

# 2019 Submission - Royal Commission into Victoria's Mental Health System

N/A

**SUB: 0002.0014.0017**

## **Name**

Anonymous

## **What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?**

"\*There needs to be a lot more funding into mental health supports and education for mental health workers on catering for specific mental health illnesses. \*All people living in Australia have a right to appropriate and respectful treatment for their illness. No patient should be turned away because the hospital is too full. \*██████████ should be audited. There should be an audit into how funds are being spent, how staff are being trained, programs provided, best practices, respectful practices, appropriate communication and treatment of clients and their families, follow up services, successes, failures, collaboration, etc. \*If staff don't know about the illness of the patients under their care, it is up to the leaders to provide opportunities to further educate their staff and learn about best treatment practices. \*Professional development for staff should be ongoing. . Its okay to acknowledge that you don't know what to do but it is unacceptable to do nothing about this. \*There should be NO zoning for clients with severe mental health illnesses, especially for severe cases!!! (You don't zone patients for cancer, or road accidents or anything else so it shouldn't be happening for mental health!) If another hospital has workers that are more expertise in an area, then that hospital should cater for the patients that have that illness. Hospital acceptance should be based on the illness and the best workers that specialize in it, and not where the patient lives. \*There should be greater communication and willingness to collaborate between doctors in public and private systems. There are people's lives at risk here! We need to have a more flexible mental health system in place! \*Our hospitals for mental health patients only provide respite or emergency services. Australia needs to focus on spending more time and money on preventative and support programs. People with mental health issues and their loved ones shouldn't have to wait until they are in crisis. Lets do something to prevent the crisis happening in the first place! If our children and youth with mental health issues were assisted properly and from an early age (rather than just let them get out of control with their illnesses) then our mental health crisis for adults wouldn't be as out of control that it is now. \*Australia needs a lot more specialist clinics, hospitals and supports in place for people of all ages suffering from mental health illnesses. If our son was overseas in the UK or USA, he would have opportunities to participate in intensive treatment programs for up to 6 hours a day, but in Australia there is one Melbourne Clinic catering for the whole of Australia. \* For optimum results, a care support worker (similar to a breast care nurse for breast cancer patients) for patients with severe mental health illnesses who can check in with the unwell client regularly are desperately required. These support workers can liaise between the client and family members or carers. These might be very similar to a Personal Helper and Mentor (PHaMs) worker, who sees or makes contact with their clients on a daily basis. These people would focus on developing in areas like building rapport, self confidence, self worth, social skills, living skills, education and employment and living in the community. \*Police need to be trained in dealing with people with mental health illnesses. Often when police are called to assist a person with poor mental health they are too heavy handed and are untrained on how to approach or speak to the unwell person. \*The Education System needs to

be trained to support and understand students with mental health illnesses. With the right supports in place, these students can thrive! \* There needs to be much more employment and education training supports in place. With the right supports in place, our son is capable of successfully working. This would be a lot better for the community and economy if he was working, rather than sleeping all day and living off benefits. \*The NDIS and Centrelink needs to be less complicated and stressful. There needs to be an online system where information from specialists are available and people dont have to continue to fill in the same paperwork again and again, especially where no changes to the health of the client have been made. The NDIS and Centrelink workers need to be trained in how to best support and work with people with low mental health. There needs to be more flexibility in NDIS and Centrelink workers communicating with mental health workers and not only the patient. Often the parents or carers arent allowed to complete the paperwork. This is where a mental health support worker is greatly needed. NDIS funding and payments for workers need to be equal to the amount that they would be getting paid to see a non NDIS funded client. \*Discharge of clients from a hospital or intensive treatment program should only take place when the client has shown signs of becoming more well or are declining in health due to the program. No patient should be discharged because you have seen them for long enough. \*More than 10 sessions for Mental Health Care plans should be available for severe cases. \*There needs to be greater supports in place after discharge of hospitals and intensive programs. No patient should be discharged unless detailed and appropriate supports are in place. If follow up meetings are appropriate then these should occur. Nothing is not good enough unless the patient has returned to 100% good health. "

### **What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?**

"\*Our GP: Dr Caitlin Harrison (Wantirna Medical Clinic) is thorough, kind and caring and hasnt given up on us during this journey. \*ARCVic (Anxiety Recovery Centre of Victoria): This organizations support, understanding and persistence to assist us has been unwavering. They have listened, empathized and provided opportunities for us to learn about our sons anxieties and illness. Where others have given up, ARCVic with their wonderful CEO Michelle Graeber, have worked hard to organize a hospital stint in The Melbourne Clinic for our son as well as a psychologist when [REDACTED] discharged our son. They provide a Healthy Minds and Body Program, which they encouraged our son to attend. From this, they have helped support and partly fund our son, attend 2 PT programs a week. They have attempted to provide mentors for our son and our family. Not everything has worked, but they have refused to give up along our journey. \*CityLife Church Community Care (High Street Road, Wantirna South): The compassion and willingness of the Community Care team to agree to go outside the box with us has allowed our son to live with the dignity and humanity that he deserves. They have provided kind and caring support workers which come once a week to support him with basic living skills. \*Relationships Australia: Our life has been such a whirlwind of chaos over the last 9 years. Our family life has been so crazy at times that we didnt even know how out of control it has been. Since being discharged from [REDACTED], my husband and I have been attending fortnightly family support meetings. The counsellor we speak to (Jess) has been so refreshingly helpful for us. \*Headspace: Headspace is a wonderful resource for assisting young people with early prevention. Our son has attended our local Headspace but the staff seeing our son kept changing and werent able to cater for someone so unwell. "

### **What is already working well and what can be done better to prevent suicide?**

I can't answer this.. I'd like to know more about supports in this area.

