



# ***MENTAL HEALTH SELECT COMMITTEE***

**Members present:**

Mr JP Kelly MP—Chair  
Ms AJ Camm MP  
Mr RI Katter MP (virtual)  
Ms AB King MP  
Mrs MF McMahon MP  
Mr R Molhoek MP  
Mr BL O'Rourke MP  
Dr CAC Rowan MP

**Staff present:**

Dr A Beem—Acting Committee Secretary  
Ms M Westcott—Assistant Committee Secretary

## **PUBLIC HEARING—INQUIRY INTO THE OPPORTUNITIES TO IMPROVE MENTAL HEALTH OUTCOMES FOR QUEENSLANDERS**

### **TRANSCRIPT OF PROCEEDINGS**

**FRIDAY, 18 FEBRUARY 2022**

**Brisbane**

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### **The committee met at 2.04 pm.**

**CHAIR:** Good afternoon. I declare this public hearing of the Mental Health Select Committee officially open. I would like to respectfully acknowledge the traditional custodians of the land on which we meet today and pay our respects to elders past and present. We are very fortunate to live in a country with two of the oldest continuing cultures in Aboriginal and Torres Strait Islander people, whose lands, winds and waters we all share.

I would like to introduce the members of the committee. I am Joe Kelly, the member for Greenslopes and chair of the committee. Mr Rob Molhoek, the member for Southport, is the deputy chair. The other committee members are: Dr Christian Rowan, the member for Moggill; Ms Ali King, the member for Pumicestone; Mrs Melissa McMahon, the member for Macalister; Mr Barry O'Rourke, the member for Rockhampton; Ms Amanda Camm, the member for Whitsunday; and Mr Robbie Katter, the member for Traeger, who will be joining us via videoconference shortly.

The purpose of today's proceedings is to assist the committee in its inquiry into the opportunities to improve mental health outcomes for Queenslanders. This is a proceeding of the parliament and is subject to the Legislative Assembly's standing rules and orders. Only the committee members and invited witnesses may participate in the proceedings. Witnesses are not required to give evidence under oath or affirmation, but I must remind witnesses that intentionally misleading the committee is a serious offence.

These proceedings are being recorded and broadcast live on the parliament's website. Media may be present and are subject to the committee's media rules and the chair's directions at all times. You may be filmed or photographed during the proceedings and images may also appear on the parliament's website or social media pages.

Please turn your mobile phones off or switch them to silent mode. I remind everyone that face masks are to be worn at all times. Witnesses and committee members may only remove their mask to speak during the proceedings. As the chair, I shall leave mine off because I have to speak potentially unexpectedly at any time.

I would now like to welcome representatives of the Association of Relatives and Friends of the Mentally Ill, an organisation I believe started in Stones Corner, as well as witnesses from Carers Queensland, an organisation that used to be in the electorate of Greenslopes—you are welcome back anytime—and Roses in the Ocean.

**BONE, Mrs Sarah, Manager, Carer Program, Carers Queensland**

**CLELLAND, Ms Irene, Chief Executive Officer, Association of Relatives & Friends of the Mentally Ill**

**EDWARDS, Ms Bronwen, Chief Executive Officer, Roses in the Ocean**

**TYSON, Ms Alexandra, Service Delivery Manager, Carer Supports, Association of Relatives & Friends of the Mentally Ill**

**WALBANK, Ms Sarah, Manager, Quality & Assurance, Carers Queensland**

**WALLACE, Dr Alexis, Member, Carer Advisory Committee, Association of Relatives & Friends of the Mentally Ill**

**CHAIR:** I would like to start by asking each of your organisations to make a brief opening statement, following which we will open the floor to questions from the committee.

**Ms Tyson:** Good afternoon. I would like to thank everyone for the opportunity to participate today and to highlight the needs of mental health carers across the whole of Queensland. I would also like to acknowledge the traditional owners of the various lands on which we are meeting today and pay my respects to elders past and present. I also wish to acknowledge the people with lived Brisbane

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experiences and particularly their families and carers, as this inquiry is incredibly important for the families and carers. It is vital for all individuals now and also for a long time into the future in terms of the decisions that are made.

For our opening I will briefly talk about ARAFMI and who we are and then I will pass over to Dr Alexis Wallace for a brief overview of mental health carers and then to Irene Clelland about the three priorities that we want to present.

I am not sure how familiar people are with ARAFMI, but it is a not-for-profit organisation that was established over 45 years ago specifically for mental health carers. We are a statewide service. We receive some modest recurrent funding from Queensland Health through the Mental Health Alcohol and Other Drugs Branch and this is specifically for mental health carer supports and programs. Our programs include a 24-hour telephone support line for carers, which is really vital because that is across the whole of Queensland and anyone can contact it; in-person and over-the-phone counselling specifically for carers; and group supports including an annual mental health carer conference, which is supported by the commission. That is held in Brisbane and last year we televised it across the state to make sure that carers in other regions were able to participate in that as well. We also have mental health carer education and we do systems advocacy for mental health carers.

Within ARAFMI we have just five paid carers plus 40 volunteers, so it is a fairly small team trying to achieve quite a lot within a large state. We provide support to over a thousand mental health carers in any year and would like to really broaden that significantly, particularly into the regional areas. Our programs continue to be adapted. Certainly in light of the pandemic we have changed a lot of programs to online and that has helped people in regional areas significantly. Across Queensland we still have a big unmet need for face-to-face supports for carers in the regions where people understand what is going on in those areas.

We have established an active carers advisory committee, which connects with mental health carers, gathers feedback and concerns, and raises them at a strategic level. Their views are being represented here today. Common themes that arise are a lack of awareness of the caring role and how this impacts on individuals, families and communities; a need to access information and support to navigate systems; difficulties in gaining access to the right services when and where they need them; being involved and consulted in planning and decision-making; and needing access to appropriate individualised respite in regions where people live. I will hand over to Alexis to briefly give her thoughts as well.

**Dr Wallace:** I am a lawyer, not a doctor, so please no medical questions. I am from Mackay and lived in Brisbane for a long time and now live on the Gold Coast. I want to take a moment to remember what we know about mental health carers.

As we know, in Queensland mental health carers come from all sectors of the community and they are all ages. A mental health carer is an IT guy looking after his girlfriend with an eating disorder. If he is not there, she does not eat. He has missed so many days of work now that his job is in jeopardy.

A mental health carer is a high school girl caring for her mother with bipolar disorder. That girl cannot go on school camp because there is no-one to watch over her mother while she is gone. She knows her mother's early warning signs and she is the one who calls for help.

A mental health carer is a man whose brother has schizophrenia. His brother does not want help. He has gone missing yet again—no phone, no address. The stress of searching for him drives the man to drink.

A mental health carer is a woman caring for her father-in-law with dementia and PTSD. He lives in her granny flat. She cooks for him and cleans for him. She manages his medication and all his appointments. She no longer has time to maintain friendships and the woman herself is experiencing depression.

A mental health carer is a young father whose autistic sons have anxiety and ADHD. He patches the holes in the walls caused by their fists and tries to patch his marriage, which has broken under the strain. His knowledge of his sons' triggers is intimate. It is a deeper understanding than their doctors will ever have time to acquire. He is the one who is close to their pain.

Carers are the backbone of much mental health treatment and care in Queensland. It makes social sense to support them and it makes economic sense to support them.

**Ms Clelland:** Thanks, Alexis. I am not quite sure how to follow that. I will speak for a few seconds so the panel can get accustomed to my accent as well as the transcriber. If there are any words that I am not pronouncing properly, please let me know and I can come back to you on that.

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ARAFMI is an organisation that engages widely with the mental health sector to ensure that carers are included in plans, decision-making and implementation of mental health policy and services. We welcome the opportunity to speak today because we are not just service providers for carers; we engage with the wider mental health sector including people who live with mental illness and use services.

Based on our connection with mental health carers, we have three main areas for consideration for the panel today. We would like to mention appropriately funded opportunities for carers to access respite services. There are funded respite options available in the state at the moment, but they are incredibly limited and not necessarily available to all carers who need them. We do recognise the positive supports that are already there, but there is a significant lack of access in Queensland to appropriate respite in particular in the regional and rural areas.

Our second point is around consideration of opportunities for carers to access and remain in employment, and Alexis made some really excellent points about carers not being able to maintain employment. This includes the opportunities for employment in carer peer roles, so patient in community settings, support nurse navigators and advocates. Across workplaces there is also a significant lack of understanding about who a mental health carer is. In the generic workplace, if people need to take time off to support the person they are caring for it is not widely understood and then jobs becomes at risk.

The third area we would like the committee to have consideration for is a carer designed and led independent peak similar to and working closely with the newly established mental health lived experience peak in Queensland, which was recently formed. It was established in July 2021, and I do not know if they have put in a submission to the committee. A mental health specific peak for mental health carers would deliver a closer connection and alignment to mental health services and to mental health policy, influence and advocacy. It would also allow opportunities to raise awareness that is so crucially needed for mental health carers specifically; allow mental health carers opportunities to contribute to the design of services for consumers and carers; and ensure that mental health carer supports are represented across statewide demographics. A mental health carer in South-East Queensland would look very different to a mental health carer in a regional area where they lack access to face-to-face supports. We would like some consideration around the entire statewide area.

They are the three areas we would like the committee to consider. We are happy to expand on any of those points.

**Ms Edwards:** I am the founding CEO of Roses in the Ocean. I, too, would like to acknowledge the traditional owners of the lands on which we are meeting today. I make the acknowledgement that we have so much to learn from our First Nations people across so many aspects of life. In suicide prevention they really have an incredible amount to contribute in terms of their way of thinking and their culture. I would also like to acknowledge people with lived experience of suicide. There will be people here that that applies to as well as many thousands and thousands throughout Queensland, of course.

To put some context around what is a lived experience of suicide, it is defined as people who have experienced suicidal thoughts, those who have made attempts on their life, people who care for loved ones through suicidal crisis and those who have been bereaved by suicide. We understand that there are so many more people who are significantly impacted by suicide in our communities as well. When we talk about a lived experience of suicide, we are really talking about that very personal experience.

Roses in the Ocean is a national lived experience of suicide organisation. We are the only organisation of our kind in Australia and, indeed, in the world. We are 11 years old. It was founded following the suicide of my brother Mark, and every single person who works in Roses in the Ocean and with Roses in the Ocean has a lived experience of suicide. We are really quite unique in that way.

