

Productivity Commission - Mental Health Inquiry

The Social and Economic Benefits of Improving Mental Health

Dear Members of the Productivity Commission's Mental Health Enquiry,

I am making a submission to share with you the challenges we have had in receiving appropriate, timely and effective diagnosis and treatment for my daughter's mental health. In a nutshell: current support is completely inadequate and as parents we don't know how to help her get better.

I want you to understand how incoherent the current system is for an ordinary person to navigate. You will no doubt hear from many professionals in the sector who will tell you what services are available, and some of these people will give the impression that things are already in place to help youth with mental health issues.

However, in practice, parents are in the dark, are not being guided to existing services, and as a result our children are falling through the gaps.

My daughter's experience with depression, anxiety, and self-harm

My 13 year old daughter has anxiety and depression, and has undertaken self-harm (cutting) and suicidal thoughts in the recent past. She has been suffering from this for at least 2 years (since she was 11 years old). It took a long time to get an accurate diagnosis and initial treatment, and we are still struggling today to get her to a steady functioning level.

My daughter began high school in 2017, aged 11.5 years. For the first term she did very well at school, she had excellent grades, made new friends, her teachers were all very happy with her (a couple let me know she was amongst the best in their class), and there were some days my daughter literally danced around the room when she got home from school saying "Best day ever!" My husband and I were so relieved she had transitioned so well to high school.

However in the final week of Term 1, she refused to go to school, which became an ongoing problem. My daughter gave a list of reasons she didn't want to go to school which included that she was worried she'd get into trouble for the days she'd missed so far, there were badly behaved boys who were rude, crude, disruptive and were making her best friend feel body conscious, that she didn't see the point of school subjects or assignments and found them boring, and so on.

I was in contact with the school as soon as I recognised we had an issue - when she'd missed two consecutive days of school and I was worried I wouldn't be able to get her back to school the next day. I was in constant dialogue with the school trying to resolve the issue. I tried everything I could to get my

daughter to school, but there is no way to compel an unwilling 11 year old who won't get out of bed. I asked the school for advice and support.

One thing I am grateful for: as my daughter had been a model student up until this point, my contact at the school was empathetic and tried to problem solve the issue somewhat rather than treating her like a "problem child" (which I have no doubt a child with poor school records or an underprivileged background would have been labelled).

However, we really didn't get the level of support, help or advice we needed from the school. It was never flagged to me that her behaviour could be anxiety or depression. The situation was exacerbated by the lack of school support for my daughter to catch up on her missed school work, which meant she fell further and further behind in her school work and felt increasingly unable to go to school for this reason. The school did offer the service of a school counsellor, however this would require my daughter to physically attend the school, and we were having difficulty achieving that.

As my daughter's illness first presented as school refusal, I spent a lot of time trying to find out if there was something in her local school triggering her, and whether there were alternative educational pathways. Would a different school environment be better suited? What about the small specialist schools for children who struggle in a normal environment (only for older children; and I was told it would not be suitable for a well behaved high achiever like my daughter); what about the education program run by the local youth centre (I never received a response to my inquiry); what about a private school (we did a trial at a local montessori school and were impressed, however my daughter's anxiety prevented her from attending the full trial)? I was very hesitant about home-schooling and distance education because I was already struggling with the emotional labour of being her carer 24/7 and had no confidence in her doing her schoolwork under my supervision. There did not appear to be any good solutions.

While I realised my daughter should see a doctor to determine if there were any medical conditions having an impact and to get a referral a psychologist, I had to cancel numerous doctor's appointments because I couldn't get my daughter out of bed to go to the appointments. This is a key access issue when the patient is unable to attend a doctor's surgery in person.

For clarity's sake: my daughter was not completely bed bound. Rather, she was like a turtle who would retreat to her bed on a bad day or if we said, did, or requested something of her that felt stressful. There were some days when she seemed her normal self and we thought we were past the bad phase. On a good day she would say she wanted to go to school with her friends and would agree to "on Monday" or "next term" or any other day. She would agree to a doctor's appointment, but refuse to get out of bed on the day it was scheduled.