**What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.**

"\*Private Verses Public Health Systems: Our son keeps getting hand past between doctors from the public and private health systems. Private mental health workers insist that our son needs to be in the public system where he can have access to a team of professionals and an intensive hospital program. Professionals from [REDACTED] say that they havent seen anything like our sons illness before. We were also told that he may as well go home with us because it seems like we know more about his illness than they do. Nurses at the [REDACTED] Adolescent Unit told our son that theyve never had any patients like our son before. The only private hospital for adolescents mental health is [REDACTED], but our sons referral wasnt accepted as there was no doctor willing to take on his case. Our son has had two stays in The [REDACTED] but the doctors there, insist they will not take our son on as a long term client. Communication between the public and private systems seems very fragile. To not step on anyones toes no one seems to be willing to collaborate or share in any way to work towards the best of the client. \*Zoning: There should not be zoning for people with mental health illnesses. Living in Wantirna, we are zoned to [REDACTED] [REDACTED], which means we are zoned to [REDACTED]. The director from [REDACTED] told us that [REDACTED], cant, wont and dont do intensive hospitalized programs. They only provide crisis and respite care. Its great that funding has been given to Monash Hospital, The Childrens Hospital and Origen but our son cant go there because of where we live. I can make phone contact with staff at the Melbourne Childrens Hospital or the Austin, or Monash but we cant take our son to any of these hospitals because of where we live. If I drive our son to an out of zone hospital they told me they will transport him to [REDACTED] There shouldnt be zoning for mental health, especially for severe cases!!! [REDACTED] seem mismanaged, underfunded, undertrained, over crowded with clients, and understaffed. They run a factory line program to extremely unwell clients and when your time is up you are discharged whether youre well enough or not. They are rigid and inflexible and if you ask questions when unsure, they will refuse to answer or speak in a way that makes you feel inferior. Many times workers are too clinical in the way of talking and approach. [REDACTED] provide you with a Crisis Line phone number to contact, and when we phoned this number in desperate need for support, the worker replied that they were too busy and for us to call them back later. He said, Good luck with contacting the emergency services and hung up without taking my name or any details. As parents we were asked to write up what we thought an OCD program would look like. Our son began to show progress following this plan and as soon as this happened, this program stopped cold turkey. We asked many times for this program to continue and for clarification of this decision. Their decisions are rigid and based on finances and sadly not the lives of their clients. Our son was treated by [REDACTED] IMT team in 2015. This team stopped all challenges we were previously doing, stopped email contact and stopped the hospital program. Their focus goal for 12months was on our sons schooling, yet no contact was made by them with his school at all and as parents, we were advised to step back from speaking with the school. Since being in this team, an extreme amount of appointments were cancelled, with no replacement appointments being offered. In 2015, the IMT team made contact with the DHS to observe us as parenting our son. This occurred over a period of 6 months. DHS findings were that this was not a matter for the DHS. They believed that our son was very unwell and not receiving the appropriate treatment from [REDACTED] [REDACTED] that he required. [REDACTED] response to this was that it was not for another agency to tell them what to do. \*In 2017 the IMT team have told the family that they will be ceasing

treatment of our son and recommend he see private doctors. We queried where we take our son when the private doctors have strongly recommended that only the public system can provide the intensive hospital program that he needs. The [REDACTED] psychiatrist replied that the family had to work that out and not them. I made contact with our sons previous professionals in the private system who all agreed that he should remain in the public system and they were willing to speak with the public doctors. The public doctors declined to speak with the private doctors. In early 2018, our son was discharged from [REDACTED]. Discharging Unwell Patients: Unwell patients are discharged whether they're well or not. There is little to no support in regards to what to do or where to go after discharge. \*Carers / Family Members: As family members and the main carers for our son, we are often left out of the loop of his care. We are the main people who have to look after him and yet we are given the least information on how to do this. His illness won't allow us to touch him or his belongings or be in the same room as him, but we are people who are trying to support him the most. \*Australia / Victoria is Greatly Lacking OCD Programs and Supports for Young People: Australia / Victoria is greatly lacking OCD programs and supports for young people, compared to other countries like USA and UK. It is not acceptable that people with such a severely debilitating illness are left with so little supports in place. Centrelink and the NDIS: The detailed and complex process of paperwork and decision making at Centrelink and with the NDIS is too complicated and stressful for extremely unwell clients and their families. We have been asked to complete the same paperwork repeatedly. Unless the workers have an empathy or understanding for the complexities of our sons illness, his paperwork is continually declined. As [REDACTED] have discharged our son, the detailed paperwork has been left for our sons GP to complete. His application for NDIS began over two years ago and we are still appealing this now. It continues to be rejected and appealed and the amount of waiting time for someone so severe is unacceptable. Many clients would be deceased before they get support. Another major issue is that the NDIS does not pay appropriate wages to the mental health workers and so they are all leaving to find different employment. Which the NDIS employers will be the least experienced and on contracts seeing the most vulnerable and unwell clients. That doesn't make sense!! PHaMS (Personal Helpers and Mentors EACH): The main objectives and aims of the PHaMs program is exactly what our son needs. In reality, he requires support from a PHaMs worker on a daily basis. Because our son and many like him are not being accepted into the NDIS for poor mental health, and the NDIS is not paying the equivalent amounts that workers were originally being paid, many workers are leaving organizations like EACH. This means that my son is left to be hand passed on again or he will be given a PHAMS worker funded by NDIS who is less experienced / trained and on a contract. He is not building rapport with workers. The workers are being underpaid, are leaving these services and they are being given too many clients to appropriately support. Currently my son is lucky to see his latest PHaMs worker once a month. In fact he hasn't seen her for over 2 months at present. These PHAMS workers tell me they don't even know if they will have jobs. Surely our most unwell and vulnerable should be being seen by the most experienced and dedicated workers in the field, not the opposite!! The latest I've heard is that [REDACTED] will be managing PHAMS in the future yet [REDACTED] discharged our son because they had seen him for too long! Mental Health 10 Session Care Plans For people with severe mental health issues, they may need to see a psychologist weekly. Ten sessions is just isn't enough for severe cases. Education Department and after education supports: My son has completely fallen through the education system. Prior to his breakdown, he was strong academically. Since he fell unwell, he became disengaged and unsupported. He still has no supports in place for education, training or employment. "