Our role in the country and in Queensland is quite multifaceted. We are very firmly with our feet in community and in grassroots. We do a lot of capacity-building training for people with a lived experience such that they can find their voice and speak their truth and actually contribute to what suicide prevention needs to look like. All of that then informs our very significant role nationally in strategic advice to government around system reform, gaps, how we fill them and innovation. We sort of sit in both of these spheres, and I cannot imagine not being in one of them. I do not know how we could provide advice if we are not right there hearing from people with lived experience all the time.

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We run a range of services from national peer warmlines to face-to-face peers in community and we are co-designing safe spaces across the country. We have done some in Queensland recently that have started to emerge. We are involved in the emerging suicide prevention peer workforce and we are very focused on the engagement, integration and partnership with people with lived experience.

In terms of how we are supported, we are based here in Brisbane. We have been locally grown. Our core funding is through the National Suicide Prevention Leadership and Support Program, which is a federally funded program. That is the only funding we receive. Everything else that we do is predominantly on a fee-for-service basis.

In terms of our primary focus, I think the core message is that suicide prevention is a really significant issue in Queensland and nationally. In terms of the mental health system, Queensland is still incredibly mental illness and mental health centric and is quite risk averse. In the suicide prevention context, an enormous number of people—about half of the people—who die by suicide do not have a diagnosed mental illness; they do not relate to mental health or mental illness being an underlying factor, an underlying cause, to their suicidal distress. When all the services that are available to support people are mental health centric, you are alienating a very large proportion of our community and it is a really big issue.

It is really important that people understand the difference between mental health and suicide. Obviously, there is an overlap; there are absolutely people who find themselves looking to end their life whose underlying causal factor is a mental illness. However, there are a lot of people whose causes are coming from relationship breakdown, housing issues, financial stresses—there are all sorts of other social determinants that come into play.

Suicide is incredibly complex. It is as complex and as unique as the people, as human beings. Our key focus and what we would be urging the committee to be considering is: how can we actually broaden the services that are available? The system is not working. It was never designed for people in crisis. We know that and our health professionals know that. Our health professionals are under enormous stress trying to support people in these situations and they are really not equipped to do so.

We are really seeking to see a lot more innovation come into the system reform here in Queensland and a much greater commitment and investment in people with a lived experience of suicide so we can actually start integrating and changing the way things are happening. If we are truly to have a 'no wrong door' approach for anyone who is in distress, that means no matter where they go, be it a clinical or a non-clinical option, that person is very well informed, they understand suicide, they understand what it is like and they can actually provide the appropriate response at that time without the knee-jerk, risk-averse reactions that often occur that pull people into our system where they are harmed and traumatised. It is a fact that is, unfortunately, still happening today in our hospitals and in our health services to many, many people.

There are a number of key options which I raised in our submission around looking for alternatives to the current system. You must be needing to work together with the health system and interact. We have a need for additional choices and options for people and non-clinical alternatives. There is a desperate need for a focus on the suicide prevention peer workforce alongside and to coexist with the mental health peer workforce. We do need that specialty.

When people who are in crisis walk through a door, they want to be with someone who has been in those shoes before and knows what it is like to want to end your life. They want to be able to connect with people. People who are bereaved want to be supported by people who have been bereaved before. There is a real need for that peer matching.

It is the same in the carers space. I could reiterate everything that has been said already and just place that overlay of suicide onto it. The people who are caring for people in crisis are the mums and dads who are literally getting up three times during the night to check if their children are still alive. They are the people who live that experience constantly. Every phone call that comes in might mean that their brother has taken his life.

I have been in that position. I lived with those phone calls from my brother for many, many years before we lost him. The enormous burden—not the 'burden'; that is an awful word to use. The incredible stress that comes into a family unit when you are trying desperately to keep somebody alive is enormous and impacts every part of your life.

I will leave it there. I am sure there are other questions, but I do not want to take up too much time. Thank you so much for the opportunity to speak with you today.

**CHAIR:** I acknowledge that the member for Traeger has joined us. Welcome.

**Ms Walbank:** Carers Queensland, too, acknowledge the traditional custodians of the lands on which we are meeting today. Thank you very much for this opportunity to inform the review of Queensland's mental health services and the future of mental health policy, service design and delivery.

For 32 years Carers Queensland has been the peak body representing the concerns and issues of family and friend carers, those ordinary Queenslanders who provide unpaid care and support to our most vulnerable citizens. This year 533,200 Queenslanders, including children and young people, will provide 357.4 million hours worth of unpaid care and support to a family member or friend, the replacement value of which has been conservatively estimated at \$16.51 billion. Our contribution to the humanity of our society is real and the contribution to Queensland's health and social care economies is tangible.

Operating across Queensland, we bring to the committee a genuine understanding of the difficulties of delivering the right service at the right time by the right person, particularly to those in our rural and remote regions and those from marginalised populations. Our advocacy is informed today by the lived experience of many in our workforce, including ourselves, the voices of those we support and the research we have initiated and participated in. While we acknowledge that much has been done to improve the mental health sector in the last 10 years, there is still much to be done.

We acknowledge the government's commitment to supporting carers via the Carer Recognition Act and to the Department of Health's policy commitment to carer engagement. We explore the department's initiative to engage carers in the design and delivery of programs and services.

Unfortunately, the translation of this commitment into practice has been inconsistent, leaving carers unsure of who to seek support from and at times very confused by the sector. Carers continue to tell us that they feel marginalised, disregarded or locked out of the decision-making processes, particularly in those situations where they have challenged the decision of the treating teams or where they have been deemed to be the source of the problem by the treating team. Yet these same carers tell us that it is assumed by those treating practitioners that they will continue to provide support, having never been consulted about their capacity or willingness to provide care on an ongoing basis or any inquiry about their safety.

The hesitancy of mental health practitioners to see and respect carers as genuine partners in the care process, people with extraordinary skill and knowledge and a genuine want to work in partnership with those in the service, remains a concern to Carers Queensland. We ask: how can we tangibly address this persistent issue?

The assumption that carers and caring families can confidently and willingly continue to provide care and support is problematic for many. Aggression and abuse within the care relationship is real. Research conducted for Carers Queensland by QUT suggests that 41 per cent of carers will experience abuse or the threat of abuse within the care relationship and yet this is rarely considered by policymakers and treating practitioners.

Both Sarah and I know of carers who have experienced abuse within the care relationship. A friend of mine had to take out a restraining order on her 30-year-old son and his girlfriend after he knocked her to the ground and attempted to strangle her while his girlfriend kicked her repeatedly. She lived in fear of the time when the restraining order would expire.

Only two weeks ago a carer told us of how her teenage child who has mental illness was threatening to kill her during an acute episode. She sought the immediate assistance and support of her local hospital, fearing for her safety and that of her child. She sat in the A&E reception for several hours and eventually left as there was no support forthcoming. I would now like to hand over to Sarah.

**Mrs Bone:** Thank you, everybody, for this opportunity. I apologise for another Scottish accent. If you need me to repeat anything, please just let me know. I am here in my current role as the manager at Carers Queensland but also as a parent of a neurodivergent young man who also lives with mental health challenges. I would like to begin by taking the opportunity to highlight the needs of the neurodivergent community and the mental health comorbidities that exist—ADHD, for example. Deloitte reported that the total of cost of ADHD in Australia in 2019 was \$20.45 billion. Parents and carers of children with ADHD have a greater occupational and social burden. There is currently no funding available for parents and carers supporting children with ADHD. Mainstream schools can be distracting environments that are unable to cater for the unique and functional needs of neurodivergent students. Behaviour can often be a manifestation of the person's disability and/or the lack of support.

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I would like to highlight the link between disabilities, including mental health, and suspensions and expulsions in the school setting and the impact this approach has on the families and carers. Please refer to the royal commission public hearing reports 2 and 7 for further information. The impact of this approach not only leads to reduction in the mental wellness for both the individual and their family members but also has a widespread consequence on their social and economic participation. Carers Queensland welcomes the \$100 million Student Wellbeing Package commitment from the Queensland government and would like to better understand what supports will be made available to those who are currently disengaged from education, many of whom are disengaged because of their disability and/or lack of suitable education pathways to meet their individual needs.

There is a definite lack of mental health services and supports for young people, particularly those under the age of 12, and a limited focus on early intervention and prevention in this space—which you have heard, I am sure, over a number of these consultations. Services are often allocated based on the severity of the condition. Waiting times can be a real challenge for families. Currently there is a 12- to 24-month wait time for access to our youth psychiatrist and other allied health professionals here in Queensland, and obviously those times will be much longer for those in regional and remote areas. Those waiting times can increase household risk and place considerable stress and pressure on many families.

Following from the lack of service availability, this would be an appropriate time to also highlight the financial disadvantage that families experience while supporting a loved one with a disability and/or illness. Gap fees to access services and medications for vulnerable families can often lead to financial hardship or the inability for them to access appropriate services and medications to improve the quality of their life.

COVID-19 has impacted the whole world. There have been additional pressures and expectations on families to provide additional care to those living with a disability and illness during periods of lockdown, homeschooling and increased community risk. In 2020 Carers Queensland undertook some COVID check-ins with carers. We checked in with over 1,200 carers during this period, 39 per cent of whom quoted a decline in their own mental health. Thirty-eight per cent reported changes in their services and 52 per cent of those carers were supporting one or more children with additional needs during homeschooling. This has an impact not only on the carers but also on carers' mental health.

**Ms Walbank:** We are trying to illustrate today to the committee that carers are in a unique and ambiguous position, both practically and conceptually. On one hand we are the pillars of the social care sector, providing innumerable hours of support; on the other hand we are also people in need of support and assistance ourselves to deal with the challenging and sometimes harsh realities of our lives. That includes understanding the diagnosis that our loved one has been given and the impact it will have on them and our family lives.

Support and assistance is readily available to those professional practitioners in the mental health sector, with professional development, training and supervision, but it is not readily available to family and friend carers. As a result, carers often continue to provide care and support when it impacts negatively on their own mental health—their emotional and physical health and wellbeing. We know of carers, some of whom have been our colleagues, unable to cope with the increasing aggression and threats of aggression from their child or their loved one with mental health problems and the inadequate support they will receive from the health and education sectors. These people have felt that there has been no option other than to relinquish their child into state care. While there is no publicly available data in Queensland on the number of relinquishments, we know from Victorian research that the cost of relinquishment is significant to the state, the young person and their family.

As practitioners we play a role in helping a caring family to understand the tricky and sometimes dysfunctional aspects of both the caring role and the sector. I know that as a practitioner of more than 40 years I was guilty of assuming that the carer or the caring family was doing a great job and by doing so I did not need to do anything else. I was guilty of employing what is called the rule of optimism. I was guilty of being blind and deaf to the situation and the needs of carers and caring families.

