: i.e. to admit an adolescent into a Psychiatric ward despite a loving and caring family wishing to support in any way possible?
    - 1. Why isn't this decision reviewed?
    - 2. Why aren't the parents given alternate options (irrespective of viability)?
      - Any alternate options must be articulated and substantiated against risk v gain and workability: admission must be a very distant last on the list of options.

- II. What support/advice is given to the family to genuinely feel other alternatives are available and can be pursued?
- III. There needs to be advice on the perils of admission into a Mental Health Facility (as stated above; dot point d.)
- e. Mental Health issues are a non-tangible entity. A supportive Adolescent Psychiatrist during this crippling patch of my life stated (in reference to my daughter): "Psychiatry isn't an exact science; we won't know what it is till we stumble across it.' This statement provided little comfort but resonates with realism.
  - i. Therapists are managing my daughter's life based on observation, recent history, familial history, opinion, adolescent perceptions as well as their own, influences, confidentiality (what the parents aren't told), conforming to governed practices despite poor/questionable outcomes and perhaps, protecting their own fears. For parents, our fears are exploited through mis-information, ill-informed, not knowing (again due to confidentiality), uncertainty, neglect, lack of support and watching our daughter decline.
  - ii. When the staff at the local Adolescent Mental Health Facility (local <sup>1</sup>AMHF; 1<sup>st</sup> admission) advised admission will be ~ 2 weeks (average stay is ~ 10 days), I was beside myself. My daughter's first admission went for two weeks, then stretched to four weeks and then 7 weeks before being discharged. Her world will never be the same.
- f. Following several extended admissions, I find myself struggling to navigate this quagmire that I have dived into. I've come to the realisation that our Mental Health system in NSW, is not geared up to support anti-institutional care?
  - i. For example, where is?
    - 1. The readily and easily accessible community-based interventions 24/7
    - 2. The network of community Mental Health Centres (MHC) with the ability to deal with the most severe conditions
    - 3. The <sup>3</sup>multi-disciplinary teams of mental health professionals at each of the community-based MHCs.
      - I. You contact CAMHS: 'Go to the ED'.
      - II. You contact Acute Care Team: 'Call an Ambulance' or 'go to the ED'.
      - III. You go the ED, you're either advised to administer 'TLC' and supported with a nervous 'good luck' or scheduled and admitted for an 'extended admission'.
- g. My daughter's incredible empathy, enduring struggles, hopes, beliefs, frailty, dreams, passion, love, aspirations, kindness, determination, wants and expressions, are being smothered 4'by diagnostic labelling and flattened and objectified by the institutional process.'
  - And 'somehow, my daughter has to avoid identifying herself by her mental health issues but rather view her anxiety/depression as just a component of the many parts that sum her up. How is that possible with her environment (surrounded by unwell adolescents), the incarceration/isolation, the lost opportunities, the belief/perception that nothing has been resolved/fixed, existing fears heightened and the want to achieve/accomplish showing only transient glimpses.' (excerpt from email sent to Mental Health Team Full email under Major check points, Parental Input: muzzled/trivialised).
- h. Whenever my daughter falls through a hole or squeezes past a crack, she crashes onto the barrier below. There are times you can reach her and other times you can only see or hear her. Either way, it is like finally reaching the 12 young boys and their coach trapped in the Tham Luang Cave in Thailand (July 2018). Their plight captivated the world. For the rescuers, the logistical dilemma provoked a few simple inquiries: Now what? How do you get them out with water levels rising? Their time critical rescue made possible by the incredible rescue efforts of a combined International and Thai rescue contingent. What seemed impossible was made possible.

 Log entry below partly captures this unfolding nightmare and the ever-destructive ripple effect.

### a. 2018

- My daughter didn't want to see Granny: and as my daughter stood at her bedroom door retreating, Granny could hear my words: "I can hear your daughter but I can't see her." "We have to find her before her voice cannot be heard."
  - I. My daughter cannot get out of the hole and we cannot reach her:
  - II. Every effort must be made now by everyone involved to find my daughter:
    - The world observed the rescue of 12 young soccer players and their coach from the Tham Luang Cave in Thailand. It's amazing what can be done when resources from all over Thailand and internationally combine. The goal was simply: get the boys and their coach out safely.
    - Lets all unite and FIND my daughter:
      - No more administrative red tape; no more pontificating, assumptions, guessing, lets wait and see....
        - Meds aren't working
        - Incarceration isn't working
        - OCD, Social Anxiety, Disordered Eating, Bipolar mixed (not yet specified), Dissociative episodes, Depression aren't cutting it?
        - My daughter constantly has stated:
          - o What is wrong with me?
          - You don't understand.
          - o Nothing is working.
          - o Nobody is helping me.
- Granny was devastated: as Granny stood outside my daughter's room crying, my daughter approached Granny wiped her tears, hugged her and said it'll be alright.
- Granny got in her car and just broke down (crying).
- The most beautiful aspect of my daughter, is her empathy towards others despite her own inner turmoil.
  - I. My daughter is waiting for us to get to her: hope is still there:
- i. Does the current construct of Mental Health in NSW utilise *legislative*, *administrative* and scientific apparatuses to support a model whereby the illness is the danger, thus creating institutions to maintain the individual and keep them separated from society/?\*<sup>4</sup>
  - 4"De-institutionalisation is a critical-practical process which reorients institutions and services, energies and knowledge, strategies and interventions, from an artificial object which is the illness (understood as a diagnostic label) towards the patient's suffering-existence and his or her relationship with the social body as a whole."
- 4. Child and Adolescent Mental Health Services (CAMHS) dismissed and abandoned (2018)
  - a. Our initial experience with CAMHS was appalling:
  - b. CAMHS played a pivotal role in abandoning my daughter and us (her parents): they were dismissive, aloof, unsupportive, circumvented our fears/concerns and made poor clinical assumptions on my daughter's recent history and presentation.
    - The Psychiatrist and Psychologist assigned to my daughter were way off the mark and both driven by process and perhaps their own ego.
    - The Psychiatrist at CAMHS has a lot to answer for:
      - 1. Within ½ hr of seeing my daughter for the 1<sup>st</sup> time (2018); more than 2 weeks post discharge), he questioned my daughter's diagnoses and the medication/dosing. Per my daughter post meeting, 'what's wrong with me dad.' In one foul swoop, a 7 week admission at a local Adolescent Mental Health Facility (local ¹AMHF), just came undone. The Psychiatrist also decided to discontinue my daughter's Melatonin. Really!! It was

therapeutically working and keeping my daughter asleep (poor sleep being a major contributor to her mood fluctuations and depression). Of all the medication to discontinue: Melatonin?? Apparently, my daughter was on too many agents, so he took her of the most benign medication that was actually helping her sleep. Very quickly my daughter's sleep became disrupted throughout the night. Her depression worsened, dissociative episodes manifested for the 1st time and suicidal ideation escalated.

- I. The next time we were 'privileged' to see the CAMHS Psychiatrist was ~ one week after her Melatonin was ceased, after presenting to the Emergency Department (ED) the previous day. The ED had informed CAMHS who were obligated to contact us and arrange a meeting. Whilst waiting at CAMHS, my daughter dissociated and the Psychologist, Clinical Nurse Consultant (CNC) and the Psychiatrist witnessed this behaviour. Despite this, the Psychiatrist turned a blind eye to my daughter's dissociative episodes; he preferred to set a date for a family meeting in 3 weeks time. The next day we presented to the ED; this preceded another 10 week admission at a local ¹AMHF (2018).
- II. The CAMHS Psychiatrist ignored the concerns of the Father and circumvented every question/concern raised. Per my daughter post the meeting; "Dad he's like a Politician; he did not answer any of your questions."
- III. The CAMHS Psychiatrist was ideally placed to make a massive impact/difference on my daughter:
  - o That he did: in a profoundly negative way.
  - O He violated every rule in Psychiatry: he ignored, he dismissed, he assumed (e.g. attention seeking or 'cry for help' or behavioural or manipulative), offered no explanation, no reassurance, new presentation post recent admission with new diagnosis and new medication should ring alarm bells (rule 101), meddled with my daughter's mental health by questioning her diagnoses and medication regime having known her for just ½ hr, just oozed with arrogance by evading every question, prayed on parental fear and the non-tangible entity of mental illness to foster his blatant disregard of the patient and their presentation...
  - The CAMHS Psychiatrist offered no explanation/reassurance. It's as if we were a burden. When I tried to contact him for support/advice during a crisis moment that my daughter was experiencing, I couldn't get a hold of him: when my GP tried to contact him, he refused to chat.

To highlight a little of the above, below are excerpts (de-identified) from a comprehensive log/diary that I have compiled since my daughter's first visit with her Private Psychologist.