During this time, we did not know she had 'anxiety' or 'depression'. All we knew was our child wouldn't go to school, and was increasingly treating her parents very badly at home too. At home she was often disagreeable, cranky, quick to anger, monosyllabic, rude, self entitled, selfish, did as she pleased and wouldn't listen to us or talk in a reasonable manner. She would stay up all night, and sleep all day. Occasionally she was violent, digging her nails into my forearms and drawing blood.

She did not behave this way outside of our home or in the presence of others, so the seriousness of the issue was not evident to others, and it made us constantly doubt ourselves and what the cause was. When seeking advice and support amongst family and friends, or reading parenting articles, the general

advice seemed to be that this 'age' is difficult and/or it was a parenting issue that required us to use different techniques. This made us feel like we had failed as parents, and it was our fault that our once-wonderful daughter had turned into a monster of our own making. I should also point out - my extended family includes a psychologist, who never picked up on my daughter being depressed, only noticed she was a more withdrawn than usual and looked tired.

It was an incredibly stressful period without any path forward that pushed both myself and my husband close to breaking point. It increased the arguments between us as we couldn't agree on how to solve the issue, and nothing we tried made any difference to my daughter's situation, other than sometimes to exasperate it, and the hostile home environment caused by her mental illness was claustrophobic.

I never had any respite from this. It didn't matter if it was term time or school holidays, I had to be supervising my daughter and it had become a very strained relationship.

Our entire world reduced during this time. We didn't have much energy for socialising, and would often have to cancel plans due to my daughter. The day of my brother's wedding I spent the whole day worrying we wouldn't be able to go to the wedding as my daughter was not getting up. Frequently when my husband got home from work he would just go straight to bed, without even eating dinner. Basic life tasks broke down - the housework piling up, eating takeaway and fast food rather than healthy home cooked meals, sometimes not leaving the house at all. Periodically I would break into tears just at the thought of this situation, which is not like me at all. *(I have been in and out of tears the last three days both as I reflect on this experience to share it with you, and because my daughter has crashed again).*

After many months of trying, I finally managed to get my daughter to a doctor's appointment (it was impossible to get her out of the house on previous attempts). Luckily the doctor had the foresight to ask all the necessary questions (for a mental health plan) in that appointment, because I couldn't get my daughter back to the follow up appointment. It took about four more months to get my daughter to a psychologist for the same reason. It took almost a year of regular appointments with her psychologist (with many appointments missed on a 'bad day') - with little improvement - before she was referred on to a psychiatrist who gave her a prescription for medication.

The antidepressants have made a huge difference, and I really wish she had been given this two years earlier. On medication our daughter is much more her normal self (mostly well behaved, loving, with a sense of humour), and she has increased capacity to go to her appointments and engage in school work.

A key challenge for accurate diagnosis and timely treatment is that teachers and health practitioners only see a patient on a 'good day', not on a 'bad day' (when appointments will be cancelled) so they are unable to realise the true level of seriousness. The longer the delay for proper treatment, the more serious the condition becomes. I have every belief that if there were an intervention with proper support and treatment when my daughter was 11 (when her symptoms were mild and she'd only missed a week of school), she would be better by now.

Once my daughter was on medication, she began to open up more and she revealed that she had been cutting herself and had suicidal thoughts. This was very scary and worrying to learn.

My husband and I have had many sleepless nights, whether because we are worried about what she might do to herself while we are asleep, or waking to hear her distraught hysterical crying.

Our daughter is now on a high dose of antidepressant, has been on medication for 3.5 months, in addition to one year of private psychology sessions. This year she started engaging in distance education and was doing well in all but one of her subjects, however has not been able to keep up with the schedule, and falling behind has inflamed her mental health (she has become a turtle again, after only 7 weeks of school, and I fear the rest of the year will be a write-off as the last two years were).