There needs to be more education available to all practitioners to understand the stress carers experience and the potential negative impact of their caring role on their own health and wellbeing when it is assumed that they will continue to provide care and support. Our own research has shown that carers, and particularly those who have had complex caring roles, have cared for more than one person or experienced abuse, have significantly poorer mental health and much lower quality of life than their peers. Data from the Australian Unity Quality of Life Survey has shown that, while most of the population enjoys a wellbeing score of between 73 and 78, carers have a wellbeing score

of 58.4—the lowest wellbeing of any population surveyed by the Australian Quality of Life Centre at the time. Carers have an average rating on the depression scale that is classified as moderate. We know that 37 per cent of carers report severe to extreme symptoms of depression and stress.

From our own research we know that some carers will use alcohol and other drugs to cope with their situation, their depression, their anxiety and their hopelessness. Some will consider suicide. It is unsurprising to us that the responses to the carer experiences survey reported in the Queensland government written briefing on page 22 suggest that carers feel somewhat let down by the sector. The bottom five domains are: ‘Your overall wellbeing’, which rated 3.8; ‘Overall, how would you rate your experience as a carer with this mental health service over the last three months?’, which rated 3.8; and ‘You were given the opportunity to enhance your abilities as a carer’, which rated 3.5. If carers are genuinely valued partners then it seems only rational that within the assessment, treatment and support planning processes we look to the health and wellbeing of the carer and their capacity and willingness to continue to provide care and support.

Carers Queensland remains committed to working in partnership with both the Queensland government and the mental health sector to provide people with mental health concerns and their carers with access to appropriate quality, culturally safe and timely services enabling people to live their most productive lives. Thank you.

**CHAIR:** Thank you very much. Sarah and Irene, I can assure you we understood you fine. Thanks to the great work of Billy Connolly I think all Australians have a rudimentary grasp of your wonderful language.

**Ms Clelland:** We are all practically related.

**CHAIR:** On a serious note, I wanted to start with a question for Carers Queensland. As a nurse in a physical rehabilitation unit with obviously some mental health aspects, one of the first things you check is people’s connections into the community via family or carers. One of the very difficult situations to deal with is where a patient indicates that they do not want family involved in their care. That makes your job extremely difficult in terms of trying to support that person back into the community. I know there are some models that have been rolled out in Victoria around carer support and involving carers in the care, and I know from colleagues in the mental health space that this problem that we have had in the physical space—and I have been aware of it since I started nursing in the eighties—is a major challenge, and it is not one that healthcare workers welcome but we have to respect what the patients are asking us to do. Are there any models that you are aware that have been able to overcome that challenge of a family member who is refusing to have families involved in care?

**Ms Walbank:** We acknowledge it is a real issue, and as a practitioner of more than 40 years experience I understand that. I do not know of any models that have successfully managed to address the issue, no.

**CHAIR:** I think back to our discharge planning and processes. We would do a lot of work around training families up to maybe help people with showering or toileting or managing feeding tubes, whatever the situation would be. I was not aware of much in the way of emotional support and preparation of people unless we were aware of some sort of a pathology and then we would get social workers and psychologists involved. Would it be your experience that it is routine for people discharged in either a physical or mental health setting to have that sort of training and support for carers?

**Ms Walbank:** Not in Queensland.

**Mrs Bone:** No, and that is one of the biggest feedbacks that we get from the community: that assumption of their capacity and ability and skills to undertake that role. That is something that is really missing. Often it would be a diagnosis and a discharge with no formal training or support. Back on that other aspect, I think one of the big issues with regard to discharge, especially in that mental health space, is the breakdown of the relationship before they have been admitted. Actually, if we can look at early intervention and prevention and it not having to get to that crisis point then the relationship should—not always, but you would reduce that breakdown of the relationship at that point so the families would be able to work better in partnership. It is often because it is a response to a crisis and the relationship has broken down.

**CHAIR:** Are you aware of anywhere in Australia or the world where discharge planning and support for carers is done well?

**Ms Walbank:** We both worked in the UK. This is a Yorkshire accent in Australia. As a specialist social worker working in an acute hospital we would actually spend a considerable amount of time working on the discharge planning, particularly for people with chronic issues. The rule of optimism  
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is real. We have practised it for a very long time and it is because we know that we work in a sector that is under-resourced. In those situations where we think a family will cope and the carers are willing, we often assume that to be the case because we do not have enough service delivery to provide. In the UK we spent considerable time working on that. We certainly had lots of performance indicators around that that we had to report on, and equally we had to report on discharges that broke down. If a person returned to the acute setting within a specified period of time, that was considered to be poor discharge planning. We did have a model and it did work to some degree. There is always dysfunction and there is always breakdown.

**CHAIR:** I think if you talk to any nurse—and I am sure doctors would have the same situation—whenever you have a friend or a relative or someone in your acquaintance circle who goes to hospital and gets discharged, inevitably you will get a phone call within a couple of days saying, ‘They told me this, this and this. Can you explain it to me?’ There is obviously a real need for some follow-up support for carers in particular but families as well.

**Ms Walbank:** I took five years out of my career to care for my mother up to her death. I found it very difficult to go from being on this side of the table, that had extraordinary power, to being on that side of the table and to be a carer. Not once in that five years, over multiple hospital admissions, was I ever asked how I was.

**CHAIR:** I certainly echo that experience. Bronwen, in your opening statement and in your submission you talk about this need to move away from a crisis focus. As a clinician, I wonder how we achieve that. In particular from a hospital perspective, our services are triggered by somebody making quite a serious attempt to take their own life. We are triggered by the crisis. Beyond the ambulance and emergency sector, we would not see a role outside the crisis response. How do we move away from that crisis response in terms of trying to respond and manage and prevent suicide?

**Ms Edwards:** I think there are two parts to that. Firstly, there will always be people who will end up in ED. When they do, there needs to be a much more compassionate and informed response. We hear from people every week, and it is a very small proportion of the people we work with all the time who are in crisis and distress, and the vast majority will not go near the health system. Those who do turn up tell us consistently that they are treated as lesser human beings. They will wait anywhere from three to 10 hours and then be released back into the same environment from which they came with no support whatsoever. There are still stories of people turning up to hospital who are being restrained and having security guards put on them. This is appalling behaviour that causes future suicidality.

The response that is made when people do intersect with the health system needs to improve significantly. Ideally, what people with lived experience want—both the people who are in distress and live with suicidal thoughts and the loved ones around them—is alternatives to that system, which is what we are seeing emerging. This model has come out of the UK in terms of safe spaces and safe houses which are non-clinical and peer-led. There is a national safe spaces network in the pipeline that we put forward to government back in 2018, and it is progressing. The states are starting to roll out these safe spaces, but when the funds are funnelled down through the hospitals, it is still deemed to be a system with which people have very low level of trust.

As I spoke about in the submission, it is fabulous to have our mental health services and our hospitals being absolutely enhanced with peers—that is a must—but in addition to that we need to offer people genuine choices so that they can go to a non-clinical, peer-led safe space and be amongst people who have been there before. These people are highly-trained peer workers who are very capable of holding space, very capable of sitting through crisis and then connecting people to the support that they need, be that clinical services or housing, finance, relationship. They are genuine alternatives, and we need to be giving people options and preventing them having to come to an ED, which was never designed for people in crisis. It is not set up that way and it is not doing the job. It is two things that need to happen simultaneously.

**CHAIR:** Could you give us a few more details about these safe havens? What are they? What happens there? How do people find out about them?

**Ms Edwards:** Sure. As I mentioned, the model of safe haven cafes came out of the UK. They have been there for quite some time, probably 12 to 15 years. There are also residential houses. Maytree in England is the best example. It has been open 22 years. It is completely staffed by previous guests and it is a place where someone in crisis can go for up to seven days. People who have made an attempt on their life can go from there into the Maytree model.

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Here in Queensland you have Wesley Mission Queensland, which trialled a three-tier model for the mental health space about six years ago in the Brisbane north region. The idea of a tier 1 is that you equip people such as cafe owners, libraries and pharmacies—just anywhere where someone might be feeling distress while they are out and about and know that if they see that little logo they can go in and they will get a nice smile, a cup of tea and someone who understands.

At tier 2, community centres are trained in suicide and understand how to hold space and have a conversation. Tier 3 is mental health services but they are peer enhanced so that people who have a lived experience of suicide were embedded in their workforce as equals and were able to offer that additional level of support.

We approached Wesley and said that we love the model, but in the suicide prevention space we need to go further. We proposed to Greg Hunt tiers 4 and 5 as an addition to that tiered model.

A tier 4 safe space is one which is completely non-clinical and is completely suicide prevention peer workforce led. Ideally, in the perfect world, they would be open 24/7. At the moment what we are seeing emerge are the tier 3s because of who has been given the funds and who is actually running them. You have peer workers, but they are insisting on having clinicians in there. That is fine for a lot of people, but there are a lot of people who will not go near a safe space with a clinician because of past experiences with the system. That is why we need both.

Your tier 4s will be that very pure model. The idea is that people can come in—no assessments, no triage, no waiting time. It is a warm, welcoming environment and they have peer workers around them. They can stay as long as they like; they can come back as often as they like. They are not going to be called ‘frequent flyers’. They are not going to be forced to go up to ED. There are trained peer workers who can very comfortably and confidently hold space for them if they are in actual crisis. There are a lot of people who use those spaces because they can feel safe there. There are a number of people around the country that I support now, just because of what we do and people we meet along the way. I have people who will literally join up to uni and go to lectures so they will not self-harm in those hours they are in a uni lecture. These safe spaces provide places for people just to be and be safe. Then your tier 5s are those extended residential options as well.

**Mr MOLHOEK:** Bronwen, what was the name of the trial that Wesley ran?

**Ms Edwards:** I do not know what they actually called it, but I can find out for you.

**Mr MOLHOEK:** It was the equivalent of a safe spaces concept?

**Ms Edwards:** It was a three-tier model of safe spaces, yes.

**CHAIR:** You can take that question on notice.

**Dr ROWAN:** I want to come back to the line of questioning from the member for Greenslopes. Dr Wallace, in relation to the inclusion of carers, in a previous role I was a deputy chief medical officer in a large, complex health organisation with the implementation of health standards. From a governance perspective, we have the Australian Commission on Safety and Quality in Health Care with its eight national safety and quality health service standards. There is one a ‘partnering with consumers’ standard. Does there need to be a further iteration of that to ensure carers’ voices are included within that?