**What are the drivers behind some communities in Victoria experiencing poorer mental**

### **health outcomes and what needs to be done to address this?**

"Zoning for severely unwell people is not acceptable. My son is zoned to [REDACTED], whose director has told us they do not, can not and will not provide a hospital program for him. They will only provide respite or crisis care. It is crazy to think that a mental health system will only provide crisis or respite but not consider prevention of getting to crisis or needing respite. To be told by private doctors that he needs a hospitalised program that only the public system can provide and yet the public system that we are zoned to say they don't do that. The health workers where we are zoned to have told us that they have never seen any one like our son and he'd be better off going home as it sounds like we know more about his illness than them. And yet they also told us he's one of the most severest cases in the state. It seems a bit odd that the most unwell person in the state is just sent home. [REDACTED] run a factory line where when they feel they have seen a patient long enough, they discharge them. Whether they are well or not. The discharge you with not support as to getting supports in place after discharge. Their main focus is discharging you so they can get to the next patient. Their systems are over crowded, under staffed and staff are under trained."

### **What are the needs of family members and carers and what can be done better to support them?**

"Before our son turned 18years mental health workers were guarded in how much we were told but after turned 18years we are now told almost nothing. We are fighting for his life and most workers can't and won't speak to us. They can hear and say they understand our pain and frustrations and yet they aren't allowed to speak to us. Many from the [REDACTED] team made us as parents and main support people, feel like we were the problem. They continued to tell us things we were doing wrong and organised DHS to observe us parent. But when DHS said that this wasn't a parent issue and that it was [REDACTED] not providing him with adequate support, [REDACTED] said it wasn't for another organisation to tell them what to do. As carers and support workers there needs to be case managers for us to give us support. I felt many times that the [REDACTED] workers were trying to break us rather than support us. Support workers need to show empathy and understanding. Mentors for parents, support groups, a person to phone and check that we are okay would be helpful. "

### **What can be done to attract, retain and better support the mental health workforce, including peer support workers?**

Training needs to be more detailed. It's okay for [REDACTED] workers to say they don't know about our son's illness. But it's not okay for them to just send the person home and not train themselves or seek help in this area. There needs to be more communication between the public and private systems. The workers that are dedicated to improving mental health need to be paid better and have ongoing jobs. The NDIS is not paying good workers appropriately and so they are leaving. The most unwell people are then receiving help from young inexperienced workers that are on contract and unsure of their job future.

### **What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?**

"My son is 19 years and has slipped through every crack. I've emailed local, state and federal politicians, our local council and even the prime minister and premiers pleading what supports there are for my son. Physically he is a fit and healthy 19 year old. With an appropriate support

worker in place he could work or complete training. At present he has nothing. Not education. Never had a long term job. No training. No during school support and no after school support. I keep asking where he can get supports but he seems to fall through every crack. He's been placed on a disability support pension. I thought with this he would have someone make contact with him and provide supports for working towards employment but no one calls him, He just gets paid for being unwell. What he really needs is a support worker / mentor (like a person with breast cancer has a breast nurse) that calls and support often in an encouraging and supportive manner. He is capable of doing so much more if had supports. The idea of a PHAMS worker sounds good, but due to the NDIS all the good PHAMS workers are leaving due to job instability and lower wages."

**Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?**

"No zoning for severely unwell people. \*There needs to be a lot more funding into mental health supports and education for mental health workers on catering for specific mental health illnesses. \*All people living in Australia have a right to appropriate and respectful treatment for their illness. No patient should be turned away because the hospital is too full. [REDACTED] should be audited. There should be an audit into how funds are being spent, how staff are being trained, programs provided, best practices, respectful practices, appropriate communication and treatment of clients and their families, follow up services, successes, failures, collaboration, etc. \*If staff dont know about the illness of the patients under their care, it is up to the leaders to provide opportunities to further educate their staff and learn about best treatment practices. \*Professional development for staff should be ongoing. . Its okay to acknowledge that you dont know what to do but it is unacceptable to do nothing about this. \*There should be NO zoning for clients with severe mental health illnesses, especially for severe cases!!! (You dont zone patients for cancer, or road accidents or anything else so it shouldnt be happening for mental health!) If another hospital has workers that are more expertise in an area, then that hospital should cater for the patients that have that illness. Hospital acceptance should be based on the illness and the best workers that specialize in it, and not where the patient lives. \*There should be greater communication and willingness to collaborate between doctors in public and private systems. There are peoples lives at risk here! We need to have a more flexible mental health system in place! \*Our hospitals for mental health patients only provide respite or emergency services. Australia needs to focus on spending more time and money on preventative and support programs. People with mental health issues and their loved ones shouldnt have to wait until they are in crisis. Lets do something to prevent the crisis happening in the first place! If our children and youth with mental health issues were assisted properly and from an early age (rather than just let them get out of control with their illnesses) then our mental health crisis for adults wouldnt be as out of control that it is now. \*Australia needs a lot more specialist clinics, hospitals and supports in place for people of all ages suffering from mental health illnesses. If our son was overseas in the UK or USA, he would have opportunities to participate in intensive treatment programs for up to 6 hours a day, but in Australia there is one Melbourne Clinic catering for the whole of Australia. \* For optimum results, a care support worker (similar to a breast care nurse for breast cancer patients) for patients with severe mental health illnesses who can check in with the unwell client regularly are desperately required. These support workers can liase between the client and family members or carers. These might be very similar to a Personal Helper and Mentor (PHaMs) worker, who sees or makes contact with their clients on a daily basis. These people would focus on developing in areas like building rapports, self confidence, self worth, social skills, living skills, education and employment and living in the community. \*Police need to be trained in dealing with people with mental health

