ROYAL COMMISSION INTO MENTAL HEALTH - KEY RECOMMENDATIONS

PREAMBLE:

I am 62 married mother of four young adults and the almost full time carer for my 20 year old daughter who is mentally unwell and has been for about 6 years since age 14. In addition to caring for my unwell daughter, I also have recent experience assisting my best friend navigate the public mental health system in NSW. As a young woman I too suffered anxiety and depression and sought help from a range of different practitioners and tried many different therapies .

During the past 6 years, our daughter has had about 8 inpatient admissions in 3 different hospitals, both public and private, both adult and adolescent wards, plus outpatient admissions in 2 different hospitals. She has been treated by 5 psychiatrists, a number of different psychologists, several general practitioners and a number of other allied health and medical professionals. Our daughter has been assigned up to 8 different diagnoses. She has been on upward of 25 different psychiatric medications – anti-depressants, anti-anxiety meds, anti-psychotics, sedatives and amphetamines. She has had 45 TMS (Trans cranial Magnetic Stimulation) treatments and attended programs for multiple different talking therapies.

After 6 years our daughter remains unwell. She turns 21 this weekend, traditionally a time for celebration. We have a solid family, financial means and education in our favour. And yet, we feel no nearer to getting the right help for our daughter. I do particularly wish to dispel the myth that affluence and/or private health cover protects families from a broken mental health system. It does not. We are exhausted, hopeful yet at times despairing but even more despairing for those out there who don't have the option of private health care and a financial buffer. If we can't navigate the system to help our daughter how can anyone? Our daughter is too sick to work, to study, to volunteer, to socialise and yet she is ineligible for any form of youth allowance or other government support. Parents like us have to fill the financial breach. A disability allowance is the only remaining alternative source of financial support for our daughter and whilst she is quite significantly mentally disabled, and has been since her school years, we have been advised that she will probably be ineligible for that too.

In our experience the mental health model is extremely difficult to navigate. It is stymied by a silo mentality, a non-integrated medical model and by regulations such as privacy legislation, patient rights etc, all of which ultimately serve to work against a patient's best interests and contribute to the delaying or prevention of recovery.

The following are my key observations and recommendations based on my personal experience of our mental health system.

Melbourne Australia

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UNDER AGE PATIENTS

Parents and guardians MUST be involved with mental care planning for all under 18s unless clear evidence of parental abuse.

- Parents and guardians of under 18s usually have day to day responsibility for the patient, need to administer any medications, facilitate all appointments, put therapeutic plans in place.
- Parents and guardians cannot be excluded from the mix. Making the parent the outsider or worse the enemy, alienating children from their families helps nobody. In our case a psychiatrist refused to deal with us and created a hostile divide between our child and her parents which was highly damaging to all of us. This approach can cause irreparable damage to the patient carer relationship.
- Our laws allow health practitioners to elect to deal direct with 15 year old children and exclude parents and guardians from the treatment team. In doing so they do their patients a great disservice by not getting a fuller picture of the child's history, family, environment etc. This approach can and does also contribute to the creation of a secondary issue – the negative health and well- being of those parents and carers. Medical personnel can refuse to share any information with these children's families even where these children live with family and family has responsibility for their care and they can be as many as 3 years from reaching legal adulthood.
- Most parents love their children and want to help. Parents need guidance in how they can help with the therapeutic process and be part of the treatment team.

FOOD AND MOOD

Mental health facilities MUST include healthy eating into the medical model

- In our experience, most mental health professionals appear to not even consider the patient's physical body in the mental health therapeutic process
- Most mental health professionals appear not to recognise the relationship between food and mood despite the scientific evidence as to its relevance.
- Vending machines and junk food options MUST be removed from all mental health facilities especially dedicated mental health facilities. Patients uber eats and equivalent delivery options be removed. Spare hospital meals to be made available for latecomers etc
- All mental health patients with any type of disordered eating to be provided with a prepared meal and/or assistance with the serving and selection of dining room foods.
- First thing you see when you walk down the corridors of most major mental health facilities is great big vending machines selling chips and chocolates and soft drinks. Why can't Department of Health/Health funds insist on healthy hospitals? Why can't health funds refuse to cover patients at hospitals who do not comply with a healthy eating model?

- Many mental health patients have eating issues which can be exacerbated in a stressful, lonely hospital environment.
- We believe that dieticians need to be involved in overseeing menus, meal planning etc for inpatients.

EXERCISE AND OUTDOORS

Mental health facilities MUST provide daily exercise, sunshine & nature and as part of every single treatment plan. All the science supports the positive impact of exercise on mental health.

- Psychiatrists, psychologists and GPs MUST PRESCRIBE exercise, sunshine and time outdoors as part of every treatment plan. Make it a compulsory component of the prescribed therapy. Include a self- monitoring and feedback reporting tool etc
- Most mental health professionals do not address exercise, sunshine and nature as a part of the therapeutic process.
- Safe internal courtyard/gardens for sunshine and nature must be part of every hospital design
- Exercise programs by trained personnel to be provided at all mental health facilities
- An exercise room to be provided at every hospital with a few basic, safe machines, exercise mats, fitballs etc.