- 2018: Unusual and new behaviour prior bed
- 2018: Unusual behaviour at school and continued at home
  - Unable to get in touch with CAMHS (recorded message): left a message for CAMHS Psychiatrist to get in touch with me
  - Present to my GP: Took bloods to check serum Epilim, ammonium and TSH
    - CAMHS Psychiatrist not available to discuss with my GP (may get back to GP tomorrow)
    - CAMHS Psychologist advised my GP to refer my daughter to ED if concerned
    - My GP gets in touch with my daughter's treating Psychologist at local <sup>1</sup>AMHF: ? Fluoxetine
    - My GP advised to discontinue Fluoxetine tomorrow a.m. until reviewed by CAMHS Psychiatrist

- Olanzapine PRN wafer @ ~ 1800 hrs (1st since discharge)
- **2018:** Scheduled CAMHS meeting with Psychologist at 10:00.
  - CAMHS Psychiatrist was in the building but did not attend to advise/assess my daughter.
  - Waisted time on producing safety plan for procedural sake only: Dismissive with our concerns and recent history
  - My daughter's behaviour was becoming worse: trying to 'go on an adventure' (with makeup, pretty dress) via absconding.
  - Olanzapine PRN Wafer at ~ 1700hrs
  - Transport to ED
  - Assessed by Psych Reg (med dosing change Fluoxetine 60↓40/Epilim700↑1000)
    - Plus advised: TLC and Good Luck
    - Discharged at ~ 2230 despite my daughter stating, her 'adventure' is to run in front of a car

### 2018

- a. My daughter woke up at  $\sim 10:30$  a.m.
- b. Phone call by CAMHS (Psychologist)
  - Scheduled a meeting with Psychiatrist and Psychologist at 1200 hrs.
- c. Arrived at CAMHS @ ~ 1145 hrs
  - My daughter was becoming more and more anxious
    - I. Demeanour dropped: gaze became unfocussed
    - II. At  $\sim$  1204 hrs (CAMHS never calls you in a little earlier), my daughter quietly got up and went for the door that leads to the vestibule
    - III. My daughter reverted back to her child like behaviour ('I want to go on an adventure')
  - CNC (Clinical Nurse Consultant) and Psychologist escorted us to their new Garden (only completed yesterday)
    - mpleted yesterday)

      I. CNC engaged a little with my daughter: describing the various tactile plants, etc.
    - II. Generally, they stood back and observed: there was no real interaction, a little compassion, a human touch to reassure. Just observation
    - III. My daughter went onto the funky round swing
    - IV. My daughter had a go at bailing out the back door (never any assistance: just observation)
    - V. Psychiatrist arrived, began the interview outside.
      - Even in her child character (partially/'mixed), my daughter was responding to his questions
      - o My daughter reverted back to her normal self and we made our way inside
  - The interview with the Psychiatrist:
    - I. I'm growing a little tired of the tactics adopted by the Psychiatrist and the lack of support, reassurance afforded to both parent and my daughter.
      - o Before I go on, this will be my caveat.
        - The only reassurance I can rationalise/derive, is their lack of immediate concern:
        - Psychiatrist was privy to ED discharge letter:
          - He made that very clear to me (stopped me talking with hand raised) when I tried to describe yesterday's events.
        - But I'm frightened and very concerned: My wife is terrified:
          - No addressing the recent presentation; no reassurance; steered conversation, history taking etc around the reason we were here:
            - o i.e. my daughter's recent childlike presentation and the need to abscond and possibly harm herself (i.e. run in front of a moving vehicle).
      - My daughter called the Psychiatrist a politician (never answers any questions; whiffle waffle and circumvents)
        - Common reply to anything from both Psychologist and Psychiatrist:



- 'I don't know your daughter well enough.'
  - o You have a whole dossier on my daughter:
  - o Info from her Private Psychologist
  - o Info from her Private Psychiatrist
  - o Volumes from her 7-week admission at local <sup>1</sup>AMHF
  - CAMHS Psychiatrist has spoken with local <sup>1</sup>AMHF's Head Psychiatrist
  - o Yesterday's discharge letter from the ED
  - o Able to observe my daughter's behaviour first hand
  - Has had countless feedback from CAMHS Psychologist
  - And now the CAMHS Psychiatrist who is seeing my daughter for the 2<sup>nd</sup> time:
    - You guessed it!
    - 'I don't know your daughter well enough.'
    - Disrespecting his patient and the family.
    - Not once was I asked, what are your concerns/fears right now?
    - Not once was I asked.
- In fact, I can't get a hold of the CAMHS Psychiatrist for some advice, council or support. You leave a message with CAMHS reception asking for the Psychiatrist..... Yeap, never returned.
- I got it: just contact Acute Care Team or default to ED
- I thought, the CAMHS Psychologist and Psychiatrist (CNC wherever she fits in), were my daughter's Mental Health Management Team.
- d. **2018:** withdrawn; crying; sitting on bed; viewing computer; self-harming; binge eating; disengaging; This is how my daughter presented prior 2017 1st admission (local 1AMHF). That afternoon, my daughter made a huge effort and bolted via the garage to abscond. Stated repeatedly: 'I want to go on the Road; I want to die.'
  - Presented to ED: Psych Reg witnessed attempt to abscond and ? dissociative behaviour: My
    daughter made it very clear, 'I want to run onto the road in front of a car; I want to die; I'm not
    safe to send home; I will run every chance I get.'
  - My daughter was scheduled:

**NOTE**: Below are excerpts logged in my phone 2018. The excerpts below support/qualify the log entries stated above.

### 2018. At Home.

CAMHS Psychiatrist strategically circumvented my daughter's recent dissociative behaviour (and what he observed) and her need to go for an adventure on the road in front of moving cars. Whatever I asked the CAMHS Psychiatrist, the reply was always the same: "I DON'T KNOW YOUR DAUGHTER WELL ENOUGH". Absolutely no support and just a cop out. The CAMHS Psychologist couldn't wait for the meeting to end. The CAMHS Psychiatrist has a whole dossier on my daughter and as a senior Clinician in his chosen specialist field of Psychological Medicine, couldn't offer a deferential diagnosis (not even a hint). 'I DON'T KNOW YOU WELL ENOUGH', best we get together with the whole family in the 3 weeks.

Imagine how that makes my daughter feel; desperate to find out why she's feeling like this but your consultant Psychiatrist cannot even probe just a little to make at least some form of assessment because he 'doesn't know her well enough'. Just abandoned my suicidal daughter. My daughter was determined to attend the school play this evening. My daughter is stage manager. Play started 1930. My daughter needed a walk @ ~ 1940. Wonderful she recognised the signs prior the giggles. Whilst walking on footpath with myself by her side, the laughter started and twice my daughter went for the road when a vehicle was approaching. My daughter suddenly snapped out of it and stated: 'I know what i want to do'. What's that? 'I want to run on the road in front of a car.' Thanks heaps for your support and reassurance CAMHS Psychiatrist. My daughter was able to go back stage and complete the show. Later stated, it all went well. This latest progress in her suicidal ideation/attempts is frightening and almost impossible to manage. What is CAMHS role??? When I've needed them, they've been anything but supportive; there is no love: child is screaming out for help, parents are terrified and CAMHS Psychiatrist needs to get to know my daughter better. How long will that take CAMHS Psychiatrist? Another two months, 1 year, 3 years, take your time CAMHS Psychiatrist.

In the interim, my wife and I have to prevent our daughter from plunging herself in front of a moving vehicle. CAMHS Psychiatrist, next time you're on the road (yes, the real world), you will come to the realisation that there are a plethora of vehicles that utilise that road. Yeap, a plethora of opportunities for a suicidal child to act on an impulse.

### 2018. ED presentation (overnight stay): No beds available: transferred to a distant Adolescent Mental Health Facility (2AMHF) via Ambulance (2hrs drive- 200km away).

My daughter was flat throughout the day.

Stayed on her bunk bed occupied by her computer: youtube, SIMS, etc. Didn't want to chat, was self-harming and bouts of crying.

Asked to come down stairs.

My daughter wanted to distract herself with cooking.

Mentioned it was going to happen: the giggles began and she bolted for the door.

Her struggles to abscond are becoming more aggressive with respect to the effort and energy she puts in. My daughter repeatedly stated: wanted to go for an adventure on the road in front of a car. 'I WANT TO DIE'. Gave my daughter an Olanzapine wafer and of to the ED (@  $\sim$  1800). I cannot even go to the toilet; we're standing guard at possible exits; deadlocking doors; the trauma to our other three kids; My wife is unable to manage my daughter at full flight, so scared to be alone with my daughter; we don't live in a prison and we cannot do anything but I think I've got it CAMHS Psychiatrist: 'You just need to get to know my daughter better.'