While the medication makes things miles better, it does not prevent periodic 'crashes' when she retreats to her darkened bedroom, staying up all night, sleeping all day, missing medical appointments, and not engaging with anyone.

I have kept her teachers up to date and they have been more accommodating than her local public school was able to be, however the pressure of workload, deadlines, and 'to keep up' seems an unsolvable battle when the state of her mental health is as fragile as it is.

It is almost exactly 2 years since this problem started. In that time she had less than a term of education. This worries me greatly, particularly as we could well be in this exact same place in another two years.

There are two issues here: mental health treatment, and education for the mentally unwell. The below delves a bit more into the challenges of accessing education when unwell:

Local public schools fail to adequately educate children who have a mental health issue. There is no modification of student's workload to take into consideration health issues, there is no process to help students catch up on work they have missed, there is no part-time or temporary alternative to allow students to carry on work at home when they cannot make it to school, and there are many factors in a school environment that contribute negatively to students' mental health (bullying, overcrowding, chaotic teaching arrangements, tests, lack of support, etc). Schools do not identify a mental health issue quickly enough or provide recommendations or advice to parents about what to do.

Our daughter wanted to go back to school, but her anxiety meant she just could not get there, and the anxiety grew and grew over time, particularly as she fell further behind in her school work. It was not clear what education alternatives or solutions were available to us.

The public school was hesitant to refer us on anywhere as there appears to be a strong belief by those who work for the education department that once a student goes somewhere else they are unlikely to come back to school and that this is considered a bad outcome for students (that they should be in the local public school). This meant we spent the first year trying to get my daughter 'back to school' rather than being directed to alternative education options that would have been more suitable for someone with mental health issues.

Additionally, the Home-School Liaison Officer gave us muddled advice and at times treated us - including my daughter - in a way that increased our stress. At one point she laid out three alternative educational options for us, but when I requested access to one of these she said there was a long wait list and my daughter wouldn't be likely to be accepted because she didn't think her health issues were "serious" enough; she then implied that my daughter would get worse if she did Distance Education due to the 'lack of socialisation'; and the third option wasn't achievable considering our inability to get our daughter to a school. It made it feel like there was no way to get a suitable education for my daughter while she was unwell.

On several occasions the Home-School Liaison Officer took the 'big stick' approach of mentioning how

the department could take legal action against us for our daughter's absence from school - she said this to our daughter as well - even though we had actively engaged with the school and department seeking help for the situation and she knew our daughter had anxiety. She kept calling this "school refusal" as if it were a behavioural issue rather than a mental health illness.

Additionally the Department of Education sent us a threatening letter, and the school sent us a letter every single week asking us to explain the days absent - even though we had already done so! Basically these letters are part of the "process" that is followed when a child misses lots of school regardless of our individual situation. It is salt in the wound when our family was already under considerable stress to have the department of education threaten us.

Once we decided to try Distance Education (last hope), we found out after-the-fact that my daughter's public school had a classroom in the library where students with anxiety were taught with extra support. If we had been told about this a year earlier it might have been an option for us, but by this time my daughter's condition had seriously deteriorated and we couldn't get her to step foot on school grounds.

The transition from school to Distance Education was a shambles - it took 3 months between when I submitted our psychologist's letter of recommendation and request to her school to when she was able to begin Distance Ed. The school contact explained that there was a lot of paperwork to an application and he was having to do it for many students in addition to his normal workload. Schools are a bottle-neck; they close down every few months for school holidays, and are under-resourced. There was nothing I could do to speed the process - I was not able to self-refer my daughter directly to a Distance Education school. I had to make many phone calls to work out what was going on, as no one kept me updated, and I had been led to believe that it would only take two weeks to process while it took 3 months!

When I first started writing this submission I wrote "My daughter is much better now - she is getting a better education via distance education and has good psychological treatment - however is likely to have years of psychologist appointments and antidepressants ahead of her," but she has since crashed, and it feels like groundhog day, like nothing significant has changed from two years ago despite all the effort, stress, and cost.