illnesses. Often when police are called to assist a person with poor mental health they are too heavy handed and are untrained on how to approach or speak to the unwell person. \*The Education System needs to be trained to support and understand students with mental health illnesses. With the right supports in place, these students can thrive! \* There needs to be much more employment and education training supports in place. With the right supports in place, our son is capable of successfully working. This would be a lot better for the community and economy if he was working, rather than sleeping all day and living off benefits. \*The NDIS and Centrelink needs to be less complicated and stressful. There needs to be an online system where information from specialists are available and people dont have to continue to fill in the same paperwork again and again, especially where no changes to the health of the client have been made. The NDIS and Centrelink workers need to be trained in how to best support and work with people with low mental health. There needs to be more flexibility in NDIS and Centrelink workers communicating with mental health workers and not only the patient. Often the parents or carers arent allowed to complete the paperwork. This is where a mental health support worker is greatly needed. NDIS funding and payments for workers need to be equal to the amount that they would be getting paid to see a non NDIS funded client. \*Discharge of clients from a hospital or intensive treatment program should only take place when the client has shown signs of becoming more well or are declining in health due to the program. No patient should be discharged because you have seen them for long enough. \*More than 10 sessions for Mental Health Care plans should be available for severe cases. \*There needs to be greater supports in place after discharge of hospitals and intensive programs. No patient should be discharged unless detailed and appropriate supports are in place. If follow up meetings are appropriate then these should occur. Nothing is not good enough unless the patient has returned to 100% good health. "

### **What can be done now to prepare for changes to Victorias mental health system and support improvements to last?**

"For people to compassionately listen to severely unwell people and their families. Severely unwell clients need a team that work together including weekly psychologist/ mental health worker / case manager/ social skills worker / employment worker / psychiatrist. There needs to be a consistent team approach. Constant hand passing on again and again (like with my son) makes people feel worthless. If experts keep giving up then the patients themselves begin to give up on themselves. For public and private systems to work together. For there to be no zoning in regards to severely unwell patients. For all people to be spoken to with kindness and respect. For severely unwell people to be provided with ongoing mentor support workers who are able to guide them to supports available to them. At the moment all I do is go around in circles contacting people who keep sending me around and around in circles. I've contacted so many people over the last 9 years and yet it feel like no progress is being made,"

### **Is there anything else you would like to share with the Royal Commission?**

"This is what I had originally typed before knowing I had to complete all these separate boxes. I think reading this in whole would be better than reading the above. To whom this concerns, Please find below a basic history of our journey with mental health assistance for our son (Now aged 19 years.) over the last nine years. Please feel free to contact me at any time in regards to this. [REDACTED] -In Tem 3 of 2010 our 10 year old son had a nervous breakdown which lead to alopecia, severe OCD, ODD and depression. These have lead to a young person with extremely low self-esteem, self-confidence, who is very disengaged with trying anything. -Over the last 9 years, we have seen a range of psychologists,

psychiatrists and mental health workers in the private and public systems. Our son has been continually passed on from workers and health systems. We have made a number of 000 emergency phone calls. He has had stays in [REDACTED], as well as visits to the [REDACTED] Emergency Department. He has been a patient in the CHYMS system, including the Intensive Mobile Team. He has seen hypnotherapists and naturopaths. He has had a youth worker, attended Headspace and been a part of PHaMs with EACH. He has been passed on so many times now that he has lost faith that anyone can assist him or understand his illness. He also struggles to build relationships as people generally dont commit to sticking with him. All professionals that have seen our son, agree that his case is extremely severe. For many years, our son was living a life of squalor, locking himself away in his bedroom. We have spent inheritance money to build our son a second storey on our house, for him to live a better life. He currently lives a life of sleeping through most of the time and often sounds dazed when we try to speak to him. He has a poor education since his breakdown in Grade 5, low social and life skills. He has no job or training experience. He told a doctor that he has been feeling 2 out of 10 or lower in happiness for many years. First, lets start with the positives: \*Our GP: Dr Caitlin Harrison (Wantirna Medical Clinic) is thorough, kind and caring and hasnt given up on us during this journey. \*ARCVic (Anxiety Recovery Centre of Victoria): This organizations support, understanding and persistence to assist us has been unwavering. They have listened, empathized and provided opportunities for us to learn about our sons anxieties and illness. Where others have given up, ARCVic with their wonderful CEO Michelle Graeber, have worked hard to organize a hospital stint in The Melbourne Clinic for our son as well as a psychologist when [REDACTED] discharged our son. They provide a Healthy Minds and Body Program, which they encouraged our son to attend. From this, they have helped support and partly fund our son, attend 2 PT programs a week. They have attempted to provide mentors for our son and our family. Not everything has worked, but they have refused to give up along our journey. \*CityLife Church Community Care (High Street Road, Wantirna South): The compassion and willingness of the Community Care team to agree to go outside the box with us has allowed our son to live with the dignity and humanity that he deserves. They have provided kind and caring support workers which come once a week to support him with basic living skills. \*Relationships Australia: Our life has been such a whirlwind of chaos over the last 9 years. Our family life has been so crazy at times that we didnt even know how out of control it has been. Since being discharged from [REDACTED], my husband and I have been attending fortnightly family support meetings. The counsellor we speak to (Jess) has been so refreshingly helpful for us. \*Headspace: Headspace is a wonderful resource for assisting young people with early prevention. Our son has attended our local Headspace but the staff seeing our son kept changing and werent able to cater for someone so unwell. Our concerns are: \*Private Verses Public Health Systems: Our son keeps getting hand past between doctors from the public and private health systems. Private mental health workers insist that our son needs to be in the public system where he can have access to a team of professionals and an intensive hospital program. Professionals from [REDACTED] say that they havent seen anything like our sons illness before. We were also told that he may as well go home with us because it seems like we know more about his illness than they do. Nurses at the [REDACTED] Adolescent Unit told our son that theyve never had any patients like our son before. The only private hospital for adolescents mental health is [REDACTED] Clinic, but our sons referral wasnt accepted as there was no doctor willing to take on his case. Our son has had two stays in [REDACTED] Clinic but the doctors there, insist they will not take our son on as a long term client. Communication between the public and private systems seems very fragile. To not step on anyones toes no one seems to be willing to collaborate or share in any way to work towards the best of the client. \*Zoning: There should not be zoning for people with mental health illnesses. Living in Wantirna, we are zoned to