### 2018 (distant Adolescent Mental Health Facility – <sup>2</sup>AMHF)

- After being punted to a distant <sup>2</sup>AMHF (200km away).
- LOCUM Psychiatrist also agreed my daughter's actual intention to throw herself in front of a car, places her at high risk. Even if she doesn't really want to do it, the accidental mishap can be fatal. Her want to abscond can be viewed as medium risk but her intent is viewed as high risk. Someone tell the CAMHS Psychiatrist that: unfortunately, all info/treatment and assessments will be relayed to CAMHS.
- LOCUM Psychiatrist cannot talk directly with Psych Team at previously admitted Adolescent mental Health Facility (i.e. local 1AMHF). Care has been handed over to CAMHS. The system is screwed.
- Cannot definitive give a diagnosis for current presentation. But any new presentation is always a concern and must be investigated.
- LOCUM Psychiatrist would not have discharged my daughter after her first ED presentation (i.e. med dose change and advised: administer TLC and good luck).

## Excerpt Summing up Point 4: Child and Adolescent Mental Health Services (CAMHS) – dismissed and abandoned (2018)

- My wife and I have been taking a risk to keep my daughter at home to promote recovery, trust, healing, confidence, independence and self-worth. We have tried very hard to keep our daughter away from the ED and of course away from an Adolescent Mental Health Facility (AMHF). The hospital transfers care to CAMHS (Community Mental Health) for ongoing treatment and support. My wife and I have been doing this alone; the CAMHS Psychiatrist doesn't know my daughter well enough to do anything. My daughter presented to him at High Risk, he abandoned her and rejected all our fears/concerns. Extraordinary dismissive from both Psychiatrist and Psychologist. There are certain checks, that Health provides (and incumbent on our Health Care Professionals) to help prevent error/an oversight/mis diagnosis/misadventure/accident/catastrophic outcome.
  - a. Despite the CAMHS Psychiatrist witnessing my daughter's behaviour; despite my daughter being discharged 3 weeks prior from an Adolescent Mental Health Facility following a 7 week admission; despite having a discharge summary from an ED presentation the previous day; despite this being a new presentation (dissociative state); despite my daughter feeling suicidal and wanting to run onto a road and throw herself in front of car; despite the fears/concerns of her parents who KNOW HER WELL ENOUGH, the CAMHS Psychiatrist was dismissive. He did not address or probe my daughter's current behaviour/dissociative state; he didn't take into consideration that my daughter has been at risk for some time (catered for by her parents); he didn't take into consideration my daughter is at High Risk and her impulsiveness during her 'dissociative' state, could be catastrophic; he did not consider that this was a major check and possibly a final check in the hierarchy. Instead, the CAMHS Psychiatrist was indifferent; he circumvented the whole meeting and steered it like a 'Politician' disregarding the patient and the parent; he just 'DIDN'T KNOW MY DAUGHTER WELL ENOUGH' and instead wanted to have a family gathering in three weeks' time; that's right, in three weeks. My daughter had reached crisis point, and the Health Care Professional who specialises in Psychological Medicine (major check

point with significant influence and capacity to direct/advise), wouldn't return my calls, avoided my daughter and failed to recognise my daughter's safety was in jeopardy and at High Risk of attempting suicide. The CAMHS Team whom my daughter had been referred to for ongoing care, treatment and support, abandoned her when she was screaming for help.

- I. How hard is it: "I want to die". "Any chance I get, I'll run on the road in front of a car."
  - It doesn't take a Psychiatrist to recognise that my daughter had an 'intent' to kill herself.
- Twice that evening whilst taking a moment from her stage-managing duties, whilst walking on the footpath, my daughter motioned towards the Road when a car was approaching (I stopped her). Per my daughter, "I know what I want to do; I want to walk in front of a car."

### 5. Continuity of Care: rhetoric only

a. 'Continuity of Care' is a real catch phrase that is deeply rooted in rhetoric only; it doesn't ring true in practice. I would have thought our adolescents with Mental Health issues, would have high priority to maintain continuity of care and every possible opportunity/leeway afforded them. This doesn't seem the case:

### Example 1.

Whilst at the ED 2018, I was advised my daughter will need to be admitted (2<sup>nd</sup> admission). The only Adolescent Mental Health Facility (AMHF) with an available bed was 740km away (or 8.5 hrs drive). No, I'm not kidding! Dr returned ~ 90 mins later and stated I've got good news; a bed has become available at an AMHF 200km away (~ 2hrs). 'This can't be happening.' Sure enough, my daughter was transferred by Ambulance to a distant <sup>2</sup>AMHF 200km away. After 2 days admission at this distant <sup>2</sup>AMHF, there was serious disapproval from staff who were also singing the 'continuity of care' mantra. No surprise, the local <sup>1</sup>AMHF closest to home (the AMHF that my daughter spent 7 weeks on her 1<sup>st</sup> admission), found a bed and my daughter was transferred to <sup>1</sup>AMHF (2<sup>nd</sup> admission duration,10 weeks).

i. This was an absolute farce. Seriously?? To suggest 740 km away as an option and then the good news, 200km away has a bed'. This isn't about the patient and their 'continuity of care' as best practice but rather a bureaucracy driven by flawed processes and individuals frightened to wrestle with officious factor's that dictate play.

### **NOTE:** Excerpts below from Galaxy 4 log highlight above example

**NOTE:** In order to deidentify and help differentiate between Adolescent Mental Health Facilities (AMHF), each facility is referenced as below:

Local AMHF: ¹AMHF
 Distant AMHF: ²AMHF
 Alternate AMHF: ³AMHF
 Different AMHF: ⁴AMHF

### 2018: At Home

Onset child laughter and ? Dissociative behaviour before bed (~ 2030).

### 2018: At Home

Picked up my daughter from school at 1230: onset laughter at  $\sim$  1220: child like behaviour. At home, pretty dress adventure, casino, invisible plane. Fell asleep for  $\sim$  3 mins.....awoke and was startled when she realised she was wearing her best dress.

Contacted CAMHS: Recorded message.

Contacted my GP: asked to drop by surgery. Took blood to check for serum Epilim, ammonium and TSH. My GP contacted CAMHS wanting to speak to the Psychiatrist; my GP was advised CAMHS Psychiatrist will get back to her tomorrow and for my daughter to perhaps under her referral, present to ED; hopeless. Not supportive at all. Went home. My GP made contact with <sup>1</sup>AMHF Psychiatrist (cared for my daughter during 1st admission).

<sup>1</sup>AMHF Psychiatrist advised to continue with Epilim and ? Fluoxetine as potential cause. My GP contacted me and advised to stop Fluoxetine tomorrow a.m. and have medication reviewed by CAMS Psychiatrist at tomorrow's CAMHS meeting (1000).

My daughter required an Olanzapine wafer at ~ 1800 for ongoing manic/dissociative behaviour.

### ED presentation (discharged @ ~ 2230).

CAMHS meeting at 1000 with Psychologist only: Psychiatrist was in the building but didn't feel it was important to investigate recent change in my daughter's behaviour or respect the concerns of both parents and GP. I had left a message the previous day for the Psychiatrist to get in touch with me. Not even a courtesy call. THIS ISN'T SUPPORT.

Didn't go to school post CAMHS. My daughter was 'low' for the rest of the day. At home, my daughter became restless, applied makeup, put a pretty dress on and then bolted for the garage door. Gave her an Olanzapine wafer before transport to ED. After several wrestles on the floor at the Emergency Department and another Olanzapine wafer at ~ 1900, my daughter was advised by a Psych Reg (following advice from his 'boss'), it's probably Dissociative; for me to admin TLC; Epilim from 700 to 1000; Fluoxetine from 60 to 40 and 'Good luck'. Got home at ~ 2300.

#### 2018. At Home.

Phone call from CAMHS Psychologist (due to ED presentation the previous day) to come in for a review with CAMHS Psychiatrist at 1200.

Sadly, the CAMHS Psychiatrist disregarded my daughter's recent/witnessed dissociative behaviour and preferred to meet in three weeks with the whole family. Whilst taking a break from her Back Stage Manager's role at a school play that evening, my daughter motioned twice to run onto the road as a vehicle was approaching (of course the childlike laughter preceded). I understand CAMHS Psychiatrist, 'you don't know my daughter well enough.'

### 2018. ED presentation (overnight stay): transferred to a distant Adolescent Mental Health Facility (<sup>2</sup>AMHF) via Ambulance (2hrs drive- 200km away).

My daughter's struggles to abscond are becoming more aggressive with respect to the effort and energy she puts in. My daughter repeatedly stated: wanted to go for an adventure on the road in front of a car. 'I WANT TO DIE'. Transport to ED post an Olanzapine wafer.