SMOKING

All mental health facilities MUST introduce smoker support across the board.

- Accept that stressed people often want and need to smoke.
- Banning smoking indoors and then providing smoking facilities outside without providing any outdoor facility for non-smokers is prejudicial.
- According to our experience and that of others we know, the absence of outdoor access except for smokers, has led to inpatients developing smoking habits in their desire to be with others and be outside of the hospital building. Our daughter developed her smoking habit as a 15 year old adolescent during her first hospital admission as inpatient at a primary Melbourne mental health facility a few years ago.
- Providing no smoking facilities outside and forcing the patients to get leave passes in order to smoke around hospital rubbish bins and air conditioning ducts is also prejudicial and just makes for grotty butt ridden hospital surrounds.
- Offering a script for nicotine patches etc without education and support is totally unhelpful and does not encourage compliance.

CASE MANAGEMENT/CO-ORDINATED/INTEGRATED CARE MODEL

All mental health providers to work hand in hand with general health providers. Compulsory, regular liaison between Psychologists and psychiatrists, GPs and other managing medical personnel.

- There is a silo mentality in the mental health system. The multiple health professionals involved in a person's care do not talk or share. Even written records are not routinely shared or transferred between medical professionals in a timely manner.
- Case management options should be made available to all mental health patients. They need a point of integration to ensure co-ordination of treatment and communication between all relevant parties.
- Money invested in addressing the physical health of mental health patients would surely save the health system/taxpayer money in the long run if we actually make people well.
- Referring doctors and appointed hospital doctors mostly have minimal contact with each other prior to and post admissions. Patients are often left in limbo unsure as to who is responsible for their post hospital care. Follow up appointments are rarely organised by the medical team.
- Social workers are not routinely involved in patient care and outreach management. Our experience is that one has to fight for these limited resources.
- Parents and carers end up as default case managers and are often ill equipped to take on the task. Finding out about treatments options and entitlements is a battle.

HOSPITAL ADMISSIONS

Mental health facilities to streamline all admission processes, forms and meetings to minimise high stress/panic during an already highly stressful time on admission day.

- Admission processes are messy, repetitive, stress inducing. Recommend that forms be issued prior to admission day and returned electronically in advance of admission where suitable. Then they should only need minor additions upon arrival.
- Hospitals need to concentrate on an admission being a getting to know you exercise, with hospital/ward tour and orientation and have a nominated person to escort new patient to first mealtime etc. This is particularly relevant to younger patients.
- Admissions never seem to run on time and the process can take many, many hours.
  Clerical admission. Financial admission. Nursing/ward admission. Doctor's medical admission.

PRIVATE HOSPITALS AND HEALTH FUNDS

The private health funding model is messed up and behind the times. Health funds have individual contracts with individual hospitals and won't deviate from that contract even if a different option would save the health fund or the patient substantial amounts of money. Medicare and health funds are not up to speed with some of the newer therapies providing better outcomes than drug therapies. As such these newer therapies do not have Medicare item numbers and are not recognised by health funds.

- For example, we recently self- funded nearly $6,000 for 30 prescribed and recommended TMS (Trans Cranial Magnetic Stimulation) Outpatient sessions at a private mental health clinic. Most health funds (excepting Medibank Private) cover TMS for inpatients but not for outpatients. We subsequently had her admitted as an Inpatient for 15 prescribed and recommended follow up TMS sessions and the health fund covered her treatment even though as an inpatient she cost them a room, meals, nursing care etc.
- Parents and carers can be put in the position of having to find large sums of money, sometimes at short notice to fund treatments options recommended by treating doctors at major mental health facilities. The alternative is to deny treatment.

OUTREACH/FOLLOW UP CARE

We need to provide follow up for patients post hospital admission.

- Most mental health patients who have been hospitalised are sent back to their homes, families, into society still unwell or at least very fragile and without follow up plans, appointments etc. There is an expectation that they will just resume daily life – study, work etc
- Discharged patients are rarely offered any form of follow up program.
- Discharged patients are not routinely followed up by hospital outreach staff.
- Social workers are not routinely involved in patient care and outreach management. Our experience is that one has to fight for these limited resources. It is left entirely up to parents and carers to help their young adults to navigate the Centrelink system regarding job readiness, youth and disability allowances and eligibilities.
- Navigating the plethora of public, private, not for profit, online, mobile app and other support services available is mind-boggling in itself. Many entities, once contacted, do not cater for the full range of people they profess to cater for. Many only provide for very low-income earners and people who have no other people resources in their lives. The rest of us so called lucky ones are left to fumble along as best we can, by ourselves and in doing so sometimes end up putting our own mental health at risk.