██████████, which means we are zoned to ██████████ Adolescent Unit. The director from ██████████ ██████████ told us that ██████████ Adolescent Unit, cant, wont and dont do intensive hospitalized programs. They only provide crisis and respite care. Its great that funding has been given to Monash Hospital, The Childrens Hospital and Origen but our son cant go there because of where we live. I can make phone contact with staff at the Melbourne Childrens Hospital or the Austin, or Monash but we cant take our son to any of these hospitals because of where we live. If I drive our son to an out of zone hospital they told me they will transport him to ██████████ There shouldnt be zoning for mental health, especially for severe cases!!! ██████████ seem mismanaged, underfunded, undertrained, over crowded with clients, and understaffed. They run a factory line program to extremely unwell clients and when your time is up you are discharged whether youre well enough or not. They are rigid and inflexible and if you ask questions when unsure, they will refuse to answer or speak in a way that makes you feel inferior. Many times workers are too clinical in the way of talking and approach. ██████████ provide you with a Crisis Line phone number to contact, and when we phoned this number in desperate need for support, the worker replied that they were too busy and for us to call them back later. He said, Good luck with contacting the emergency services and hung up without taking my name or any details. As parents we were asked to write up what we thought an OCD program would look like. Our son began to show progress following this plan and as soon as this happened, this program stopped cold turkey. We asked many times for this program to continue and for clarification of this decision. Their decisions are rigid and based on finances and sadly not the lives of their clients. Our son was treated by ██████████ IMT team in 2015. This team stopped all challenges we were previously doing, stopped email contact and stopped the hospital program. Their focus goal for 12months was on our sons schooling, yet no contact was made by them with his school at all and as parents, we were advised to step back from speaking with the school. Since being in this team, an extreme amount of appointments were cancelled, with no replacement appointments being offered. In 2015, the IMT team made contact with the DHS to observe us as parenting our son. This occurred over a period of 6 months. DHS findings were that this was not a matter for the DHS. They believed that our son was very unwell and not receiving the appropriate treatment from ██████████ that he required. ██████████ response to this was that it was not for another agency to tell them what to do. \*In 2017 the IMT team have told the family that they will be ceasing treatment of our son and recommend he see private doctors. We queried where we take our son when the private doctors have strongly recommended that only the public system can provide the intensive hospital program that he needs. The ██████████ psychiatrist replied that the family had to work that out and not them. I made contact with our sons previous professionals in the private system who all agreed that he should remain in the public system and they were willing to speak with the public doctors. The public doctors declined to speak with the private doctors. In early 2018, our son was discharged from ██████████. Discharging Unwell Patients: Unwell patients are discharged whether theyre well or not. There is little to no support in regards to what to do or where to go after discharge. \*Carers / Family Members: As family members and the main carers for our son, we are often left out of the loop of his care. We are the main people who have to look after him and yet we are given the least information on how to do this. His illness wont allow us to touch him or his belongings or be in the same room as him, but we are people who are trying to support him the most. \*Australia / Victoria is Greatly Lacking OCD Programs and Supports for Young People: Australia / Victoria is greatly lacking OCD programs and supports for young people, compared to other countries like USA and UK. It is not acceptable that people with such a severely debilitating illness are left with so little supports in place. Centrelink and the NDIS: The detailed and complex process of paperwork and decision making at Centrelink and with the NDIS is too complicated and stressful for extremely unwell clients and their

families. We have been asked to complete the same paperwork repeatedly. Unless the workers have an empathy or understanding for the complexities of our sons illness, his paperwork is continually declined. As [REDACTED] have discharged our son, the detailed paperwork has been left for our sons GP to complete. His application for NDIS began over two years ago and we are still appealing this now. It continues to be rejected and appealed and the amount of waiting time for someone so severe is unacceptable. Many clients would be deceased before they get support. Another major issue is that the NDIS does not pay appropriate wages to the mental health workers and so they are all leaving to find different employment. Which the NDIS employers will be the least experienced and on contracts seeing the most vulnerable and unwell clients. That doesnt make sense!! PHaMS (Personal Helpers and Mentors EACH): The main objectives and aims of the PHaMs program is exactly what our son needs. In reality, he requires support from a PHaMs worker on a daily basis. Because our son and many like him are not being accepted into the NDIS for poor mental health, and the NDIS is not paying the equivalent amounts that workers were originally being paid, many workers are leaving organizations like EACH. This means that my son is left to be hand passed on again or he will be given a PHAMS worker funded by NDIS who is less experienced / trained and on a contract. He is not building rapport with workers. The workers are being underpaid, are leaving these services and they are being given too many clients to appropriately support. Currently my son is lucky to see his latest PHaMs worker once a month. In fact he hasnt seen her for over 2 months at present. These PHAMS workers tell me they dont even know if they will have jobs. Surely our most unwell and vulnerable should be being seen by the most experienced and dedicated workers in the field, not the opposite!! The latest Ive heard is that [REDACTED] will be managing PHAMS in the future yet [REDACTED] discharged our son because they had seen him for too long!