### Admission to distant Adolescent Mental Health Facility – <sup>2</sup>AMHF (200km away)

I stayed in the isolation room with my daughter. At ~ 0730, having nodded off for a moment, I looked at the door.....my daughter had just walked out and she was now legging it. In hot pursuit was myself and at least three other nurses; my daughter made it to the foyer: she was incredible. Managed to sprint whilst wearing socks on a vinyl surface. My daughter was given an Olanzapine wafer. Had breakfast an hr or so later and then fell asleep. Special Nurse arrived ~ 1100 hrs. Psych Reg arrived to inform there were no beds available. Possibly a bed 740km away or 8.5 hrs drive (Psych Reg was serious). 'Are you kidding? No we're not going to AMHF 740km away!!' Psych Reg spent the next 90 mins trying to track down a bed. Found one at distant <sup>2</sup>AMHF 200km away. What happened to continuity of care, ability for whole family to visit, familiarity with facility/staff to lesson blow on fears/anxiety......??? The most vulnerable child was carted from pillar to post. This is neglect.

Transported to distant <sup>2</sup>AMHF. Stayed with my daughter that night.

#### 2018

Reviewed by LOCUM Psychiatrist who sated **continuity of care** was best (i.e. original <sup>1</sup>AMHF closest to home). Appeared a little miffed why my daughter couldn't be accommodated - sort of intimated bed managers have a way to move/manipulate beds to open availability.

Walked out of distant <sup>2</sup>AMHF 1300 to go home. Got home at 1730 hrs.

### 2018: Transfer from distant <sup>2</sup>AMHF to local <sup>1</sup>AMHF (closest to home; same AMHF as per 1st admission).

Left home at 0955 and arrived at distant <sup>2</sup>AMHF at 1220.

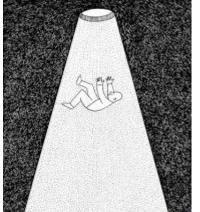
At ~ 1300, we were advised local <sup>1</sup>AMHF has a bed available. My daughter was very happy to hear this yet had mixed emotions: she was still going to be in a confined setting without 'freedom'.

Nevertheless, best for my daughter re **continuity of care**; proximity from home and ability for the whole family to visit; familiarity with environment/staff which all help treatment, recovery/healing and how to best manage her mental health.

Patient Transport Vehicle not an Ambulance arrived at 1745 hrs to transport my daughter back to local <sup>1</sup>AMHF.

Pt (patient) Tx (transport) Officer + Nurse Combo. This is far from ideal. Basic life support and 1st aid only; side by side stretcher configuration; I sat behind my daughter, hard to comfort/reassure/interact and simply chat. My daughter is high risk at spontaneous and instinctive behaviour that could easily lead to misadventure and accidental catastrophic

outcome. Comforting her throughout this period (adding that she gets motion sickness), is just pivotal and basic patient care.



Transport Nurse was advised by distant <sup>2</sup>AMHF not to allow me to view/read my daughter's transfer notes. I'm at least entitled to my daughter's discharge summary. Pt Tx Officer drove and Nurse sat front passenger. Barrel of laughs; a word was hardly uttered. I'm so glad I travelled with my daughter: for support, comfort and to continue the high vigilance on her safety.

At least the highway driving, fading light and rainy weather put my daughter to sleep for most of the trip.

As a result of distant  $^2$ AMHF staff booking a Pt Tx Vehicle instead of an Ambulance, meant a significant delay in their arrival. Add to that: No observation; no checking to see how the patient was going, 'is everyone OK'; no updates on distance left; no

reassurance; no care.... just 'Patient Transport'.

Arrived at local <sup>1</sup>AMHF just after 2000 hrs. My daughter became a little restless: her child like behaviour kicked in re adventure, laughter, unbuckling her seat belts etc. Otherwise, very cooperative and polite.

Psychiatrist took to my cause and made efforts to get the Pt Tx vehicle to turn around, pick me up and Tx me back to distant <sup>2</sup>AMHF. I was very appreciative but I would rather make my own way back to distant <sup>2</sup>AMHF than dance around plutonic/idle chatter with two people caught up with themselves.

The Pt Tx turn around thing, wasn't happening and time was precious. She (Psychiatrist) suggested a cabcharge to train Stn. Great idea!! Very appreciative of all the effort they made to accommodate me.

Caught a cab to train station, waited 10 mins and boarded a train for distant <sup>2</sup>AMHF location (~2.5 hrs). Walked from distant train station (depart 0035 hrs) to distant <sup>2</sup>AMHF (arrived 0125 hrs): 50 min walk. Picked up my car and drove to home address (arrived 0338 hrs)

Got up at 0530 to take care of my other 3 children as my wife left at 0500 for a school camp

### Example 2:

References my daughter's 3<sup>rd</sup> admission. Once again, presented to ED and there were no beds at local <sup>1</sup>AMHF where she spent her 1<sup>st</sup> admission (7 weeks) and 2<sup>nd</sup> admission (10 weeks). My daughter was admitted for 3 days in a ward with a special (i.e. Nurse: one on one care), before being transferred to an alternate <sup>3</sup>AMHF. Explanation given, no beds available at local <sup>1</sup>AMHF. After 5 weeks at this alternate <sup>3</sup>AMHF where my daughter's mental health significantly declined, she was transferred to a different <sup>4</sup>AMHF. Per her discharge summary:

"My daughter has been engaged with a private psychologist and psychiatrist; initially Private Psychiatrist and more recently with a different Private Psychiatrist (who was also the treating Psychiatrist at the local <sup>1</sup>AMHF). She was not re-admitted to the local <sup>1</sup>AMHF on this occasion as the local <sup>1</sup>AMHF Psychiatrist is now her private treating Psychiatrist."

### News to me?? I was told there were no beds available at the local <sup>1</sup>AMHF.

This is an extraordinary admission by the Psych Reg (alternate <sup>3</sup>AMHF) who scribed my daughter's discharge summary. I suspect a Freudian slip. My child was transferred to the alternate <sup>3</sup>AMHF because she visited a Private Psychiatrist (who was also employed at the local <sup>1</sup>AMHF) once as a Private patient following her 2<sup>nd</sup> admission. I was advised for 3 days whilst my daughter was admitted in the Hospital Ward (with one on one special Nurse care), that there were no beds available at the local <sup>1</sup>AMHF.

Just playing with people and their lives:

- ii. I begged the head of Psychiatrist, to 'continue my daughter's care at the local 

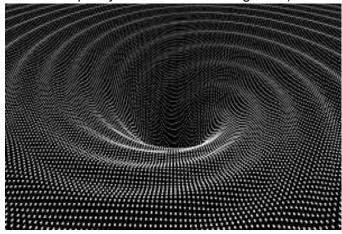
  <sup>1</sup>AMHF. 'Continuity of Care' is pivotal in treatment and recovery. They flogged my daughter into a facility that frankly should be bulldozed.
- iii. The damage inflicted by the alternate <sup>3</sup>AMHF was significant:
  - 1. My daughter now can add PTSD to her mental health issues due to her admission at the alternate <sup>3</sup>AMHF.

### 6. Extended admissions: no to institutionalism (2018)

- No incarceration
- No isolation
- No intuitionalism
- Mental Health should be modelled on nations with the best approach:
  - According to the World Health Organisation (WHO): ¹'The Trieste model of public Psychiatry is
    one of the most progressive in the world.' Trieste continues to strive for innovation which has led to
    a model of community care that today is an international benchmark.
- o <sup>1</sup>'It was in Trieste, Italy, in the 1970s that the radical psychiatrist, **Franco Basaglia**, implemented his vision of anti-institutional, democratic psychiatry. The Trieste model put the suffering person-not his or her disordersat the center of the health care system.' In other words, with de-institutionalisation, <sup>4</sup>'the ill person is at the centre of the process, in all of their uniqueness and complexity, so that it becomes possible for the patient to become an active participant, 'hero' in their cure and rehabilitation.'
  - We are far from this....
  - o Extended admissions causing more harm.
    - After a specified period at the different <sup>4</sup>AMHF, my daughter escalated her self-harm (particularly cutting): now her arms look like a dog has mauled them: her scars are noticeably unsightly and will always serve as a reminder to my daughter and those looking at her arms (impossible to ignore), of her mental health issues: <sup>4</sup>AMHF may as well have plastered on her forehead, "I have a problem with my Mental Health."
      - My daughter entered <sup>4</sup>AMHF with very few scars (barely visible):
      - Her arms are now adorned with scars.
        - There is an apathy/desensitisation within the institution (at least that's the impression given), when kids self-harm (e.g. cutting):
        - "Just poor coping strategies", I'm advised.
        - 'But my child's forearms look like they've been mulled'.
        - 'They're survival scars', they proudly explain.
        - Serious'!!!
        - The scarring is forever both mental and physical
        - The stigmatism will be relentless
        - The impact of this on my daughter's anxiety, depression, OCD, suicidal ideation and mood fluctuations is massive
        - How does my daughter put on a pretty dress, a bathing suit, a T-shirt without these self-inflicted scars reminding her of her mental health struggle? Without reminding and telling others of her mental health issues? Without reinforcing and identifying herself by her mental health issues, instead of viewing her anxiety/depression as just a component of the many parts that sum her up?
    - Dropping any child into these institutions irrespective where they lie on the spectrum of severity is careless/reckless and surely obviously hugely damaging. My daughter has adopted and significantly exacerbated her poor coping behaviours.
    - The staff at all these facilities are lovely and amazing people but they go along with a model (doing their job) that adds further harm. Everyone preaches through their own experiences

and beliefs. I'm far from convinced that all the staff believe in their current practice or the stipulated guidelines. Others will defend their position, the institution, the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*–5) and their pride/ego because they feel they have to:

- o In these asylums, my daughter's world has been compressed into a pinhead:
  - Scope to challenge her fears has diminished
  - She has all but lost her resilience
  - Everything has become a trigger
  - No responsibility
  - No accountability
  - Will Avoid, Interact and seek Reassurance
- She is isolated (away from mainstream activities; a social setting that offers that community feel and the capacity to foster social integration).



- o Institutional corridors that lead to bedrooms are lined with locked doors. They resemble a prison; it's regimented, confined, entry/exit from any door requires swipe/key access, every movement requires permission, the cries and screams of unwell children echo beyond the institution's confined walls further traumatising all those caught up in its' nefarious web and as my daughter's Grandmother stated, 'we are making them mad.'
- o Alternate <sup>3</sup>AMHF should be bulldozed.

My view on alternate <sup>3</sup>AMHF reflects on its location, design, ambience, questionable supervision/security, confinement and ethos. My daughter significantly declined at alternate <sup>3</sup>AMHF after spending 5 weeks at the facility without leave.

- o If admissions of any length continue to exist, then there must be an intermediate phase (in the community) for adolescents to progress towards (a stepping stone), once discharged from an acute mental health facility. The system now is setting up these children to fail. It's like trying to progress from the first Model T Ford to a Lamborghini; it doesn't happen. Nor is it practical or realistic, to throw children out into the real world after a significant period of detachment.
- o Mental health facilities must resemble or appear to resemble a normal everyday establishment:
  - e.g. school, office, shopping centre, sporting facility, adventure centre, art facility, etc
- Community based support must be pinnacle and optimum for metro and regional
- o Community and family are the perennial drivers to working through mental health issues
- Family support must be overwhelmingly bolstered
  - Family is so important but the aggrieved parents feel misinformed, left out, misguided, blamed, trivialised, demeaned
  - Art therapist was fantastic/passionate and provided support via encouragement, time, explanation, understanding, belief and the power of expressing/communicating via drawing/art (the unspoken word).
  - Best family support is to be informed and advised with correct information:
    - Schooling is a good example:
      - Reintegration with my child's school failed soon after she commenced: 3<sup>rd</sup> attempt, 1<sup>st</sup> with different <sup>4</sup>AMHF: I advised plan wasn't workable and beyond my daughter at that stage; I was overlooked by idealism & hope. Lots of time waisted, which meant more time isolated in different <sup>4</sup>AMHF.
      - My daughter was advised she was accepted into another school: it was never the case and you can only imagine the disappointment my daughter experienced; there was no Plan B because this was a certainty. The

- school Term was about to begin and my daughter was left stranded. this again added more time incarcerated in this institution.
- With respect to schooling options/bureaucracies/support:
  - I spent many hours sourcing information/advise from educational authorities which I passed onto different <sup>4</sup>AMHF.
- o Parents often marginalised/disempowered by:
  - Questionable techniques re family meetings:
  - Control/compartmentalised approach
  - Doubtful partiality (human factors)
  - Contrived settings
  - Being poorly informed
  - Investigative techniques that need to be more robust
  - No one overseeing progress:
- As parents we should be interviewed by an independent body (at least once per month) to allow us to speak freely beyond the contrived setting of the family meeting to facilitate constructive feedback. This should be done individually and as a couple.
  - Good example is the military: they remove senior upper rank and allow troops to offload to a captain or equal: this provides genuine feedback which is passed on without any retribution.
- o Better profiling of the adolescent (particularly pre admission):
- If extended admissions continue to exist in their current capacity, then the adolescent must be comprehensively profiled so as to better understand from the onset, how to best manage them. This would certainly limit their stay, allow for a cohort that was more comparable and they'd be more likely to adopt better coping strategies
- o Effectiveness of psychotropics and their prolific use should be reviewed
- All Psychologists/Psychiatrist to have a standardised philosophy of anti-Institutional community care, that places the suffering person and not his or her disorders at the centre of the health care system.
- Psychologist/Psychiatrist/Mental Health personnel to get together (i.e. get everyone involved including previous Therapists) and comprehensively review each case.
  - Ongoing uncertainty remains; multiple diagnoses, multiple medications and multiple months incarcerated:
    - Your daughter is complex (said by several Psychiatrists)
    - Never had someone like your daughter before
    - Her intellect has got in the way
- During my daughter's admissions:
  - She is draped with daily nursing support/reassurance, psychotherapy (individual/group), music/art therapy, group activities, dietary support (Dietician), Religious support, regimented routine/structure, isolated (cocooned) from the mainstream community/society, etc
  - Once discharged and thrust outside the walls that have managed her exclusion (detachment) and provided a sanctuary, the local Child and Adolescent Mental Health Service (CAMHS) begins outpatient family support: i.e. only one meeting per week for 1hr:
    - This just isn't practical and fuels the adolescent's vulnerability
    - It's like quitting a crippling addiction, 'cold turkey'.
    - There should be in place a comprehensive, progressive and transitional weaning of habitual support, to allow the adolescent the best opportunity, to reintegrate back into the community.

### o Incentivized approach (rewards or consequences) is damaging

- **1.**Incentivised Diet and Nutritionist:
- This can really do your head in:
- Nutritionist telling my daughter (and parents), based on her calorie intake she can only exercise for ½ hr/day (BS ideology).

- Studies on Mental Health have repeatedly indicated that exercise improves mood, decreases/alleviates depression, increase vitality and spirit etc
- the dodgy ½ hr walk (considered exercise), barely gets their bodies warm
- No motivation for the kids at all.
  - My daughter was very active and loved participating in various sports. If my daughter exercised (irrespective of her motive), as she doesn't have an eating disorder but rather disordered eating in the form of maladaptive behaviour (?), exercise would elevate her mood (increase her endorphins, serotonin, dopamine), she would thoroughly enjoy it and you might find she may consume a few more calories (food) because she'll be hungry.

#### Instead:

- The system inadvertently encourages apathy
- The adolescents lose their tone, posture/physique; as a result, decline further adding to their poor mental health
- Stupid guidelines like these are just 'killing our kids'.
- Just another closed loop that destroys. On the one hand I'm advised, 'Psychiatry isn't an exact science; we won't know what it is till we stumble across it.' Conversely, their trying to incorporate science to solve that something that hasn't been stumbled across:
  - Not enough calories → no exercise → increase depression → increase isolation (avoidance) →
  - Not enough calories → no exercise → increase depression → increase isolation (avoidance) → increase reassurance seeking → increase lethargy →
  - Not enough calories → no exercise → increase depression → increase isolation
     (avoidance) → increase reassurance seeking → increase lethargy → increase self-harm/suicidal ideation → decrease social interaction → decrease self-worth →
  - Not enough calories → where does it end???
    - You must have three meals/day + morning tea and supper + nutritional supplementary drinks = Calories (per reference range)
    - The revolving door is gradually spinning faster and faster and stepping out becomes more and more difficult or near impossible without inflicting serious harm.
- What's wrong with having two reasonable meals each day? Compromise rather than dictate. My daughter is confined in an asylum and the energy required to function is far less than:
  - o Catching a bus and train to and from school (carting a heavy bag)
  - o Attending water polo training early a.m. before school
  - o At school moving all over the campus to attend different subjects.
  - Engaging and socialising
  - After school activities (band, school play, swimming training, etc)
  - o etc
- This incentivized approach (rewards or consequences) just doesn't gain traction and has become harmful. For my daughter, the questionable effectiveness of incentivised reward schemes is intrinsically linked with her maladaptive behaviour derived perhaps by her wrangling with obsessions/rituals and motivation drawn from negative attention. Unfortunately, external rewards don't translate to creating better intrinsic behaviours.
- **2.** Incentivised *Leave Status* further demonstrates this detriment:
  - At the beginning of my daughter's admission at <sup>4</sup>AMHF, she was advised about do's and don'ts. <sup>4</sup>AMHF had a 'leave' hierarchy that reflected the adolescent's behaviour. Poor