There are many times when clinicians are seeing patients with mental health disorders or drug or alcohol problems—even those in aged care—where an intervention takes place or conversations take place. The most pivotal person who needs to be there and included in that information is the carer, because they are almost like the navigator once the person not only hears that information but also is discharged and is going back to a GP and other community providers. Under most circumstances, people want those people included. Sometimes they do not want them included, but that is only because they are unwell at a particular point in time. In those standards, and particularly within the consumer standard, does there need to be further consideration of how carers are incorporated, or a standalone standard, to try and drive some of this within the governance processes of organisations so that the voices of carers are heard and respected?

**Dr Wallace:** I have to be perfectly honest: I do not know if that is an appropriate vehicle or if that is the right place to incorporate that measure, because I am not familiar with that framework. I know from personal experience that—the chair touched on the issue of discharge—you do get a diagnosis and off the person goes, and the clinician sees the patient. We need the clinician or whoever it is at the hospital to do this and also see the carer and link that carer in with I do not know what—an organisation, a phone number, a hotline—because that person, that carer, is affected greatly in most cases. That is what did not happen to us and I do not think has happened for the other carers that I speak with.

**Dr ROWAN:** I am happy for this to be taken on notice. It is really asking the question about whether there is a forcing process to include carers so that they are seen, heard, respected and understood. When you have a large, complex system, what is the mechanism to ensure it is delivered across the system?

**Ms Clelland:** A few years ago Mental Health Australia commissioned a document called *A practical guide for working with carers of people with a mental illness*. It is a very comprehensive guide that has practice standards attached to it. When ARAFMI put a submission into the Productivity Commission we recommended that this was formalised and mandated as practice with clinicians. It is a really easy guide to read, to understand and to navigate for when clinicians are working with families.

The chair talked about consent and somebody saying, 'I don't want to consent to my family being involved.' The response to that is not just, 'Okay, thank you. I'll put that on a piece of paper.' Most clinicians do not do that, but I think some of the carers in the room would agree that that has been experienced. This document gives clinicians a guide as to how to talk to people living with mental illness and the families about regaining consent or maintaining a positive relationship so that they can work together. There are quite a few standards in here they are super easy for clinicians or treating teams in hospital or clinical environments to take on and some nice standards that you can tick off in addition to that.

**CHAIR:** Can I ask you to table that document so that we can have a copy of it?

**Ms Clelland:** Absolutely.

**Ms Tyson:** That was one of the links in the submission, so we should be able to get it to you.

**Ms Clelland:** Does that help answer that question? While there is nothing formally that exists, I think most carer organisations would be supportive of it. It was written and developed with mental health carers. All of the mental health carer associations across Australia contributed to it and it was a lived experience network that developed the document.

**Dr ROWAN:** Is that used by Queensland Health in the public system or in the private sector in Queensland? If not, why not?

**Ms Clelland:** It is not used anywhere. It has been widely promoted amongst all of the mental health carer organisations across Australia. We have pushed it at every opportunity. I think some people fear taking it on formally as there are practice standards in it. Even if you take away the practice standards as an auditable requirement for what you do, it contains nice, easy-to-read information. If a clinician is struggling to engage with a family member or somebody who is so unwell that they are not able to consent or not consent, they can have practical conversations with family to still allow the treatment and support to be family or carer inclusive without breaching somebody's right to consent to not have that engaged.

**Dr ROWAN:** At the moment it would be used as a guideline, as opposed to a mandated standard that has to be followed?

**Ms Clelland:** Yes, but it is not a scary document. It is a nice easy guide with examples.

**Ms CAMM:** In terms of my experience with the system, I have cared for a grandmother in aged care. There is a practice standard in terms of falls et cetera. The experience is that you as the carer and others in the family go home with all of those processes ticked off before anyone is released. Is it your experience that when it comes to mental health that is not the case? How does it compare to a physical illness in an older cohort?

**Ms Walbank:** I think you have touched on the issue here. It is the consent of the person who is receiving treatment at that point in time. We have heard many stories of carers who have literally received a telephone call to say, 'Discharge is happening. They are coming home.' There has been very little consultation. Where carers have tried to advocate that they are included in that process, I know of certain cases where the treating team have problematised the carer: 'The carer is the problem so we will not include them'. The reality is that there are not enough supports in the community for people to receive what they need at the right time, so it comes back to the carer and the caring family. Carers Queensland would absolutely support the mandating of additional guidance that can be implemented across the country. From our own experience, we know that sometimes the best lever for change are those things that are imposed arbitrarily on us.

**Ms Clelland:** We also need to recognise that carers are becoming potential consumers. When they are working together they are seen as an additional support, which is absolutely what they are. You would not dream of not including housing or community psychiatry post discharge, so you should

include the carers in that. Carers are also potentially consumers and they are not getting linked to the appropriate supports for them whilst the person they are caring for is receiving treatment. It is a double-sided issue where they are not getting what they need.

**Ms Edwards:** From the suicide context, there are a couple of things that have just started to emerge. There is the Way Back Support Service which we have in Queensland. In the Murrumbidgee Way Back they have trialled a peer enhancement which we co-designed with Beyond Blue some years ago. They have three peers in that service. Two of them are people with lived experience of suicidal crisis or attempt, but one is a lived experience of family and carer. When someone enters the Way Back after a suicide attempt, they have the option for their carers or family—whoever that trusted other is—to get some peer support as well. It is a different peer, and it is important that it is not the same person who is working with both. That has been trialled and it has been extended.

On the Gold Coast here in Queensland, there is a new carer support service for people who are caring for loved ones who are suicidal. It is the first of its kind. We co-designed it with Wesley and the Gold Coast PHN in February-March 2020. The greatest support the carers are getting is actually connecting with each other and being able to support each other in that way. It is sort of the first thing. In the suicide context, there is nothing for carers other than that crossing of paths. There is nothing to help people know how to keep their loved ones alive. It is the same with bereaved. We have the wonderful standby support after suicide service. There is a peer enhancement of that being trialled in New South Wales now. In Western Australia we are providing additional peer care companion volunteers because there is just so much need. We need to supplement that. There is a lot of opportunity to supplement it with peers who have been in the same place.

**Ms KING:** I acknowledge all of your contributions today; they were very powerful. I can say that I recognised myself in some of them, thank you very much. Bronwen, is term 'suicide lived experience peer worker' a correct term?

**Ms Edwards:** It is emerging, but suicide prevention peer worker.

**Ms KING:** Suicide prevention peer workers, but particularly if we are talking about peer workers who have themselves experienced suicidal crisis. You talked about extensive training for these peer workers. Is there already a training model in place? Where would somebody go to get their training to enhance their ability to provide peer support?

**Ms Edwards:** In Australia, in terms of foundational peer support there is the certificate IV in mental health peer work. There is the option of doing one module which touches on suicide, but it is pretty light on. Then you have intentional peer support, which is another program doing the foundational peer training but not specific to suicide. As a result of that, our organisation has written curriculum and deliver curriculum called 'SP peer worker'. There are a number of variations of that. One is for crisis support. That is for people with a lived experience of crisis themselves who want to be peer workers supporting people in crisis. There is also a bereavement variation. A carer variation is halfway through co-design, and a youth variation has been co-designed for the Youth Aftercare program in New South Wales. That is all that exists. This is a very new peer workforce. The mental health peer workforce has been around for decades, but this is a really specialised contextualisation. Hopefully we start seeing it in AOD, eating disorders and all sorts of things so that you are peer-matching appropriately.

The other really important thing that must continue to be developed is the support that happens afterwards. Once again, we have actually developed organisational readiness training to be working with staff and managers on how to value and work with peer workers as well as individual peer mentoring and professional development group co-reflections. All of that is really important. Most of the time when you look to peer mentor a peer worker, their issues are not actually related to them having a lived experience providing peer support. The issues they are having are with the organisation that they are employed within, because typically peer workers have not really been valued as much as they ought to. It is getting better, but there is a long way to go.

**Ms KING:** Thank you for that. I was hoping to hear about how we can ensure that peer workers are safe through their peering journey, but it sounds like you have covered off on some of that with those structures and processes.

**CHAIR:** I want to come back to discharge planning and management, because I think it is very interesting what we have been talking about here this afternoon. I have been doing discharges for 30 years—and I worked in the same hospital where Dr Rowan was the deputy boss—in public, private and all sorts of environments. Realistically, the systems are geared to tick off a series of boxes and get the person out of the hospital. From a clinical perspective, our job is done: the person is better and is well enough to go home. We are doing a better job of trying to link people into services: 'Here Brisbane

is your GP letter. Here is your medications. Make sure you have your clothes and your valuables back and see you later.’ It would take a major change in the way we manage things, I think, to move in that direction. From a clinical perspective, in this day and age, discharge means that someone else is coming. The minute that person is out of that bed, there is another person coming in. They are acutely unwell and more complex and they take your attention from a clinical perspective, because the discharged person is better and going home and the next person is still in danger of being very critically unwell. Irene, are you aware of anywhere around the world that has taken that step of really significantly changing the way we think about discharging patients?

**Ms Clelland:** I think I can answer your question but, first of all, thank you for your honesty. That is probably the first time I have heard someone in the system be completely frank about the discharge process. That is very refreshing. I think it is really positive for what the select committee will do moving forward, because it means that you recognise that significant changes need to happen in the discharge process.

To do the proactive bit first, there are too many people living with mental illness in hospital. The role of shifting the systems is to significantly reduce hospital admissions and provide more appropriate supports to people living with mental illness in the community. Whilst it is around suicidality particularly, Bronwen has some really good examples of doing that without people being hospitalised. That said, there are people who for their own safety need to be hospitalised.

I am not aware of any specific models, per se, that I could quote, but I know that in Scotland the discharge processes are significantly different. The consumer leads the discharge process. They are the ones at the centre of who the services are and whether or not they are ready to come out. It is not a perfect model, but there are many more opportunities for the person leaving hospital to decide what their transition looks like, including who their supports are, what types of services are available, funding et cetera.

I do not think there is a perfect answer. If there were models that were used around the world we would be talking about them in Queensland or we would be talking about them Australia-wide, but I would like to see it go to the more proactive bit, that we need to stop people being in hospital when they just do not need to be and make sure that community services are more appropriate.

**CHAIR:** I just want to put a caveat on my statements in that I am not a mental health nurse and I have not worked in mental health since the 1980s. The discharge planning in a rehab setting is generally very high and very good, but most discharges do not happen from a rehab setting; they happen out of acute medical wards, surgical wards et cetera.