Mental Health 10 Session Care Plans For people with severe mental health issues, they may need to see a psychologist weekly. Ten sessions is just isnt enough for severe cases. Education Department and after education supports: My son has completely fallen through the education system. Prior to his breakdown, he was strong academically. Since he fell unwell, he became disengaged and unsupported. He still has no supports in place for education, training or employment. Our recommendations and suggestions towards improvement: \*There needs to be a lot more funding into mental health supports and education for mental health workers on catering for specific mental health illnesses. \*All people living in Australia have a right to appropriate and respectful treatment for their illness. No patient should be turned away because the hospital is too full. [REDACTED] should be audited. There should be an audit into how funds are being spent, how staff are being trained, programs provided, best practices, respectful practices, appropriate communication and treatment of clients and their families, follow up services, successes, failures, collaboration, etc. \*If staff dont know about the illness of the patients under their care, it is up to the leaders to provide opportunities to further educate their staff and learn about best treatment practices. \*Professional development for staff should be ongoing. . Its okay to acknowledge that you dont know what to do but it is unacceptable to do nothing about this. \*There should be NO zoning for clients with severe mental health illnesses, especially for severe cases!!! (You dont zone patients for cancer, or road accidents or anything else so it shouldnt be happening for mental health!) If another hospital has workers that are more expertise in an area, then that hospital should cater for the patients that have that illness. Hospital acceptance should be based on the illness and the best workers that specialize in it, and not where the patient lives. \*There should be greater communication and willingness to collaborate between doctors in public and private systems. There are peoples lives at risk here! We need to have a more flexible mental health system in place! \*Our hospitals for mental health patients only provide respite or emergency services. Australia needs to focus on spending more time and money on preventative and support programs. People with mental health issues and their loved

ones shouldn't have to wait until they are in crisis. Let's do something to prevent the crisis happening in the first place! If our children and youth with mental health issues were assisted properly and from an early age (rather than just let them get out of control with their illnesses) then our mental health crisis for adults wouldn't be as out of control that it is now. \*Australia needs a lot more specialist clinics, hospitals and supports in place for people of all ages suffering from mental health illnesses. If our son was overseas in the UK or USA, he would have opportunities to participate in intensive treatment programs for up to 6 hours a day, but in Australia there is one Melbourne Clinic catering for the whole of Australia. \* For optimum results, a care support worker (similar to a breast care nurse for breast cancer patients) for patients with severe mental health illnesses who can check in with the unwell client regularly are desperately required. These support workers can liaise between the client and family members or carers. These might be very similar to a Personal Helper and Mentor (PHaMs) worker, who sees or makes contact with their clients on a daily basis. These people would focus on developing in areas like building rapport, self confidence, self worth, social skills, living skills, education and employment and living in the community. \*Police need to be trained in dealing with people with mental health illnesses. Often when police are called to assist a person with poor mental health they are too heavy handed and are untrained on how to approach or speak to the unwell person. \*The Education System needs to be trained to support and understand students with mental health illnesses. With the right supports in place, these students can thrive! \* There needs to be much more employment and education training supports in place. With the right supports in place, our son is capable of successfully working. This would be a lot better for the community and economy if he was working, rather than sleeping all day and living off benefits. \*The NDIS and Centrelink needs to be less complicated and stressful. There needs to be an online system where information from specialists are available and people don't have to continue to fill in the same paperwork again and again, especially where no changes to the health of the client have been made. The NDIS and Centrelink workers need to be trained in how to best support and work with people with low mental health. There needs to be more flexibility in NDIS and Centrelink workers communicating with mental health workers and not only the patient. Often the parents or carers aren't allowed to complete the paperwork. This is where a mental health support worker is greatly needed. NDIS funding and payments for workers need to be equal to the amount that they would be getting paid to see a non NDIS funded client. \*Discharge of clients from a hospital or intensive treatment program should only take place when the client has shown signs of becoming more well or are declining in health due to the program. No patient should be discharged because you have seen them for long enough. \*More than 10 sessions for Mental Health Care plans should be available for severe cases. \*There needs to be greater supports in place after discharge of hospitals and intensive programs. No patient should be discharged unless detailed and appropriate supports are in place. If follow up meetings are appropriate then these should occur. Nothing is not good enough unless the patient has returned to 100% good health. "

14.04.19

To whom this concerns,

Please find below a basic history of our journey with mental health assistance for our son (Now aged 19 years.) over the last nine years.

Please feel free to contact me at any time in regards to this.

██████████

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-In Tem 3 of 2010 our 10 year old son had a nervous breakdown which lead to alopecia, severe OCD, ODD and depression. These have lead to a young person with extremely low self-esteem, self-confidence, who is very disengaged with trying anything.

-Over the last 9 years, we have seen a range of psychologists, psychiatrists and mental health workers in the private and public systems. Our son has been continually passed on from workers and health systems. We have made a number of 000 emergency phone calls. He has had stays in The ██████████ Clinic and the ██████████ Adolescent Unit, as well as visits to the ██████████ Emergency Department. He has been a patient in the ██████████ system, including the Intensive Mobile Team. He has seen hypnotherapists and naturopaths. He has had a youth worker, attended Headspace and been a part of PHaMs with ██████████. He has been passed on so many times now that he has lost faith that anyone can assist him or understand his illness. He also struggles to build relationships as people generally don't commit to sticking with him.

All professionals that have seen our son, agree that his case is extremely severe.

For many years, our son was living a life of squalor, locking himself away in his bedroom. We have spent inheritance money to build our son a second storey on our house, for him to live a "better life." He currently lives a life of sleeping through most of the time and often sounds dazed when we try to speak to him. He has a poor education since his breakdown in Grade 5, low social and life skills. He has no job or training experience. He told a doctor that he has been feeling 2 out of 10 or lower in happiness for many years.

**First, let's start with the positives:**

**\*Our GP:** ██████████ is thorough, kind and caring and hasn't given up on us during this journey.

**\*ARCVic (Anxiety Recovery Centre of Victoria):** This organization's support, understanding and persistence to assist us has been unwavering. They have listened, empathized and provided opportunities for us to learn about our son's anxieties and illness. Where others have given up, ARCVic with their wonderful CEO ██████████, have worked hard to organize a hospital stint in The ██████████ for our son as well as a psychologist when ██████████ discharged our son. They provide a Healthy Minds and Body Program, which they encouraged our son to attend. From this, they have helped support and partly fund our son, attend 2 PT programs a week. They have attempted to provide mentors for our son and our family. Not everything has worked, but they have refused to give up along our journey.