One way to look at this is: the treatment is not effective, has it been a waste of time and money? The other way to look at it is: without the treatment, things would be a lot worse and she might have killed herself by now. That's how hopeless things feel, I have no idea what is in store for us, how to help her (I can't) and I am afraid things won't ever get better.

So here's a problem that I thought I had left behind but in the last two days have found myself with again: her mental health care plan needs to be reviewed by her GP (the health care plans automatically expire after a set date or number of sessions) so we can access publicly subsidised psychological care; but my daughter couldn't get out of bed to go to her GP appointment yesterday, and I don't know when I will be able to get her to see her doctor. We had a psychology session booked for today, and I decided we would pay the whole cost ourselves out of pocket because we so urgently need our daughter to have this help (we can't wait for the mental health plan to be reasserted); however I couldn't get my daughter to leave the house to go to the psychologist's appointment.

For at least the fourth time in the past two years I have searched for an alternative service that can help give us the support we need when we have a child with severe depression who cannot access standard

services. There are countless websites and organisations claiming to give mental health support and advice, but they are in practice useless. I rang a helpline (not the first time), explained our situation, and asked “What can we do?”, and they had nothing to help this situation but refer me onto a social support group. That is what it feels like: we are awash with people who say simplistic things like “I’d really recommend you get your daughter to see her doctor, to get the mental health plan, to see her psychologist...” as if I hadn’t already tried, as if I could magically transport her to these places against her will.

I don’t know what to do. I feel like my daughter needs more intensive treatment but there don’t seem to be options, and those that I have heard to exist privately cost tens of thousands of dollar (all our savings) for a short stint without any guarantee of working. Sometimes I worry she will kill herself. Sometimes I worry this will bankrupt us. We are living between a rock and a hard place, and sometimes it is hard to breathe.

My daughter’s psychologist has just called me to recommend we try CAMHS again (Child & Adolescent Mental Health Services). I called them four months ago, requesting help for my daughter when the psychologist sessions didn’t seem to be enough - and at that time they told me they couldn’t help because I was engaged with private health care professionals. So I know there is some publicly available treatment, but we seem to be locked out of it. My daughter’s psychologist says we just have to keep trying, as she knows of similar cases being accepted, and it might just depend on who answers the phone on the day. *(N.B. When the psychologist rang them today to put forward our case, they did not have my earlier call on file. Apparently they are meant to record all requests, but whoever answered the phone the day I called did not follow protocol. The psychologist has now got our case put before triage to consider it and I am waiting to hear back how that goes. I don’t even really know what services they give, only that we need more help and they are apparently the only thing available for more serious cases).*

I have spent the last two years doing everything I can to navigate the system to get support for my daughter, and I am educated (Masters degree and other post-grad qualifications), we are not wealthy but are able to reshuffle our budget to pay for a certain amount of medical care - yet this ‘system’ is impossible to understand. It shouldn’t be so hard to get appropriate mental health care for a child so obviously in need of it.

We are glad there is some government subsidisation of the costs, as we couldn’t afford it otherwise. Her treatment is still very expensive, even with medicare rebates. We are glad we are in a financial situation currently where we are able to pay the out of pocket costs, because if this had happened even a year earlier we would not have been able to afford it and I don’t know what we would have done. She is currently seeing her psychologist every fortnight (and has been seeing her for over a year), she has seen her psychiatrist three times in the past 3.5 months, she has to revisit her GP periodically for her mental health care plan to be reviewed. We are glad that her GP and psychologist have chosen not to charge us the cancellation fees on all the appointments we have cancelled last minute when I couldn’t get my daughter to the appointments, and we know this comes at a cost to them as those are hours they could have booked with someone else.

But we need more help.

I apologise that this is such a long submission, and that I’ve barely even touched the many questions raised in the Issues Paper. It is hard to gather my thoughts, to be succinct, when under such stress. I am also racing the clock, as I only heard about this review a few days ago, yet the deadline is today.