**Ms Clelland:** That is fair enough. We understand the challenges that health providers in hospital settings have. It is not a criticism of them, but I do not think your experience is much different. We do have very excellent working relationships with most clinicians and treating teams, but I think we all recognise that the system is not serving consumers or families particularly well because it is overloaded in the wrong area. It should not be focused at that peak end of hospitals.

**CHAIR:** I do not if you have had your car serviced lately, but you get at least six phone calls and three emails asking if you are happy after it is done!

**Ms CAMM:** I acknowledge and thank you all here. I can very much relate. I lost my father to suicide and have family members with chronic mental health, so I have lived experience. I think many on the panel share those experiences, so thank you for sharing. I think you speak for those who do not have a voice and who are forgotten. Bronwen, who do you think is best placed to lead with regard to the support and frameworks that you have outlined in your submission? We hear that the response to mental health and suicidology is clinically led, but you have outlined what I think is a really important point: there are many cases of either suicidal thoughts or people with suicidology who do not have chronic mental health or may not even be aware of that. We see in the state of Queensland that it is traditionally Queensland Health, but, when you are looking at other models and more universally where there has been success, who is best placed to lead that? What are those examples where you have seen that leadership—or are we not even there yet when it comes to how we respond to not only those in need but also carers and those in our community? I see a lot of fragmentation across the state. Even in my community everyone is working together, but across three local government areas they are all doing different things and different plans. There is a lot of resource and a lot of will but a lot of fragmentation, and that creates a lot of gaps within a system or a lack of capacity. Can you speak to that?

**Ms Edwards:** It is an enormous question. If we look at the national recommendations from Christine Morgan and the task force which was led by the Compassion First document and what have you, I honestly believe that Australia has the answer in front of us. That report is the first one I have read in my 11 or 12 years in this space that actually makes sense and speaks to what people with

lived experience want to see. It is a whole-of-government approach. This is not just for Health. There is a massive culture change required right across the board. We are actually releasing on Monday a whole suite of resources around lived experience informed and inclusive culture change for service providers, organisations and government departments. Every aspect of government has outward-facing services. All of those services will at some point have an intersection with community. The way in which those services are delivered causes stress. There are opportunities right across the board for to us do everything better.

As all of the national recommendations now point to, this system reform needs to be led by people with lived experience. If you look at Queensland, in some areas—and fairly few areas within Queensland—you can see the pattern of mental health consumers and carers being represented. In others it is non-existent. In terms of suicide, it is completely non-existent. There has really been little to no genuine investment in the lived experience of suicide in Queensland. There was a bit back in 2015-16 when all the PHNs needed to do their strategic planning, but it is pretty tokenistic. It is people with lived experience who need to lead this change. They need to be put into designated lived experience roles, in decision-making positions. We need a partnership with the people who know what they need.

The answers are in front of us. To me, this is an incredibly exciting period of time of potential and opportunity in suicide prevention. Unfortunately, the people in power are still the people who need the greatest influencing, but the answers are there. A lot of what people with lived experience of suicide are asking for are actually peer-led initiatives. There is enormous appetite for volunteering in the suicide prevention space, it seems—more so than in the mental health space. I get that, because mental health consumers and carers have had to fight so hard for so many decades to be heard, recognised and valued, and they have finally got there. There seems to be a big appetite for both volunteers and paid roles in the suicide prevention space. Quite frankly, I think we will need to mobilise an army of volunteer lived experience workers as well, because the need is so huge.

When you look at a 20-year-old figure of 65,000 suicide attempts a year in the country—that is 20 years old, and we know that the level of distress has been increasing—there is a need for really innovative, different, highly accessible support. If you look out in regional, rural and remote areas, the health services are so transient, it is impossible to get into services and you build a relationship but then that person transfers out and back to the city—not a lot of people stay for a long time—so it is very hard for them. But the community stays. If you build capacity of community and you embed people with lived experience and give them the skills then you have sustainable support. To me, it is about capacity building, sustainability, leveraging lived experience and trusting them that they are not vulnerable; they are robust, highly sophisticated, intelligent people who just happen to have had a lived experience of suicide and have an awful lot to offer.

**CHAIR:** Healthcare professionals for the most part are very heavily reliant these days on evidence based practice. Have you had experiences where you have tried to work with people with lived experience who have a very different view of the way things should proceed versus what the evidence might be telling healthcare professionals? How might you deal with that tension?

**Ms Edwards:** Absolutely; over years, yes. The World Health Organization cites lived experience of suicide as being critical to national suicide prevention strategies. Our work has been cited by the World Health Organization as representing best practice. There has been a real shift in the research sector, particularly in the last five years, from evidence based to evidence informed. There now is that appetite, understanding and acceptance that actually what is coming out of working with people with lived experience is in fact evidence. That has really been embraced, I think, through the national recommendations where they are saying, 'These people with lived experience actually know what they need and this is the evidence base that we need to be working on.' Of course, you have to invest in evaluation and research and you have to learn along the way, but too many people are dying to wait 10 years to get some more evidence. It takes forever for it to be translated. We have to be doing things that we know are not going to do harm. Obviously they will be improved, but we have to be implementing, learning and continuously improving, because we do not have time. The sense of urgency is enormous—it has been for years—and it just needs to be understood that the stakes are so high.

**Mrs McMAHON:** My experience with suicide is predominantly as a first responding police officer. Obviously there is a crisis that has occurred. Whether it is the correct response to call police, when someone is threatening, particularly where there might be weapons involved, police will often attend prior to ambulance. Police are often working under the Mental Health Act in terms of their powers—from my recollection, a clinically significant disturbance of thought, mood, memory or perception. Under that guise, police officers will hang their hat on that definition and use their powers to take someone to the local hospital for an emergency assessment, notwithstanding the statistics

that say that only 40-odd per cent of those people are likely to have a mental illness. We are moving towards co-responder models with mental health workers, police and ambulance. Do you have any further guidance, insight or advice on what a first responder component should look like when the job is about someone who either is attempting or has uttered some ideation in relation to that? What is the most appropriate response to that that is able to triage onsite without having to necessarily touch the mental health or Queensland health system?

**Ms Edwards:** It is a dream, and it is coming. The co-responder model is absolutely what people would be seeking. We understand that there are times when police will be called either by someone else or by someone within that actual house. First of all, we need to support our first responders. They really need more support and training to really understand, because they are put in horrific situations all the time. That is one thing. That co-responder model, of a person with lived experience of that crisis or attempt being able to accompany ambulance or police, is ideal.

I realise that all the different jurisdictions have different laws, but I know that in New South Wales, because of all the safe spaces we have recently been implementing, they did go and talk to New South Wales ambulance so that the ambos are actually allowed to take someone directly from a place to a safe place and do not have to drop them to ED. It is about things like that—just removing some of the barriers so that the first responders have more options. With the co-responder models here in Ipswich, where they have had mental health clinicians go out, they have had a significant reduction in ED presentations, which is great for everybody. From a lived experience perspective we would say that is fabulous, but it would be even more perfect if someone with lived experience could be going and meeting that person as well.

**Mrs McMAHON:** I know that in terms of training our first responders ARAFMI used to be involved in regular delivery of training to police recruits, QAS and so on. Does that continue? It used to be the mandatory in-your-own-time, after-hours lecture?

**Ms Clelland:** It does not continue at the moment. ARAFMI significantly was stripped of funding over the past few years for the cash-in of NDIS. We have a very small portion of funding at the moment. We provide quite a considerable amount under the funding that we have, but we still are linked to the police referral service. We do not currently provide the training. We are open to doing that. We might need some more resources to make sure it is not volunteer based and that we are paying our volunteers appropriately for that. We still work with the police on the referrals when people have been in the system and then need carer connections.

**Mrs McMAHON:** I am interested in talking about carers. I acknowledge to the committee that I am a carer for my son. It used to be a paid federally funded position until the eligibility criteria changed. All of a sudden, I no longer need the money to replace the TVs or fix the walls! I am interested in carers leave. You were saying that carers are often people with jobs who are trying to balance the need to be a carer and their workplace. Within Queensland's IR system, a lot of employees have access to carers leave. It is a finite period; it is usually under their sick leave. What could or should carers leave look like? Obviously as a parent you often access carers leave whenever children are sick and home from school, but, if you are actually a carer for a person with a disability or a mental illness, what does a really responsive carers leave system under Queensland's industrial relations look like that recognises the responsibility that do have?

**Dr Wallace:** I will leave it to Irene. I am just nodding in real agreement. That is a great place to possibly look to put it: in carer leave. It is not something I have turned my mind to on a policy point.

**Ms Clelland:** Again going back to the UK model—some of my colleagues will attest to that—the leave model is different. It is heavily subsidised by the government, but it is not a case that you get 10 days leave a year and if you use it you run out. There is quite a significant portion of funding available for people when they cannot work. From an ARAFMI perspective and any organisational perspective, I would expect that employers are open to working with families on flexible working arrangements—if they need leave, they do not need to put in big submissions to us to evidence that they are carers; we take at face value—and that there is the capacity to provide more unpaid leave. I will not give too much detail on this, but we have had mental health carers in our workforce who have considered quite seriously resigning because they cannot balance the work and caring components of their lives, and we have worked with them very closely to ensure they stay in employment. From an industrial relations perspective, there needs to be a significant change to more flexible leave arrangements, whether it is paid or unpaid, and not having to jump through hoops to evidence what that is about.

**Dr Wallace:** We know from research in the UK that a carer will start to disengage from their employment when their caring responsibilities equal to or are greater than five hours per week. They will move to part-time, they will move to prolonged absences, they will go to lower paid positions, they

will move into casualised employment and in some cases they will just leave. The economic cost of a person leaving the workforce is extraordinary. We know that the replacement cost for an employer is more than 100 per cent of the salary of that person who disengaged. Carers Queensland is working actively to support carers to return to work through one of our new initiatives. Today, our estimate of our cost-benefit analysis of that particular program of returning carers to the workforce is \$3.26. For every dollar invested, we are returning \$3.26 to the economy. You are right: the model is very different in the UK. It is certainly more generous and more flexible. It is more responsive to assisting organisations to keep valued employees.

**Mrs Bone:** There definitely needs to be support financially in terms of leave. There is also that flexibility. It really is about the education for employers with regard to what that caring role looks like. For example, if you get three phone calls for suspensions every week, you will need to leave that meeting and you need to pick that child up. It is just that capacity building of employers to understand that you can still meet your KPIs and you can still be a really valued member of that staff team; you just might not be able to do it nine to five. Flexibility and capacity building is so important, because carers are so valuable to the economy.