behaviour could incur 'no leave' for a specified period (and required reviewing by a Dr) and better behaviour was rewarded with varying leave statuses. In other words, my daughter's behaviour was being incentivised. <sup>4</sup>AMHF also mandated the importance of leave (pre requisite for admission). However, with my daughter's constant maladaptive behaviours (often sabotaging her leave status), her leave would be revoked until further review. Once my daughter's grandmother arrived to take her 'off ground' leave for a few hours but was refused because 4 hours remained on a 24 hour curfew due to maladaptive behavioural self-harm. Just ridiculous. Therefore, her incarceration continued without frequent intermittent exposures to the outside world, further spiralling her into the abyss. Now, the push is to get her to discharge and no matter how much self-harm my daughter inflicts on herself, the whole leave hierarchy has been thrown out the door. What does that teach her?? I protested this earlier (deaf ears) – apparently, we 'need to teach my daughter responsibility and accountability' (yeap, I get it: but it doesn't work). Every adolescent is different and a comprehensive profile earlier will have dictated best course of action.

- Kids need sun, activities, a focus beyond themselves, anti-institutional social interaction, a normal life. That is, ¹′...a shift from managed exclusion to a true social inclusion, at least to a degree were users become individuals with the rights and standing of other citizens.' Not asylums, that endorse:
  - A mixed cohort with severity ranging from either end of the spectrum
  - Greater reliance
  - Perpetual reassurance
  - Loss of resilience
  - AIR: Avoidance, Interacting, Reassurance Seeking

### 7. Parental input: muzzled/trivialised

- This was a thread that popped up throughout my experience of individuals and Institutions involved with the fragile and non-tangible entity of Psychological medicine. However, certain Psychologist/Psychiatrists were able to better incorporate parental input in order for these Mental Health professionals to better validate or make sense of info/perceptions offered by my daughter.
- Below are excerpts from my log airing my thoughts/experience:

### Excerpt 1 (e.g.1)

### 2018: At Home

- Parental input is thwarted significantly:
- The adolescent is interviewed first:
  - o The parent(s) are then brought in for their input
  - o This is a very difficult position and raises some serious flaws in the seemingly standardised approach.
  - o The adolescent may:
    - Manipulate
    - Tell you what they want you to hear
    - Bend the truth
    - Misrepresent the facts
    - Have wrongly perceived things
    - Erect walls and remain defensive
    - Be in denial and so reality is skewed
  - Then the therapist brings in the parent(s):
    - Parents have no idea what has been said
    - Awkwardly listen to the therapist briefly outlining what has been discussed
    - You don't want to contradict or antagonise your daughter
    - There is confidentiality between parent and daughter: just as there is between therapist and patient (which the therapist's keeps reminding us).
- o It's extraordinary superficial:
  - My daughter cannot talk openly and freely with her parents in the room (out of fear, respect, love)
  - Parents are calculated in what they divulge as to not damage the bond/trust between them and their daughter: taking into consideration the greatest % of recovery/treatment is done at home. Medication and

therapy constitutes a very small %: if therapy is unwilling to consider the observations from parents who are good historians but rather indulge in the adolescent's distorted and perceived reality, then therapy is based on a warped idealism. The child is left drifting with a friend rather than a navigator.

### Excerpt 2 (e.g. 2) 2018: At Home

- The first CAMHS consult fell in to three distinct phases:
  - ~ 20 mins with both my daughter and I; the CAMHS Psychologist and Psychiatrist were also both present.
  - ~ 45 mins with my daughter (alone)
  - ~ 10 mins (hurried) with me (alone)
  - o It's the lack of 'me' time that is concerning:
    - As the carer, observer, navigator, therapist and father, you must afford 'me' the time to
      validate and clarify any embellishments or skewed reality that my daughter articulates. It also
      gives me the opportunity to discuss my feelings, views and understanding with respect to
      treatment, progress and prognosis.

# (e.g. 3) Comments below refer to Family Meeting 2018 Meeting focussed on my email (a father expressing his concerns), 2018.

- There is a distinctive weakness in the approach to Family meetings that disempowers the parents and validates the Institutions authority.
  - Continual therapy with my daughter divulges only one point of view: introducing the parents
    inside the arena without the opportunity to authenticate some of my daughter's concerns or
    her recall/perception of events, perpetuates a skewed and unbalanced picture. As parents,
    we are reluctant to discuss/elaborate or challenge in fear of upsetting our daughter. The
    setting is simply contrived. Authority is exercised by the institution's personnel and as
    parents, we cannot compete against this.
  - Parents should be interviewed together (as a couple), then separately and then brought
    together with our daughter. This process should be implemented from the onset (admission)
    and repeated throughout my daughter's stay. Root Cause Analyses/Investigations rely on
    individual submissions which can be probed against each other. This strengthens the
    investigative method.



### A few words on the above stated Family meeting:

- a. I wrote an email (see below) to an AMHF summarising my daughter's past year in terms of admissions, medications, diagnosis, Rx and current status following a four-day period where my daughter became very unsettled requiring sedation and was scheduled.
- b. This last year has just been excruciating. I was left shattered following this meeting, physically unwell and unsupported. I'm emotionally spent as I watch my beautiful daughter slide. That night, I had a nightmare. It's a recurrent dream (since ~ 10 yrs of age) that for the 1<sup>st</sup> time I found myself trying to yell for my father for help (who has passed away). Also, for the 1<sup>st</sup> time, I was woken up during this nightmare by my wife.

- Excerpt from email 2018: full email below
- Yet still, after 18 months, my daughter continues with: 'You don't understand', 'you don't get it', 'it's not like that', 'don't worry about it', 'nothing', 'it's OK, 'doesn't matter'.... Only now my daughter has an arsenal of poor default coping behavioural strategies and a major 'arrest in her development'. How does my daughter recover from this? How does she recover? We need some feedback beyond the contrived setting of the Family meetings.
- c. I've invested a ton of emotion in this email and was basically pleading with the Team to shed some information: The email concluded (Excerpt from email 2018: full email below)
  - "I agree!! My daughter needs to get out and stay out. Right now, her resilience is being further tested by a looming discharge: she's exhausted and her resistance (which parallels her fears) will rise to the challenge; her guilt and shame will feed a negative closed loop and furthermore, she'll mimic harmful practices to validate her status (combination of conscious and subconscious). My daughter has utilised her capacity to dictate play through this vicious cycle for some time. Why? How do we pull it up?
  - My wife visited our daughter yesterday afternoon and advised, 'Our daughter is OK today.' Shaking, trembling, withdrawn, slumped posture, relying heavily on sensory items, depleted concentration... This has been extraordinary protracted and I cannot fathom the thought in the near future, when I inquire about my daughter's wellbeing. 'OK today; she's under a table, shaking, banging head, drooling, unfocussed gaze, moaning, arms heavily dressed, wearing a gown......"
  - What is the general consensus/thoughts with respect to my daughter's diagnosis, behaviours and moving forward?
- d. Instead of the Team acknowledging the distress, concerns and fears of the parent, they appeared to take offense and as a result, prepared a calculated approach/plan (i.e. next scheduled meeting, two days post email was sent), that felt accusing and left me devastated. Just dreadful. As a parent in this awful predicament, I'm already stretching my emotional and mental limitations. Their response implied, don't inquire, question or raise concerns/thoughts with us (even though this may not reflect their intentions).
  - There is no other forum in this unnatural, compartmentalised and debilitating setting, that I can inquire or provide feedback in a structured/constructive manner.
  - No matter what mode of communication I use to have my voice heard, to advocate for my daughter, it should always be embraced. Feedback of any type in these circumstances, is invaluable and must always be received as constructive (another basic 101 rule.)

### Email sent to the AMHF Team 2018 '12 Months on'

Hi Psychiatrist

It's been a rough couple of days for my daughter. In fact, it's been a tough year for my daughter. Prior my daughter's 1st admission 2017, discussing options/strategies or having a conversation that touched on my daughter's anxiety/depression was almost always met with the usual rhetoric: 'you don't understand', 'you don't get it', 'it's not like that', 'don't worry about it', 'nothing', 'it's OK, 'doesn't matter'... It made no difference how varied our approach was, my daughter's response was always the same. Therapy with my daughter's private Psychologist and Psychiatrist had made little impact and within this 7 month period, my daughter's state of mind declined.