A few key points I hope come through:

1. We need all departments (whether it be a school or education department, or the tax office, or centrelink) to act with *compassion, empathy and patience* when people are struggling, rather than taking a judgemental or punitive approach. People often struggle for a long time before they receive an official diagnosis, but that doesn't mean they don't have it.
2. We need better access to mental health services:
 - a. Clear streamlined communication and advice so that people can easily find the services they need when they need it.
 - b. Improved processes relating to access of services (the referral path, duration of mental health plan, number of appointments allowed through medicare, etc) so that people aren't cut off right when they need it most.
 - c. Increased flexibility of service delivery for patients, taking into consideration they sometimes need care outside of standard office hours and/or delivery of care at home.
 - d. Greater affordability. When health care is expensive, it means many can't access it. Realistically, all of our family needs mental health support though this time, due to the stress, but we prioritise our daughter's treatment because her case is the most important (and thus her parents have no treatment). I don't know anyone who uses medical care without needing it. I do know many people who delay care due to costs.
3. When someone is mentally unwell, it takes a toll on the whole family. Everyone is pushed to breaking point. Whatever the statistics are on mental health, you have to multiply it to count everyone involved.
4. From a "productivity" perspective, primary carers often can't rejoin the work force (or study) because the needs of our children extend indefinitely. Playing 'support role', shepherding my child to health appointments during standard work hours, advocating for my child's education and health, with a high level of unpredictability (dependent on her mental health; will it be a good day or a bad day, are we in crisis mode, etc) which cannot be accurately scheduled or planned around.

Additionally, I am concerned for my daughter, who is bright and did well in school until anxiety and depression prohibited her from accessing an education over the last two years due - who may not have much more education in future years for the same reason. Without better treatment, I don't know what kind of life she is going to have - if she will ever be employable. It is heartbreaking when you have a child who has so much potential, yet who is struggling with the basic essentials of life. We need better intervention strategies to help youth access quality mental health care early and have an educational pathway that provides an education without causing or exasperating mental health issues.

5. I believe the increase in mental health issues in our society is due to our society failing to meet our basic needs as human beings. If we really want to tackle this challenge, it must be considered holistically. Housing insecurity, job insecurity, financial stress, fear-mongering, etc, all have an impact on not just an individual's mental health, but how resilient and supportive our community is.

As one example, if people are stuck in the rental market (as our family have been), on average

you move every two years due to short term leases and price hikes, children grow up without a place they can really call “home,” renters don’t have the ability to put down firm roots in the local community (get to know neighbours, make friends, volunteer locally, etc) before they are moving house again, and this means that the whole community suffers. Even if you own your own home, when your neighbours are increasingly transitional, this leads to more disconnection, loneliness and reduced friendship, support and trust. We don’t have support networks in our community like what my family had when I grew up. And my daughter has no place she can feel is really hers. This is a systemic intergenerational issue.

Many thanks for reading my family’s experience.

Below are some further notes I made when I intended to address more of the Issues Paper questions.