**Dr ROWAN:** Bronwen, although suicide prevention is a huge area and needs multiple strategies at multiple levels of government, I want to ask about this notion of what I would term a multilayered suicide prevention peer worker framework of intervention that occurs at multiple levels. We talked earlier about co-responders and some of those situations that police officers or ambulance officers find themselves in in terms of having support from a suicide prevention peer worker. When I was in my professional training as a psychiatry registrar, one of the hardest things was when you were on call. You alluded to this before when you said that half the people who die of suicide do not have a mental health diagnosis. If you are a registrar working on a Friday night and someone either self-presents or is brought in by a relative and they are in crisis for a reason—financial stress, relationship breakdown, domestic violence circumstances—what do you do with that person at that point in time? They do not necessarily need to be in an acute bed, but sometimes as a 25-year-old psychiatry registrar you think, ‘Well, am I going to risk-manage them and put them into there?’ That could be worse for their health outcomes. How do you connect this person into somewhere, because they really do not have a diagnosis but they are in crisis and are at risk? It is really around that suicide prevention peer worker as to what can be done. Is it a multilayered framework that needs to be implemented?

**Ms Edwards:** I think this is where the national safe spaces network comes in and where your tier 4s and 5s come in. If you have multiple safe spaces available and you have enough peer workforce engaged, a peer could come to the hospital and accompany that person back to a safe space. The safe space is funded adequately so it does not have to close at 10 pm or 11 pm. It is building that capacity. That is where people want to be—or take them to a residential safe space. That then incorporates helping carers, families and significant others. If your loved one is in a residential safe space with peers and is being supported, the carers get to sleep the night. There is that respite that comes as well. There has recently been released the lived experience peer workforce guidelines through the National Mental Health Commission. It is a great place to start. It did not have suicide prevention input specifically to it, but there is work starting to be done in that space. Yes, it is these alternative non-clinical spaces that need to be everywhere. They have to be scalable and then they have to be staffed.

**CHAIR:** We have had one or two questions taken on notice today. If anybody has taken a question on notice, we ask you to supply responses to the secretariat by the close of business on Friday, 25 February. It is possible that members of the committee will have questions that they have not been able to get to this afternoon due to time constraints. We may furnish further questions via the secretariat to people who have appeared here today.

I would certainly like to thank you all for the time you have taken to make submissions and to appear here today. On behalf of the committee, we certainly want to thank all of the people in your organisations for the volunteer work and caring work they have done over the past couple of years. It has been a pretty tough few years. I am sure it is always tough for carers, but when you throw COVID on the top of that it goes up a notch. We do greatly appreciate the work that you all do. Thank you for the work that you do in the suicide prevention space. It is greatly appreciated. We know that cannot be easy work.

**Proceedings suspended from 3.31 pm to 3.43 pm.**



**CHAIR:** The committee is taking a trauma informed approach to its inquiry. Should this session raise any issues for you, the secretariat has details of a range of support organisations that can assist. I remind all those who are watching the broadcast or reading the transcript that if today's hearing raises any issues for you, please seek support. This information is also available on the committee's website.

**MORTON, Associate Professor Dr James AM, Private capacity**

**MORTON, Mrs Louise, Private capacity (via videoconference)**

**CHAIR:** I invite you to make a brief opening statement.

**Mrs Morton:** James and I both welcome you allowing us as parents to talk to you and discuss the pathway that we have found ourselves on with our son Andrew. I do not know if you know anything about our son. He is a 22-year-old fellow with autism, intellectual impairment and also bipolar disorder.

**Prof. Morton:** Andy has an IQ of about 46. He went to special school at Mackenzie Special School and he flourished while he was there. His autism in an ironic sort of way had become a strength. He is very organised. He thinks ahead. In some ways, his autism allows him to function above his IQ. He had a lot of early intervention and his journey led to forming the AEIOU Foundation, which is a project that has been very much central to our family.

On leaving school and entering the world away from school, under the NDIS he had a variety of providers. The set routines and the organisation that he was used to became very fragmented. In that situation his mental health deteriorated profoundly. He lost a lot of weight. He became an extremely sad figure—from someone who was happy and very ebullient—and he started to develop very aggressive outbursts. We moved into a new house in Holland Park. I am not sure what the local neighbourhood would have thought, but we required the police on four occasions when this boy, who loves his mother more than anyone else in the world, became physically violent to all family members but extraordinarily to his mum.

We had to have the police out on four occasions. On the first occasion it required six policemen to settle him down and the ambulance men eventually to give him ketamine because all the standard forms of restraint did not work. The ambulance then took him off to PA Hospital. There was nowhere else for him to go at that point. That was really the start of our journey. We ended up having to take him home that night, because there was not a place for him. On the fourth occasion he had to be tasered and the police reached for a gun because he hit one of the police. Both Louise and I would commend the police force and the ambulance force for what they did to help us. We were on a fast dial. They came very quickly and they showed incredible restraint and care in looking after Andy—and, I am sure, for other people in this situation.

On the first time he went in the ambulance, the ambulance men commented to me what a common occurrence it is for them to have a person with intellectual impairment who becomes aggressive and violent and who gets carted off in an ambulance to the PA and then there is nowhere for them to go after that. Our journey from there was one of trying to seek health expertise to help him. Andrew has a paediatric psychiatrist that he had since the age of four, Professor James Scott, who is very well known. Eventually my brother, who is an endocrinologist at the Mater, went and knocked on the door at Cathy Franklin's at the MIDAS unit at the Mater and Cathy came out. Cathy has unique expertise in dealing with autism, intellectual impairment and psychiatric disorders. Eventually a pathway led, after trying many medications, to Andy receiving ECT. Getting ECT for him was incredibly problematic and difficult. It was only the fact that Professor Scott had admitting rights at the Royal Brisbane hospital that that was able to happen.

ECT for us was an extraordinary experience, because within one dose of ECT the old Andy re-emerged for a little period of time. It is an extraordinary treatment. One of the things that Louise and I would be very keen to see out of this committee's work is that ECT gets demystified a bit. It carries very negative things with it. There are a lot of psychiatrists who are extremely opposed to it. I genuinely feel that it saved Andy's life. He now gets ECT still on a weekly basis a year and a half later. Whenever we try and do more than a week, he starts to get agitated and aggressive. He is on lithium, escitalopram and risperidone, but with that combination he is happy; he functions well.

I was sitting at home very early on New Year's Day. The first thing he did was change all the calendars in the house, before he would talk to anybody. We have three children; he is the middle of three children. In many ways he is the one I would least want to see leave home, because it is such a happy place with him around, but the journey getting there was very challenging and very  
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problematic. We have every resource available to us in the world. I cannot think of what is happening out there for people with intellectual impairment as a comorbidity to psychiatric illness. What happens to those people who do not have the protection, the support and the connections that Andy had? I might go back to Louise, because I have dominated things a bit, just to give her version of that and what her call is as a mother so close to her son who is disabled.

**Mrs Morton:** What would the committee really like to understand about our plight? What is it that we can say or you need to understand?

**CHAIR:** Perhaps we will go to some questions, and that might help to provide that for you. I have a fairly significant interest in the issues of people with intellectual disabilities and the physical health setting, which is more where I have worked as a nurse. I have also had the great opportunity to work for a number of years with adults with intellectual disabilities and then come back into nursing. I was quite shocked at the lack of skill, understanding and ability of all health workers to accommodate and to adjust their practice for people with intellectual disabilities. Has that been your experience of your interactions in the healthcare system?

**Mrs Morton:** When Andrew needed to first access ECT he was most unwell. As James said before, we were only able to access ECT for him at the beginning because he was so violent. Because Professor Scott was able to have admitting rights to the Royal, I would have to bring him to the Royal as an outpatient in their lockup mental health unit, but I would have to accompany him and stay with him. He would have the ECT and then I would take him home again. That is a very unusual situation because there was no provision or ability to look after Andrew in hospital as a very vulnerable, intellectually impaired, very unwell, mentally ill patient. The psychiatric ward at the Royal, from what I saw, certainly could never have accommodated Andrew with the types of clients that they were seeing at that time. He was just so vulnerable. We were in a very privileged situation in that our private doctor had public admitting rights.

Once he became much better, he was able to access then the Belmont Hospital, which is closer to our home, but that was only after many treatments at the Royal Brisbane because they had the security staff. It took two ex-SAS officers to get Andrew up on a bed to actually give him ECT. He was that violent. He was certainly willing to take on one of them, but when the second one arrived he decided to acquiesce. What I am saying is that he could not have been seen in a regular setting, simply because of his inability to communicate and his inability to consent. I felt quite comfortable doing this and assisting Andrew because I have a nursing background, but that is not everyone's plight. That would be an extremely confronting situation for any carer or parent who has not had the background that I have.

**CHAIR:** Louise, could I try and understand why the Royal Brisbane was not able to have your son as an inpatient? In my experience at the Royal and other hospitals, we have cared for people who are violent. Usually these days it involves one-on-one nursing rather than what we used to do, which was chemical restraints. Why were they unable to keep him in the inpatient unit?

**Mrs Morton:** I think simply there was probably overcrowding.

**Prof. Morton:** Louise made an incredibly pertinent comment about his vulnerability under care. He might be 22 and six foot two, but his mental age is five or six.

**Mrs Morton:** His interests lie with Thomas the Tank Engine and *Sesame Street*. That is really the kind of interests that he has. As you know, the types of patients in a locked-down mental health unit are the sickest of the sick. I feel very sorry for them. Even when I was waiting for Andrew, they were very upset and thought I was staring at them. Heaven knows how Andrew could have managed that setting.

**Dr ROWAN:** Thank you for your submission. The issues you have raised there are very powerful. Certainly the Royal Australian and New Zealand College of Psychiatrists has talked about this being an area that needs particular focus—those Queenslanders who have intellectual impairment and comorbidity when it comes to mental health. I am particularly interested in your experiences and the recommendations around a specialised unit. This really cuts across both disability services and health. Apart from identifying your personal experiences—obviously you have given a lot of thought to this and experienced the system and the navigation of that—should that service be within Health itself or in Disability Services? That is a question around governance when we are talking about a unit like that.

Louise, as you have articulated as well, there are some human rights aspects to this in terms of having people with intellectual disability in those acute mental health units and the vulnerabilities they experience in there. There is also escalation that can happen because of the other complexity,  
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acuity and types of patients there. I am particularly interested in the types of clinicians, the model of care and where it would sit, given your experiences and the fact that you have given this a lot of thought over a period of time.