Fast forward and 12 months later following:

- Seven weeks admission at local <sup>1</sup>AMHF (2017)
- ED presentation: 2018
- ED presentation: 2018
- 2 days admission at distant <sup>2</sup>AMHF (2018)
- Ten weeks admission at local <sup>1</sup>AMHF (2018)
- 4 days admission on Hospital Ward (2018)
- 5 weeks admission at alternate <sup>3</sup>AMHF (2018)
- Admission at <sup>4</sup>AMHF (2018)
  - o Plus trialled on a myriad of anti-psychotics (Olanzapine, Risperidone, Paliperidone, Quetiapine), various mood stabilisers (Sodium Valproate, Lamotrigine, Chlorpromazine), anti-depressants (Fluvoxamine,

Setraline, Fluoxetine, Valdoxan), sedating/PRN meds (Promethazine, Lorazepam), Melatonin to help with sleep and IM Midazolam, Droperidol and Ziprasidone for episodes of acute behavioural disturbance. I feel the placebo effect of any combination of medications far out ways their effectiveness.

- Varying diagnoses including: Social Anxiety Disorder, Depression, Depression with Dissociative features,
   OCD, Bipolar disorder not otherwise specified, Disordered eating and a suggestion of Borderline
   Personality Disorder.
- My daughter is currently taking Lamotrigine and Quetiapine.

And despite the above stated, my daughter still responds with, 'you don't understand', 'you don't get it', 'it's not like that', 'don't worry about it', 'nothing', 'it's OK', 'doesn't matter'...

Notwithstanding the amazing Psychotherapy and support that has been afforded to my daughter and almost 12 months since her 1st admission at local 1AMHF (2018), my daughter has the need following a therapy session with her Therapist to:

- Attempt strangulation at ~ 0200 requiring 5mg IM Midazolam/isolation + Promethazine and Valium with evening meds;
- Required antibiotics (flucloxacillin) for an infected self-inflicted wound that she keeps digging at;
- Attempt strangulation @ ~ 0500 which was managed with 100mg Quetiapine PRN and an additional 100mg Quetiapine PRN at lunch (that'll be 500mg Quetiapine for the day where does it stop?);
- Promethazine @ ~ 1620 following head banging, shirt around neck, shaking and agitation.
- Again, restrained and sedated with 5mg IM Midazolam 2030hrs post agitation, 'unable to settle', crying, shaking, banging head, refused PRN and not responding to Nursing de-escalation. As a result, my daughter has been made an involuntary patient.
- Each time we contacted <sup>4</sup>AMHF to ascertain my daughter's status or were contacted by <sup>4</sup>AMHF, we've been greeted with, 'I don't know if someone's has called you? Often informed some time post the incident' and there is always that sense of dread, what's happened now?

I'm advised, my daughter's therapy with her Therapist was the potential cause for her distress early a.m. Additional stresses include the push for increased leave frequency/duration, issues with eating/food and the need to imitate/follow the poor coping behaviours displayed by other adolescents. The influences certain adolescents are having on each other is incredibly detrimental.

Sitting with my daughter in a meeting Room with a Nurse (one to one care) and having to watch her try to string a sentence together whilst appearing to be somewhat drowsy (per my daughter, 'I'm tired'), was just demoralising. My daughter's demeanour, posture, tone, physical stature have all waned. Scars depict her torment and will always serve as a reminder. Yet somehow, my daughter has to avoid identifying herself by her mental health issues but rather view her anxiety/depression as just a component of the many parts that sum her up. How is that possible with her environment (surrounded by unwell adolescents), the incarceration/isolation, the lost opportunities, the belief/perception that nothing has been resolved/fixed, existing fears heightened and the want to achieve/accomplish showing only transient glimpses.

In the past 18 months I've observed my daughter's decline. It's a nightmare that evolves and it's getting more frightening. As parents, we're not privy to discussions my daughter has with her Therapist. We don't have any more to go on apart from anxiety/depression. We're feeling out of the loop and constantly left to ponder: Where are we at? What's happening? Any breakthrough? There's no change? My daughter is getting worse? What are we doing? What choices to we have? Where to from here? The Philosophy encouraged upon my daughter is to concentrate on the now and how to move on. How is the now different from 18 months ago? 'You don't understand', 'you don't get it', 'it's not like that', 'don't worry about it', 'nothing', 'it's OK, 'doesn't matter'.... Only now my daughter has an arsenal of poor default coping behavioural strategies and a major 'arrest in her development'. How does my daughter recover from this? How does she recover? We need some feedback beyond the contrived setting of the Family meetings.

I agree!! My daughter needs to get out and stay out. Right now, her resilience is being further tested by a looming discharge: she's exhausted and her resistance (which parallels her fears) will rise to the challenge; her guilt and shame will feed a negative closed loop and furthermore, she'll mimic harmful practices to validate her status (combination of conscious and subconscious). My daughter has utilised her capacity to dictate play through this vicious cycle for some time. Why? How do we pull it up?

My wife visited my daughter yesterday afternoon and advised, 'Our daughter is OK today.' Shaking, trembling, withdrawn, slumped posture, relying heavily on sensory items, depleted concentration... This has been extraordinary protracted and I cannot fathom the thought in the near future, when I inquire about my daughter's wellbeing. 'OK

today; she's under a table, shaking, banging head, drooling, unfocussed gaze, moaning, arms heavily dressed, wearing a gown....."

What is the general consensus/thoughts with respect to my daughter's diagnosis, behaviours and moving forward?

Kind Regards

Father



<sup>2</sup> "You all asked him for something, his hand. I offered him something, my hand. A drowning man is in no position to give you anything." Let us remember not to ask anything of someone who is drowning.

### Love and support

My 10 year old niece stated to her mother just recently: 'I want to be her (my daughter's) Petronus, to protect her from all the dementors" (Harry Potter). I was in tears when I heard this.

- Petronus: Spirit guardian primary protection against Dementors
- Dementors: inhuman evil that feeds on people's fears

### SUMMARY/CONCLUSION

My daughter

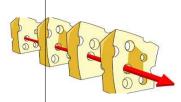
Anxious, depressed with suicidal ideation and frightened

Courageously reaches out to School Councillor (Clinical Psychologist) and dismissed (2016)

- → **Private Psychologist's** (2017) assesses via Multidimentional Anxiety scale/depression index/+ OC component and labels her:
- → My daughter validated her illness via the internet and her Psychologist's endorsed her own validations:
- → Referred to Psychiatrist
- → This labelling of the intangible entity known as mental health, has continued throughout my daughter's journey.
- → Expert in adolescent psychological medicine (Private Psychiatrist), strongly advised admission.
- → Advocated for psychotropic medications, incarceration, isolation and institutionalism.
- → Any decision to admit a child/adolescent must be reviewed, alternate options discussed first and advice given on the perils of admission:
  - E.g. the potential for institutionalism, the pitfalls of incarceration, the ripple effect of mixing with other very unwell adolescents, the isolation, loss of resilience, exacerbation of existing fears and creation of new ones, loneliness, developmental arrest, trauma, dependence/reassurance seeking, continued/strengthened avoidance, the habitual obsessive interactions with negative thoughts made worse by poorly stimulated ward environments:
- → Does the current construct of Mental Health in NSW lend itself to anti-institutionalism?



- → **CAMHS** Psychiatrist (following 1<sup>st</sup> 7 wk admission @ local ¹AMHF):
  - 1<sup>st</sup> meeting, after ½ hr:
    - Questioned diagnoses
    - Questioned medication
    - Discontinued Melatonin
  - 2<sup>nd</sup> meeting:
    - Dismisses dissociative presentation
    - Disregards Parental concern
      - Dismissed basic medical red flags (rule 101):
      - Recent admission
      - New diagnoses
      - New medication
    - The Psychiatrist judged and abandoned my daughter at a most defining moment based on, 'I don't know her well enough!
  - Post 2<sup>nd</sup> meeting with CAMHS Psychiatrist:
    - Readmitted next day: ED → distant <sup>2</sup>AMHF → local <sup>1</sup>AMHF
    - Pharmacogenomics (genetic testing) revealed my daughter is a slow metaboliser of the SSRI antidepressant that she was taking at the time. Therefore, excess levels of the SSRI had accumulated in her system (overdose), which caused her to shift more towards mania and dissociate.
    - 2<sup>nd</sup> admission (local <sup>1</sup>AMHF) stretched to 10 weeks due to a complete medication change, in order to reach therapeutic levels and to observe efficacy.
  - Demonstrated subjective bias has by far outweighed objectivity.