████████████████████ The compassion and willingness of the Community Care team to agree to “go outside the box” with us has allowed our son to live with the dignity and humanity that he deserves. They have provided kind and caring support workers which come once a week to support him with basic living skills.

████████████████████: Our life has been such a whirlwind of chaos over the last 9 years. Our family life has been so crazy at times that we didn’t even know how out of control it has been. Since being discharged from ██████████, my husband and I have been attending fortnightly family support meetings. The counsellor we speak to (Jess) has been so refreshingly helpful for us.

**\*Headspace:** Headspace is a wonderful resource for assisting young people with early prevention. Our son has attended our local Headspace but the staff seeing our son kept changing and weren’t able to cater for someone so unwell.

#### **Our concerns are:**

**\*Private Verses Public Health Systems:** Our son keeps getting hand past between doctors from the public and private health systems. Private mental health workers insist that our son needs to be in the public system where he can have access to a team of professionals and an intensive hospital program. Professionals from ██████████ say that they haven’t seen anything like our son’s illness before. We were also told that he may as well go home with us because it seems like we know more about his illness than they do. Nurses at the ██████████ Adolescent Unit told our son that they’ve never had any patients like our son before. The only private hospital for adolescents’ mental health is ██████████ Clinic, but our son’s referral wasn’t accepted as ‘there was no doctor willing to take on his case.’ Our son has had two stays in ██████████ Clinic but the doctors there, insist they will not take our son on as a long term client.

Communication between the public and private systems seems very fragile. To not “step on anyone’s toes” no one seems to be willing to collaborate or share in any way to work towards the best of the client.

**\*Zoning:** There should not be zoning for people with mental health illnesses. Living in Wantirna, we are zoned to ██████████ which means we are zoned to ██████████ Adolescent Unit. The director from ██████████ told us that ██████████ Adolescent Unit, “can’t, won’t and don’t” do intensive hospitalized programs. They only provide crisis and respite care. It’s great that funding has been given ██████████ but our son can’t go there because of where we live. I can make phone contact with staff ██████████ but we can’t take our son to any of these hospitals because of where we live. If I drive our son to an out of zone hospital they told me they will transport him to ██████████ There shouldn’t be zoning for mental health, especially for severe cases!!!

████████████████████ seem mismanaged, underfunded, undertrained, over crowded with clients, and understaffed. They run a factory line program to extremely unwell clients and when your time is up you are discharged whether you’re well enough or not. They are rigid and inflexible and if you ask questions when unsure, they will refuse to answer or speak in a way that makes you feel inferior. Many times workers are too clinical in the way of talking and approach. ██████████ provide you with a ‘Crisis Line’ phone number to contact, and when we phoned this number in desperate need for support, the worker replied that they were too busy and for us to call them back later. He said, “Good luck with contacting the emergency services” and hung up without taking my name or any details.

As parents we were asked to write up what we thought an OCD program would look like. Our son began to show progress following this plan and as soon as this happened, this program stopped 'cold turkey'. We asked many times for this program to continue and for clarification of this decision. Their decisions are rigid and based on finances and sadly not the lives of their clients.

Our son was treated by [REDACTED] team in 2015. This team stopped all challenges we were previously doing, stopped email contact and stopped the hospital program. Their focus goal for 12 months was on our son's schooling, yet no contact was made by them with his school at all and as parents, we were advised to step back from speaking with the school. Since being in this team, an extreme amount of appointments were cancelled, with no replacement appointments being offered.

In 2015, the [REDACTED] team made contact with the DHS to observe us as parenting our son. This occurred over a period of 6 months. DHS' findings were that this was not a matter for the DHS. They believed that our son was very unwell and not receiving the appropriate treatment from [REDACTED] that he required. [REDACTED] response to this was that it was not for another agency to tell them what to do.

\*In 2017 the [REDACTED] team have told the family that they will be ceasing treatment of our son and recommend he see private doctors. We queried where we take our son when the private doctors have strongly recommended that only the public system can provide the intensive hospital program that he needs. The [REDACTED] psychiatrist replied that the family had to work that out and not them. I made contact with our son's previous professionals in the private system who all agreed that he should remain in the public system and they were willing to speak with the public doctors. The public doctors declined to speak with the private doctors.

In early 2018, our son was discharged from [REDACTED].

**Discharging Unwell Patients:** Unwell patients are discharged whether they're well or not. There is little to no support in regards to what to do or where to go after discharge.

\***Carers / Family Members:** As family members and the main carers for our son, we are often left out of the loop of his care. We are the main people who have to look after him and yet we are given the least information on how to do this. His illness won't allow us to touch him or his belongings or be in the same room as him, but we are people who are trying to support him the most.

\***Australia / Victoria is Greatly Lacking OCD Programs and Supports for Young People:**

Australia / Victoria is greatly lacking OCD programs and supports for young people, compared to other countries like USA and UK. It is not acceptable that people with such a severely debilitating illness are left with so little supports in place.

**Centrelink and the NDIS:** The detailed and complex process of paperwork and decision making at Centrelink and with the NDIS is too complicated and stressful for extremely unwell clients and their families. We have been asked to complete the same paperwork repeatedly. Unless the workers have an empathy or understanding for the complexities of our son's illness, his paperwork is continually declined. As [REDACTED] have discharged our son, the detailed paperwork has been left for our son's GP to complete. His application for NDIS began over two years ago and we are still appealing this now. It continues to be rejected and appealed and the amount of waiting time for someone so severe is unacceptable. Many clients would be deceased before they get support. Another major issue is that the NDIS does not pay appropriate wages to the mental health workers and so they are all leaving to

find different employment. Which the NDIS employers will be the least experienced and on contracts seeing the most vulnerable and unwell clients. That doesn't make sense!!