**Prof. Morton:** I think there is really a stunning opportunity to do something very special here. The chair mentioned that this is actually beyond psychiatry and goes towards general health. These people as adults have often complex medical needs as well. Personally, as a haematologist who works in bone marrow transplantation where we have a specialist unit for Queensland—that has worked very well and that unit is now world-leading because of the size of the population that it supports—I would like to see investment in a hospital getting really good at this.

Our experiences with the MIDAS unit were what changed things for us. The MIDAS unit is a very small service at the Mater hospital. I do not think it matters which hospital, but I do think the Mater is uniquely placed to develop expertise, led through the MIDAS unit, that moves across campus so that culturally across that entire campus ED, medical services and the surgical services have unique expertise in caring for people with intellectual impairment as people—whether their problems need an operation; whether their problems are about monitoring their complex medical needs; when they need an acute admission, an emergency department that is a place where the ambulances can take these people; and when they need admission, a secure place where they are admitted with staff who have expertise in their unique care needs.

I think there should be an investment in a hospital developing that expertise, centred on something like the MIDAS unit, where you have someone with unique capacity who not only trains the next generation of professionals—be that psychologists, psychiatrists—but also implements that expertise and skillset across the entire hospital. There would be training programs in nursing, surgery, medicine and emergency. We could have a place with expertise for looking after these people in Brisbane but then a hub-and-spoke model out into other hospitals around the state.

I spoke to Dr Franklin about this. There are GPs in the bush who have an interest in this area. That expertise can build capacity across a network, and it would be linked to research so that it was made better. That, to me, is the best solution for this. Trying to build capacity everywhere would be extremely hard, but I think building unique expertise that then was broadly shared but focused and hubbed in research is the best solution for dealing with this. I think you could have a service that would be equal to anywhere in the world. It would be a service that then monitored and followed people with intellectual impairment in the community around their general health and their psychological health and linked in with what happens with the NDIS.

We talk about disability services, but that is now the NDIS. Who argues for a package for these people? Who is their advocate when they go to get their supports needed for their package? The NDIS is very complex and difficult and it is still in a frame of learning, but I do not know who argues for a package of support for these people who do not have an elegant family spokesman. We know that NDIS packages are a function of who argues and what they ask for. That, to me, is a solution that I would see well worth investing in.

**Mrs McMAHON:** Thank you for letting us understand Andy's story. My interest is in that transition that he had from that school, structured environment to the big bad world, I guess. We have heard a number of submitters talking about the issue of that age 18 where they transition from a child youth mental health service into the adult service and the difficulty that is experienced. We have had quite a few advocates suggest that youth mental health should be from 12 to 25. Could you talk about Andrew's journey from school? From your submission and what you have told us—and as a parent of an autistic child—there is the trepidation of leaving that safe, structured, routine space. What supports and what options are there available to a young person once they leave the safety of school? What options were there for Andrew, or what would you like to see?

**Mrs Morton:** I totally support it to 25. I believe that is a common occurrence overseas. Certainly Andrew fell off a cliff when he finished school. The special school was fabulous. I had tried to implement more to-taste programs before he finished school. They were just not up to the task. Certainly, the NDIS was in its infancy then so I am sure the services are getting better, but he definitely was someone who could have done with an environment where he went from the special school and was then supported into the community activities that he was about to undertake, rather than it just being left to parents or carers who really are not au fait with this situation. His bipolar came on, which is very typical at that kind of age as well. It was a double whammy.

**Mrs McMAHON:** Can I ask then about your experience with the NDIS? You are right that it is extremely complex, and also when you have a disability—which the NDIS is primarily there for—and you have the intersection with mental health. You made a reference in your submission to NDIS Brisbane

providers not wanting to have a bar of him because of the behaviours he started to display. Where is the NDIS lacking in that area, or is it something where the mental health space needs to pick up this gap?

**Mrs Morton:** The NDIS was very early, and I am sure the programs are getting better. By and large, services for disabled individuals post schooling were really geared around being compliant—more or less not complex-needs people. We found they were usually for people in two groups—very low functioning or physically impaired services—but not for people with an intellectual disability with potential mental health issues as well. There was nothing catering for that.

It was not until Andrew became much better through ECT that he was able to actually re-engage with the community. It is extremely isolating once you have a mental health issue and you are intellectually impaired, because Andrew could not explain or express himself in a way that others could understand. By and large, the people who work in a lot of the post-schooling programs are, like childcare workers, fairly poorly paid and inexperienced in this situation. They were good people but they just did not have the skill set to deal with someone like Andrew or others like him—and he is not alone—so they end up having to just be at home. That is crushing for people. Thankfully, I did not have to get to a job, but I do know of people who have children and the same thing happened and they have ended up having to relinquish their jobs and simply care for these people because there was nowhere else for them.

**Prof. Morton:** Could I make some additional comments—firstly, on schooling. Andrew went to a special school. There is a big push in some areas to shut down special schools; that would be a dreadful thing.

**Mrs Morton:** Oh, yes.

**Prof. Morton:** Andy flourished in a special school, where he did not in a mainstream school. The concept that you can be with mainstream peers and it will all be happy is unicorn theory. Just like sportspeople hang out with sportspeople and people who dress in black hang out with people who dress in black, Andy wanted to hang out with kids who were interested in *Toy Story* and things like that. He flourished in a special school.

Secondly, special school finishes too early. It finishes in grade 12 because that is when the education system finishes. They might give them an extra year. I think there needs to be a real look at the curriculum of special schools, because having a curriculum about learning English and maths is not what is going to help these people succeed when they leave school. They need a curriculum which is about the things they need for life. Andy is still learning. They finished when he was 18—because it finishes when you are 18—but he still could learn. I think special schools finish too early. There should be investment in a proper post-school program. We send our kids to TAFE or university after they have finished school, and I think there needs to be something similar for people with intellectual impairment to build their capacity for the world.

The NDIS really only has the trigger to operate funding ratios. They can fund you to have more people but they do not have the capacity to fund different people. Really, the only trigger they have to offer is to say, 'We'll give him one-on-one staff.' I must say that, once Andy was better, they have been very good. The only place where Andy could go was Bestlife, which is a local program of overnight stays. Through all of this that was his saviour, because the people there were so passionate and they really loved Andy and they made a happy place for him to go to with other young people he knew. Again, I think that was reflective of a program he had done in school and had continuity through school. They knew him and they were able to continue to work with him under the NDIS.

I do not necessarily think the answer is asking the NDIS to do better; I think we probably need to do better with our special schools program and the transition out of special schools into mainstream—like I said, have a college for these people. It is just a different sort of college with a different sort of learning, but it is building their capacity and their ability to cope with that next step in an environment where they are comfortable and where the people know them well and you have continuity. You just have this sudden stop and you no longer have the people you have worked with for years and years. For kids on the spectrum, social anxiety is one of their biggest problems. When you put them in a situation they do not understand and with people they do not know who do not understand their need for telling them the day before what they are going to do and not to change it at the last minute, it is a situation that will cause them to crumble.

I do not think the answer is changing the NDIS. I think it is looking at what we do with our special schools. Like you have said, I think that transition from special school to the real world is something we could do so much better.

**CHAIR:** I hasten to say that I do not think there are any plans to shut down special schools in Queensland.

**Prof. Morton:** But there is always this pressure from academics. There are academics who say, 'There shouldn't be special schools,' and 'It's the right of a child to be with their mainstream peers'—when really the right of a child with a disability is to be in the situation where they are most comfortable and learn best. I sometimes think that in the corridors of academia and such we actually trample all over the rights of people with a disability by trying to create a world which we think is what they want, rather than listening to parents who have been on the journey and have a good understanding of where they are most comfortable and most happy.

**CHAIR:** For several years I ran a recreation program for adults with intellectual disabilities, and the relief families felt when they found something where their young person felt comfortable and accepted was quite incredible. I have two questions. You both have health backgrounds and understand the system reasonably well. You moved between emergency care, some acute care and then into the private system. How did you find the process of navigating between all of those different parts of the health system?

**Prof. Morton:** Could I comment first? Louise is the better commentator, but I just want to comment on the acute-care situation. It was pretty alarming. Andy went to the ED at the PA. He got ramped, like always happens, and then got taken off into a side ward which was where they put people who had psychiatric problems but there was no next place. They found an adult psychiatrist to come and see him, who saw him and offered some advice. We were given some names of private practitioners we could ring—none of whom were prepared to accept Andy. In the private sphere, it is pretty shameful that if someone is complex the private psychiatrists do not want to know about it—they just don't. It is like there was nothing.

**Mrs Morton:** You contacted four psychiatrists, didn't you?

**Prof. Morton:** Yes, because Dr Scott was away at the time, and none of them would take him on. This is a doctor ringing another doctor, so you have no chance. In terms of the private sector and providing pathways for people with complex needs, unfortunately, too much of psychiatry is about people with mild things and investment in that. The real investment needs to be about profound and severe. There is no-one interested in looking after people with profound and severe. Louise might comment.

**CHAIR:** Just before going to Louise, can I ask about that particular point? Do you think that is a function of the fact that the health funds might drive that—not so much in an intentional way, but if you have a mild to moderate mental health issue, there is a fair chance you may have worked for a while, paid health insurance and be in a situation where you have that capacity to access a health fund?

**Prof. Morton:** No, because it was not a function of us having health insurance or whatnot. It is because there was nothing. It is because people did not want to know about it because it was hard—whether there are not enough psychiatrists around so they are all busy, or whether you get the same fee for looking after someone who lies on their couch and talks about their problems at home as you get to deal with someone who is incredibly complex. There is no differential reinvestment for that. In the public sector, there was nowhere to go. The PA had nowhere to send us and they had nowhere to care for him that night. There was no alternative but to take him home that night. There was nowhere—literally nowhere.

**CHAIR:** Can I pose an additional question to you, Louise, and you can answer the previous one as well. One thing I think we would be interested in is whether anybody in the system anywhere asked about your welfare and how you were travelling as a parent, as a carer.

**Mrs Morton:** I will admit that when we left the PA they had a mental health nurse come and visit us at home and they were lovely. They were the ones who actually suggested the names of private doctors we could try, of which we had no luck. We needed that second opinion for Andrew because without that we could not get ECT for him and we felt it was worth giving it a go. So we were desperate. Honestly, I can remember pleading with these nurses—saying to them, 'Do you know anyone? Where can I go?' To be perfectly honest with you, no, there was no support for me, but James and I can support each other. I was all about Andrew. I think it is too much to expect that we would be cared for as well as Andrew, when Andrew could not even get care.