- → The term *Continuity of Care*, is pontificated as a power making for righteous idealistic care; in reality, it is rhetoric only.
- → 1<sup>st</sup> admission: 7 wks at local <sup>1</sup>AMHF
  - 3-4 wks post 1<sup>st</sup> admission, my daughter represents at an ED
    - Advised 740km away was the closest facility with a bed available
    - Above reconsidered: transferred 200km away to distant <sup>2</sup>AMHF
    - Distant <sup>2</sup>AMHF was annoyed by transfer decision to their facility. They cried 'Continuity of Care'. Several days later, a bed became available at local <sup>1</sup>AMHF.
    - Transfer from distant <sup>2</sup>AMHF to local <sup>1</sup>AMHF
  - o 2<sup>nd</sup> admission: 10 wks admission at local <sup>1</sup>AMHF
  - 4-5 wks post 2<sup>nd</sup> admission my daughter represents at an ED
    - No beds available at local <sup>1</sup>AMHF
    - Spent 3 days in Hospital Ward
    - Transferred to alternate <sup>3</sup>AMHF
      - Reason give: 'No beds available at local <sup>1</sup>AMHF'
      - Post 5 wks admission at alternate <sup>3</sup>AMHF (where my daughter's health significantly declined; no leave for five weeks), she was transferred to a different <sup>4</sup>AMHF.
    - Per alternate <sup>3</sup>AMHF discharge letter (re transfer from Hospital Ward to alternate <sup>3</sup>AMHF):
      - She was not re-admitted to local <sup>1</sup>AMHF on this occasion as the Local <sup>1</sup>AMHF Psychiatrist is now her private treating Psychiatrist."
         News to me?? I was told there were no beds available at the local <sup>1</sup>AMHF.
  - This is an extraordinary admission by the Psych Reg (alternate <sup>3</sup>AMHF) who scribed my daughter's discharge summary. Throughout this, I pleaded to maintain best practice and facilitate my daughter's Continuity of Care. Her vulnerability and fears were exploited by a care system driven by process. This caused her health to deteriorate.



- → Extended admissions are far from the Trieste benchmark model of community care (supported by WHO), in Public Psychiatry. 'The model put the suffering person-not his or her disorders-at the centre of the health care system.' It's a 'vison of anti-institutional, democratic psychiatry.'
  - No Incarceration
  - No Isolation
  - No Institutionalism
- → Instead, we have *managed exclusion* Institutional care that acknowledges deleterious consequences such increased avoidance of typical stressors, development of an arsenal of maladaptive behaviours, trauma and constant reassurance seeking (in addition, *the perils of admission* as per summary point under, *Private Psychiatrist*)
  - What happened to NO AIR? i.e.
    - NO Avoidance
    - NO Interaction
    - NO Reassurance seeking
  - In addition, following a long stint of managed exclusion, my daughter has to deal with a significant recovery period of which crucial aspects include: Illness, Developmental Arrest and Reintegration (school, home, etc).

- → Institutional care:
  - Desensitised to self-harm
  - Scarring is forever
  - The stigmatism relentless
  - The impact on existing mental health issues, is huge.
- Mixed cohort with a severity ranging from either end of the spectrum, is reckless
  - Better profiling
  - Effectiveness of psychotropics and their prolific use should be reviewed
  - All Psychologists/Psychiatrist to have a standardised philosophy of anti-Institutional community care, that places the *suffering* person and not his or her disorders at the centre of the health care system.
- These asylums have compressed my daughter's world (everything is a trigger)
- Socially isolated from mainstream activities that offer a community feel and the capacity to foster social integration.
- If admissions of any length continue to exist, there must be an intermediate phase for adolescents to progress to. This current pluralistic practice that flogs adolescents into the real world post an extended phase of managed exclusion, must stop. The system injects a huge potential in 'setting up these children to fail'.
  - On admission significant emphasis was placed on maximising leave to better support community/school integration, to strengthen independence, manage her mental health with better coping strategies, yet still her rhetoric showcases her mindset: 'you don't understand', 'you don't get it', 'it's not like that', 'don't worry about it', 'nothing', 'it's OK, 'doesn't matter'.
  - What's been achieved? A stack of trauma has been thrown into the mix, we're making them mad (per Granny) and somehow on discharge, my daughter is meant to progress from the first Model T Ford to a Lamborghini?
- Mental Health facilities must resemble or appear to resemble community based establishments (e.g. school, shopping centre, church, office, sporting centre, etc).
- Community based support pinnacle and optimum for metro, regional and rural
- Community and family perennial drivers to working through mental health issues
- Family support must be overwhelmingly bolstered:
  - Aggrieved Parents feel misinformed, left out, misguided, blamed, trivialised, demeaned, disempowered
  - Compartmentalised settings creating barriers: any forum utilised for constructive feedback must be welcomed.
  - Questionable techniques re family meetings
  - No one overseeing progress
  - Parents should be interviewed by an independent body (regularly), to allow parents to speak freely beyond the contrived setting of the family meeting to facilitate constructive feedback.
  - Schooling integration and navigating jurisdictional bureaucracies must be better researched, idealism removed, parental concerns factored:
    - This cost my daughter months of additional incarceration.
    - Increased Institutional trauma (e.g. self-harm escalated).
    - Need to be better informed and resourced because this is simple basic support, my daughter and us (parents) required.
- o Incentivised approach (rewards or consequences), creates more harm. 'One size Fits all' approach is problematic for e.g. for my daughter, the questionable

effectiveness of incentivised reward schemes is intrinsically linked with her maladaptive behaviour derived perhaps by her wrangling with obsessions/rituals and motivation drawn from negative attention. Unfortunately, external rewards don't translate to creating better intrinsic behaviours.

- Incentivised Nutritionist ideology deepens depression/withdrawal
- Incentivised Leave Status further confines and isolates.
- Art therapist was just fantastic/passionate and provided parental support via encouragement, time, explanation, understanding, belief and the power of expressing/communicating via drawing/art (the unspoken word). More space and resource should be invested into art, music, activities, sport...
- Kids need sun, activities, a focus beyond themselves, anti-institutional social interaction, a normal life. That is, 1...a shift from managed exclusion to a true social inclusion, to afford them the individuality to become individuals with the rights and standing of other citizens.
- 4"De-institutionalisation is a critical-practical process which reorients institutions and services, energies and knowledge, strategies and interventions, from an artificial object which is the illness (understood as a diagnostic label) towards the patient's suffering-existence and his or her relationship with the social body as a whole."



# **Parental input is thwarted/trivialised** by Therapist technique/perceptions, human factors, systemic process, adolescent confidentiality??

- → This last year and half has been unbearably excruciating and I'm already stretching my emotional and mental limitations. I've dived into the hole to search for my daughter and I've bumped into obstacles that fall under the cloak of support, professionalism, care...
  - Parents have a voice that all can hear but who's listening?
  - Mental Health Professionals need to acknowledge the distress, concerns, and fears of the parent irrespective the type of forum utilised to communicate (e.g. email '12 months on'. Major Check Point, dot point 7: Parental input muzzled/thwarted).
    - There is no other avenue in this unnatural, compartmentalised and debilitating setting that I can inquire or outline my concerns in a structured/constructive manner.
  - Feedback in any format is invaluable and must always be received as constructive (another basic 101 rule).

My submission depicts my observations/experiences and thoughts. It's intended to highlight shortfalls via the SWEES CHEESE model and the incredible power of subjective bias which perpetrated the initial insult (School Council dismisses my daughter's cry for help), the pitfalls of extended admissions/institutional care and to endorse a model of care (supported by WHO), of 'anti-institutional, democratic psychiatry' that places the 'suffering person and not his/her disorder at the centre'. We should be 'shifting from managed exclusion to social inclusion, affording the individual the same rights and standing of other citizens'. In other words, 'the ill person is at the centre of the process, in all of their uniqueness and complexity, so that it becomes possible for the patient to become an active participant, 'hero' in their cure and rehabilitation.' The philosophical underpinnings of Franco Basaglia (Trieste model), and his international de-institutionalisation movement (to abolish the mental health hospital, not reform it), 'overwhelmingly motivates to remove the destructive power imbalance in mental health care and prevent the marginalisation of people who are mentally ill.'

As parents, we are extraordinarily grateful for the amazing work performed and support afforded by so many people (Health Care Workers, teachers, etc) involved in my daughter's care. Their devotion and patience has been remarkable and their efforts will always be etched in the thoughts of my beautiful daughter. My daughter has stated on several occasions, 'Nurses have become my surrogate parents.' She is incredibly appreciative as are her parents.

Wri	tten	by:
The	Fatl	her

### Reference

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<sup>3.</sup> https://www.aph.gov.au/Parliamentary Business/Committees/Senate/Former Committees/mentalhealth/report/e03

<sup>4.</sup> http://www.triestesalutementale.it/english/doc/norcio-et-al 2001 mhd.pdf

<sup>5.</sup> https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(18)30426-7/fulltext