[REDACTED] The main objectives and aims of the PHaMs program is exactly what our son needs. In reality, he requires support from a PHaMs worker on a daily basis. Because our son and many like him are not being accepted into the NDIS for poor mental health, and the NDIS is not paying the equivalent amounts that workers were originally being paid, many workers are leaving organizations like EACH. This means that my son is left to be hand passed on again or he will be given a PHAMS worker funded by NDIS who is less experienced / trained and on a contract. He is not building rapport with workers. The workers are being underpaid, are leaving these services and they are being given too many clients to appropriately support. Currently my son is lucky to see his latest PHaMs worker once a month. In fact he hasn't seen her for over 2 months at present. These PHaMs workers tell me they don't even know if they will have jobs. Surely our most unwell and vulnerable should be being seen by the most experienced and dedicated workers in the field, not the opposite!! The latest I've heard is that [REDACTED] will be managing PHAMS in the future... yet [REDACTED] discharged our son because they had seen him for too long!

#### **Mental Health 10 Session Care Plans**

For people with severe mental health issues, they may need to see a psychologist weekly. Ten sessions is just isn't enough for severe cases.

**Education Department and after education supports:** My son has completely fallen through the education system. Prior to his breakdown, he was strong academically. Since he fell unwell, he became disengaged and unsupported. He still has no supports in place for education, training or employment.

#### **Our recommendations and suggestions towards improvement:**

\*There needs to be a lot more funding into mental health supports and education for mental health workers on catering for specific mental health illnesses.

\*All people living in Australia have a right to appropriate and respectful treatment for their illness. No patient should be turned away because the hospital is too full.

\*[REDACTED] should be audited. There should be an audit into how funds are being spent, how staff are being trained, programs provided, best practices, respectful practices, appropriate communication and treatment of clients and their families, follow up services, successes, failures, collaboration, etc.

\*If staff don't know about the illness of the patients under their care, it is up to the leaders to provide opportunities to further educate their staff and learn about best treatment practices.

\*Professional development for staff should be ongoing. . It's okay to acknowledge that you don't know what to do but it is unacceptable to do nothing about this.

\*There should be NO zoning for clients with severe mental health illnesses, especially for severe cases!!! (You don't zone patients for cancer, or road accidents or anything else so it shouldn't be happening for mental health!) If another hospital has workers that are more expertise in an area, then that hospital should cater for the patients that have that illness. Hospital acceptance should be based on the illness and the best workers that specialize in it, and not where the patient lives.

\*There should be **greater communication** and willingness to **collaborate between doctors** in public and private systems. There are people's lives at risk here! We need to have a **more flexible mental health system** in place!

\*Our hospitals for mental health patients only provide respite or emergency services. Australia needs to focus on spending more time and money on **preventative and support programs**. People with mental health issues and their loved ones shouldn't have to wait until they are in crisis. Let's do something to prevent the crisis happening in the first place! If our children and youth with mental health issues were assisted properly and from an early age (rather than just let them get out of control with their illnesses) then our mental health crisis for adults wouldn't be as out of control that it is now.

\*Australia needs a lot **more specialist clinics, hospitals and supports** in place for people of all ages suffering from mental health illnesses. If our son was overseas in the UK or USA, he would have opportunities to participate in intensive treatment programs for up to 6 hours a day, but in Australia there is one [REDACTED] catering for the whole of Australia.

\* For optimum results, a **care support worker** (similar to a breast care nurse for breast cancer patients) for patients with severe mental health illnesses who can check in with the unwell client regularly are desperately required. These support workers can liaise between the client and family members or carers. These might be very similar to a **Personal Helper and Mentor (PHaMs) worker, who sees or makes contact with their clients on a daily basis**. These people would focus on developing in areas like building rapport, self confidence, self worth, social skills, living skills, education and employment and living in the community.

\***Police need to be trained** in dealing with people with mental health illnesses. Often when police are called to assist a person with poor mental health they are too heavy handed and are untrained on how to approach or speak to the unwell person.

\*The **Education System needs to be trained to support and understand** students with mental health illnesses. With the right supports in place, these students can thrive!

\* There needs to be much **more employment and education training supports** in place. With the right supports in place, our son is capable of successfully working. This would be a lot better for the community and economy if he was working, rather than sleeping all day and living off benefits.

\*The **NDIS and Centrelink needs to be less complicated and stressful**. There needs to be an online system where information from specialists are available and people don't have to continue to fill in the same paperwork again and again, especially where no changes to the health of the client have been made. The NDIS and Centrelink workers need to be trained in how to best support and work with people with low mental health. There needs to be more flexibility in NDIS and Centrelink workers communicating with mental health workers and not only the patient. Often the parents or carers aren't allowed to complete the paperwork. This is where a mental health support worker is greatly needed. NDIS funding and payments for workers need to be equal to the amount that they would be getting paid to see a non NDIS funded client.

\***Discharge** of clients from a hospital or intensive treatment program should only take place when the client has shown signs of becoming more well or are declining in health due to the program. No patient should be discharged because you have seen them for long enough.

\*More than 10 sessions for Mental Health Care plans should be available for severe cases.

\*There needs to be **greater supports in place after discharge** of hospitals and intensive programs. No patient should be discharged unless detailed and appropriate supports are in place. If follow up meetings are appropriate then these should occur. Nothing is not good enough unless the patient has returned to 100% good health.

**People we have contacted in regards to our concerns:** \*Prime minister of Australia / Victorian Premier / Victorian opposition leader, local politicians / ARCVIC / Beyond Blue / GP / Children's Help Line / Parents Line/ Headspace / Eastern Health doctors and the director / private psychologists and psychiatrists / well know mental health workers such as Michael Carr Gregg / Sabina Reeves / Andrew Fuller / presenters running presentations and forums run by ARCVIC / the chief psychiatrists department of Victoria / Eastern Health Patient Advocacy / Mental Health Commissioner / EACH carer support people / Centerlink / Medicare people / NDIS/ Police / Ambulance / Emergency Department / School teachers / School principals / Relationship Australia counsellors / Tandem