**Prof. Morton:** My wife is an incredibly strong person. She is a uniquely strong person. The real difference occurred when my brother knocked on the door of Cathy Franklin and she came and visited our home. She consulted in the home. That is when we had that second opinion and things started

to move forward. I just do not think you should have to fight so hard to get to that step. I think that step should exist, automated in the system. As I said, we never knew about it; we only found it because my brother works at the Mater and was able to inform us about it.

**Mrs Morton:** Andy just lay in a bed until that time.

**Prof. Morton:** I have a picture on my phone of him in his bed looking sad, with nowhere to go. He was not eating; he lost 25 kilos. It was just a downward spiral. It was not until Adam suggested we try this and we knocked on the door of Dr Franklin—she visited our house, met Andy and spoke with Louise—that things changed. That should happen automatically. If a person with an intellectual impairment becomes unwell and they come to an emergency department, a system should be activated at that point. We stumbled though it to eventually come upon it, but it took ages. There should be a system and an area of expertise that is widely known that is the gate that is opened at that point. It should have been opened on that first visit to the emergency department at the PA, rather than having resources that tried to help us but really had nowhere to send us.

**Dr ROWAN:** From listening to all of those things—the lived experience and the information that carers and parents have—I am not sure how many other Andys exist out there and how many parents are in a similar situation. In relation to special schools and education and what happens in health and employment opportunities, are there any solutions or recommendations from a government perspective—given that you are here today, and it is great you are coming before the committee to voice that—about what engagement needs to happen across government to understand how many Andys exist out there and what is the prevalence of people who are dealing with this? Queensland is a very decentralised state and those people who may exist in rural and regional Queensland. What are your thoughts about what needs to happen with that engagement of lived experience and what carers and parents and others have experienced so they can have input into all of those sectors—whether it be schools, education, health or employment?

**Prof. Morton:** I think there are a lot of Andys out there who do not have parents, full stop. They do not have anybody.

**Mrs Morton:** Cathy Franklin would know a lot about that.

**Prof. Morton:** I think disability is looked at as disability as a whole, but physical disability and intellectual disability are completely different things. They wear the same cap, but the cap of an intellectually disabled person who does not have an obvious physical disability is a very different cap to that of someone who has a physical disability but has a normal intellect. Their needs are completely different. It is a very unfair thing to say but I think much of policy is around physical disability. I do not mean to downplay it and I may not say it very well, but the fix is a physical fix. Intellectual disability is far more challenging. It is not easy to fix. You cannot fix a brain; you have to build processes that are protective and supportive. I think it is an area that is in the too-hard basket.

I cannot help but think that a lot of the solution is by having a centre of excellence. We would advocate that the Queensland government consider creating a centre of excellence in this area. I mentioned interacting with other parts of the hospitals, but it is far more than that. As you said, it is interacting with schools. I am part of the Icon Group. They proudly released their Belonging policy this week and right at the end was 'abilities'. I was talking to the lady responsible for it about whether there are opportunities for people with an intellectual impairment to participate. It just has not been worked out. When we talk about people with autism working, it is IT companies and high-functioning autism. No-one has dug into intellectual impairment and the pathways forward for them because it is very hard. I think the answer lies in starting by having a centre of excellence, investing in it well, creating a hub and spoking from it and having it have a role and an influence in all of the areas you have mentioned, because that is where the expertise lies.

**Ms KING:** Thank you both for being here. Sadly, what I hear from my community, which is a lower socio-economic community in many respects, is that those services continue not to exist for people with more complex intersections of intellectual impairment, behavioural issues and mental illness, which is troubling. Could you please explain more about the MIDAS unit at the Mater? What does it offer? Who does it care for? What do you know about the staffing?

**Prof. Morton:** The MIDAS unit is a very small unit. I think it has a budget of a little under a million dollars a year. It is limited to providing a consultative service, so where there is trouble they can provide a consult and suggest a plan, but they have no capacity for continuity or follow-up. It does not extend beyond that. Its leader trained in the United Kingdom so she is uniquely trained. I have a copy of their submission here. I think their submission does not go far enough. We need to think very big about this. This committee provides a unique opportunity to create a fork in the road. It is a very

small unit. It is housed in a little old building that was the original Mater hospital and it is co-located with another service that was funded by the Queensland government that is a research arm but is unfunded at this time.

The problem is that when you spend \$800,000 you do not get very much. If you spend \$1.6 million you get a little bit more of 'not very much'. I personally think this requires a very big initiative. That is why I come back to the concept of a centre of excellence. I do not know how you fund a centre of excellence. I do not know how that intersects with federal funding about CRCs and that sort of thing. I would like the Queensland government to be very bold and do something that has perhaps never been done before in this space. That changes things. You are right about the demography here. We are wealthy but we are usual. But that provides us with an opportunity to be a voice, which is why we have done this. There is no voice for those people in your community of low socio-economic areas to ask for support. There is no capacity for the people there who have intellectual impairment to ask for support.

**Mrs Morton:** Bear in mind, too, that a lot of intellectually disabled young folk have intellectually disabled parents. They simply do not have the wherewithal to be able to navigate and to also be proactive for their child, even if they wanted to. They cannot be an advocate.

**Mr MOLHOEK:** Louise and James, thanks so much for coming and sharing your story today. Have you come across Dr Harry McConnell from Griffith University?

**Mrs Morton:** I have not, no.

**Mr MOLHOEK:** He has a longstanding vision to establish a centre of excellence around neurodiversity, based on a model in North America which looks at everything in terms of intellectual disability and handicap. I thought you might have encountered him. You have inspired me to get back on the phone and chase him up and say, 'I think it's time to dust off the proposal.'

**Prof. Morton:** I have not, and thank you for raising it. Our involvement is not academic; it is just an experience that we have had. Neurodiversity is an interesting word. We try to make things sound good and I do not think that helps. This is about intellectual impairment. I think it needs to be called what it is so that the people who have it can get help. Neurodiversity—I do not really understand that. We have many challenges with AEIOU because of the broadness of the autism spectrum and the fact that nowadays we diagnose eccentricity or people who think differently or have a certain personality type who really do not have a disability. That is perhaps a little controversial, but this is about the really hard and difficult end and people who really struggle and get damaged very badly as a consequence.

**Ms CAMM:** Thank you, Dr Morton and Louise for sharing. I have personal experience. I am a carer for a 62-year-old intellectually disabled aunty. I always thought South-East Queensland was better placed, but after hearing your experience today I am better informed. Regional and smaller areas have had a community based solution. My grandfather and many others who had a number of children back in the 1970s had to come up with the same solution. I share your sentiments about special schools and the bent for integration into the mainstream. We are talking about very vulnerable people. I am sorry to hear about your experience. Thank you. You are being brave: you are speaking on behalf of so many who cannot.

How does the NDIS intersect with mental health support? It is my experience and the experience of many in regional Queensland that there is a shift to the personalised, one-on-one, individual service structure of the NDIS. While it has created a competitive market and choice for people, has that choice addressed the mental health elements or has that been lacking? For example, I have seen a shift in those with intellectual disability moving to one-on-one support rather than groups, being able to be around those they most relate to. With that comes an ability to connect to others. That also supports mental health and good outcomes and socialisation with their peers. What has your son's experience been with the NDIS?

**Mrs Morton:** I contacted the NDIS very early in this acute phase with Andrew. I said that we need something else for Andrew to do because he is not well, he has some obvious anger issues and he is very fragile. There was nothing. There was no service that they could recommend or that they knew of, other than maybe one-on-one care in our home. That was not really anything different to what I was providing anyhow.

**Prof. Morton:** His care with the NDIS now is very group based. He goes to a number of providers and he cannot wait to get out the door. Functioning well, with the NDIS he has a great life, but when he was unwell—

**Mrs Morton:** No, there was not.

**Prof. Morton:**—there was not anything. There is always this difficulty of who is responsible for what. Where is it a Health responsibility, where is it NDIS and how do the two link? One of the other problems with the NDIS is who they will listen to. The NDIS, in my experience, sometimes actively precludes the health sector. ‘Lobbying’ is the wrong word; acting as an advocate for a person: I think the NDIS does not like that. That has been an experience. Certainly when he was sick it came down to hiring someone one-on-one to try and take him to things. We have a very robust young man who does that, but even he would have bring Andy home at times. It is a really hard one.

For the NDIS to work, you have to get someone well first. We have to have a system that can help these people to get well. Lithium was discovered because a doctor worked in a mental health facility and tried it and it worked. It was part of what helped with Andy, but how many of the people with intellectual impairment, behavioural problems and challenges are getting proper psychiatric input into their condition so that their behaviours are modified? There is that aspect of it. Whose responsibility is that? Is that the NDIS and therapy support to ask for in the package? Is it the health system? How do they interact? There are silos at the moment.

**Ms CAMM:** I am hearing from you that there is not that interaction or recognition.

**Prof. Morton:** No, there are silos at the moment. The NDIS is very challenged. The NDIS has promised too much to too many. The remit of the NDIS is profound and severe disability. That is what the Productivity Commission set up and that was what tier 3 funding was about. I hear from my patients who have diabetes that the NDIS is paying for their lawn to be mowed. That is not what the NDIS was created for. We really need to get the NDIS back to what it was for, which is profound and severe, so that it can invest in these pathways rather than looking at how to save money, which is what it is doing at the moment.

**CHAIR:** Based on some experiences I have had around particularly progressive neurological conditions as well as mental health conditions, the NDIS is reasonably good when it comes to people who have a permanent ongoing disability but for something that fluctuates and changes over time it is not so fit for purpose.

**Prof. Morton:** It probably needs to connect better with the health sector around the changing needs of people. The other thing about the NDIS is that change is slow. You might have a new need, but the NDIS does not have the flexibility to react quickly to what that new need might be.

**CHAIR:** We probably need another whole inquiry into the speed with which governments of any persuasion change.

**Prof. Morton:** What the NDIS is trying to achieve is massive. It is not easy.

**CHAIR:** On that note, we will pull it up there. I would like to thank you both for taking the time to make a submission. It is a very important area that you have highlighted in your submission which is why we wanted to bring you in. We thank you for the work you have done in various spheres over many years but particularly over the last couple of years with the COVID situation. It has made life for health professionals extremely challenging. I would like to thank our Hansard reporters and our secretariat for their support today. I declare this public hearing closed.

**The committee adjourned at 4.32 pm.**