Structural Weaknesses in Healthcare

1. Provide more clarity, transparency and communication about services available and how to access them. It is difficult for parents to know what is available or how to access services for their children:
 - 1.1. Schools did not refer or recommend services, even when we requested advice.
 - 1.2. Seriousness of problem is underestimated by everyone - parents, friends, teachers, doctor, psychologist, services - delaying access to the correct treatment. The longer the delay in receiving mental health diagnosis and treatment, the more serious the illness becomes, the harder it is to treat. How can we ensure problems are identified as ‘mental health’ earlier rather than deemed behavioural or parenting problem? How can we ensure health professionals see patients on ‘bad days’ not just ‘good days’ so they have a truer sense of seriousness?
 - 1.3. We were given contradictory advice from different education and health staff, including been initially told there were long wait lists for the mental health adolescent day unit and we were unlikely to be considered ‘serious’ enough, or eligible - discouraged from applying. Need more availability and access to these services.
 - 1.4. Funneled into the private system (via GP referral) before even aware of public options.
 - 1.5. When desperately in need of additional support and we found out about a public youth mental health service, we were told they couldn’t help us because my daughter was already booked in to see a private psychiatrist and psychologist.
 - 1.6. Are not allowed to utilise both public and private services. Must choose one or the other, and if you’ve started on private then that is the stream you are on.
 - 1.7. Private services quickly add up to be very expensive, even with a medicare rebate on some of it. Cannot afford the level of care our daughter really needs. This means it will take longer for her to get better.
 - 1.8. There is a lot of “noise” online - dozens of website and organisations purporting to provide services and advice for mental health, yet most of this is repetitive, basic, and theoretical. In terms of real practical help, there is a shortage.
2. Gaps in the system to be filled
 - 2.1. Need to remove obstacles that are preventing access to services. Allow self-referrals to initial services and any health practitioner to be able to extend the duration of the mental health plan rather than it running out so quickly. More affordable services (or more rebates).

- 2.2. Need GP, psychologist, and psychiatrist 'home visits' for patients who struggle to leave the house, at least for initial diagnosis and treatment and 'bad days' when patients relapse.
- 2.3. Need to allow medicare rebates for the occasional phone or skype appointment on days when a patient can't make it out of the house but can speak on the phone. (Otherwise we have to cancel last minute, which is not good for either patient or psychologist).
- 2.4. Need support programs for carers of children with mental health issues. Both me and my husband have come close to breaking point, and there is just nothing to help us (nor can we afford to start seeing psychologists ourselves when all our money is going to our daughter's treatment). Online I am told there are support programs for carers, but have not been referred to any and cannot find any specific information for me to access them. I rang a helpline and they could not provide information on the phone - said it required "research" to determine one near me - and that they would email me (awaiting email).
- 2.5. Need more clarity for parents to understand the process, what to expect, how to help, and a 'stop light' system so we know what to do if we find out child has been self harming or having suicidal thoughts (what types of behaviours are in the green, the amber, and the red - when to see a doctor versus psychologist versus psychiatrist versus go to hospital), how to take care of our children when they are cutting and have suicidal thoughts?
- 2.6. Need quality resources for children/adolescents to help them self-manage their anxiety, depression and self-harm for when they are alone and crashing to help them pull out of it.
- 2.7. Need a higher availability of health professionals - many have long wait lists, and this is not good enough when you have a seriously depressed and self-harming child.
- 2.8. Need preemptive strategies to improve wellbeing so kids don't get anxious and depressed in the first place.
 - 2.8.1. Schools need to change their culture. They need to put wellbeing first - above even education - and treat all kids (even those who struggle or misbehave) with empathy, compassion and understanding, working with them to solve problems rather than being punitive, and inserting more joy into the school day.
 - 2.8.2. Schools need to be better resourced to provide this level of care.
 - 2.8.3. Not wanting to get off topic - but some European countries do this better. For example, understanding that kids need to have a stable teacher and classmates rather than switching them all the time - so they can develop trust and quality relationships.
 - 2.8.4. Need to put an end to all bullying, whether in school, workplaces, or parliament.
- 2.9. I would really love to see some kind of wellbeing 'camp' or 'retreat' where families can go that combines mental health treatment with a holiday. Like the NSW government run sports recreation camps, but with some combination of (a) targeted mental health care for the patient, (b) support group for parents, (c) family fun to strengthen bonds, alongside other families going through the same thing (d) family education to strengthen interpersonal communication, improve resilience, and help all the family work on improving their wellbeing - learn mindfulness, deeper listening, etc (e) support group for patient so they realise they are not the only one who feels the way they do & learn how to manage their child's mental health problem. This is exactly what we need. We need it when we are at our lowest, but it's also something I would sign up for tomorrow rather than any other kind of holiday.
- 2.10. Respite care, or support so we don't feel we need respite care. Really: when you are close to a break down, but you have responsibilities you can't escape from, the whole family starts to free fall.