### Final Submission - 23 March 2016

Ingrid Adamson – Responsed to evidencepage 2	
Stephen Stathis – Response to evidencepage 4	
Lesley Van Schoubroek – Mental Health Commissioner 15 February 2016page 8	
Subacute Beds – Questions and Issuespage 8	
Risks associated with being treated in the Community, for young people with Severe a	-
Mental Health Conditionspage 10	
Example – Kids in Mind to CYMHSpage 17	
The Parental Experiencepage 18	
The Complexities of Comorbid Conditionspage 21	
Response to Dr Anne Brennan's Supplementary Statement dated 22 February 2016	Page 22

It is my hope that I can further assist the Commission with the information I am providing in this my final submission, and by raising issues and asking questions that can be considered in the context of the closure and what needs to be considered in the development of future models. I have been very frank in my observations and very open in my provision of personal information. I know I do this at the risk of being misjudged in both my intent and my ???? Everything I state is with the pure objective of trying to contribute in a way the will help young people who have severe and complex mental health problems and their families. Not just BAC young people and their families, but all families who currently struggle with the mental ill-health of their child and all those to come.

Without the frank and honest analysis of how the BAC process was conducted and the frank and honest analysis of the services and systems in place for young people today and in future, I don't know how the service development will ever truly meet the real needs of these young people and their families. I know one criticism I am leaving myself open to is that I am not a clinician. I don't pretend to be, but I have lived this life as a parent of a young person with

. I have met and discussed with many parents, clinicians and others about my child and others in all of that time. I have read and researched widely. I believe I am asking honest, well informed questions that need to be asked. Any system must be responsive to constructive criticism in order to improve and better help those it exists to serve. I am prepared to ask those questions in order that the system can be improved for all.

I intend to respond to some claims and evidence of some witnesses; give some perspective on experience with having comorbid conditions and the consequential experience of being parent. There are many issues I would like to discuss further and witness claims to which I would like to respond, however I have chosen what I believe are the most important that deserve closer examination.

#### 1. Ingrid Adamson

In the cross-examination of Ms Adamson by Mr Fitzpatrick, he questioned her about the parents presentation to the Steering Committee on 4 December. Mr Fitzpatrick states it was a 'very small group'. I am concerned Mr Fitzpatrick was trying to imply the small numbers were from a lack of interest.

to that meeting at own expense.

was going to come from but was unable at the last minute. I asked about teleconference for access but Ingrid told me the facility was unavailable in her email on 25 October 2013. At this stage I only had contact with several families. There was no process for families to have contact with one another. I had come by the contacts with these families via their contact with Alison Earls, and her passing on my contact details to them. It was not possible to have contact with all parents for this reason. Other families may have not had the capacity for many reasons to make a submission to the Committee, or be even sure what the offer to make a submission was about because they had no background to how it came about, but were not put in contact with myself and

others by WMHHS. That meeting was also on a work day, which would have precluded other parents from attending had they been able to contribute.

As for the implication we were presenting for our own children, I completely reject that. and I were **explicit in our purpose** for describing experience of getting to Barrett, and for me providing snapshots of other young people's experience in my address to the committee. It was specifically for the Committee to hold these examples in their mind when deciding on the model of service – to understand what young people and their families had been through before getting to BAC, and to ensure that whatever they came up with in their model, catered for the extreme severity of young people like — these were not average teenagers with mild symptoms or successful experiences of mental health services (See Attachment 1). We wanted them to be clear for whom they were designing their model, if their brief was for extended treatment and rehabilitation services for young people with severe and complex mental health issues – we wanted them to know exactly what that looked like in reality, as many of them may not have had exposure to that level of severity, nor understood what the young person had gone through before getting to BAC – ie. service inadequacy and inability to treat the young person. It had nothing to do about representing our own children for our own purposes. The detail in the parent submission bears out our concern and commitment to services for the whole cohort. The were to show them what had handed to Campbell Newman, and again to highlight as case studies who they were designing services for.

From the summary of the meeting: "I also stated to them that I explained that my presentation focused on making the Committee aware that whilst they have a particular task to do, they are part of a bigger process and that I felt it was important that they were aware of what was happening at the same time as their work. I started by stating that the Committee's work started with and is based on the ECRG's recommendations; that initially the two processes - Barrett closing and a new model of care to replace Barrett - appeared to be linked: one closes, the other opens. It has been regularly stated the alternative would be available in early 2014. I quoted from letters and statements from WMH, the Minister etc to very that. I said that the further the process went on, there seemed to be a gap appearing between the two processes, to now when it seems like they are two completely independent events. I referred to Recommendation 3 that acknowledges the RISK if BAC closes before Tier 3 available: this recommendation states 'wrap-around care' "ESSENTIAL" and that The availability of BAC funds was a "significant benefit". At this stage, wrap-around care is nonexistent, and risk is significant because of that." I don't believe any of that indicates were presenting for ourselves and our own children. I would be very interested to know, what if any questions were asked of WMHHS or CHQ or actions were taken by the Committee after making them aware of this, and of our concerns. Perhaps it was just considered not part of the Committee's remit.

Upon the completion of our presentation, there was absolute silence. There was not a single question from any of the Steering Committee. One person thanked us for our presentation.

#### <u>Under questioning from Mr Mullins about the meeting on 4 November:</u>

"The second issue just relates to the meeting of 4 November 2013. At that meeting, did you make it clear to the parents who were present that the tier 3 service was likely to be the two beds – two sub-acute beds at the Mater or Lady Cilento?---We certainly said subacute beds were a part of the

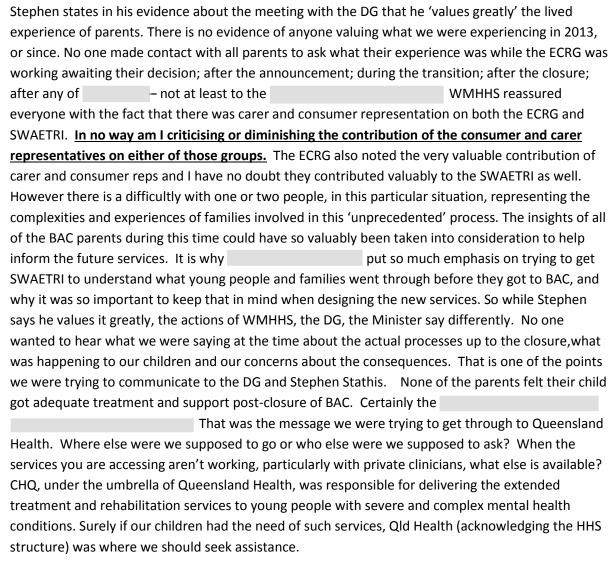
model. We did not confirm any formal arrangements that had been reached or negotiated or discussed. That wasn't our place to do that at that meeting."

There was **ABSOLUTELY NO** mention of beds or any other aspect of the model at that meeting. As I stated above, there was complete silence at the end of our presentation and apart from one thank you from one committee member (Judi Krause may have thanked us and dismissed us as well) there was not one question or comment from any of the Committee about the model,our submission or our presentation. There certainly wasn't any discussion. And in the debrief with Stephen Stathis afterwards, there was no mention of sub-acute beds either – no detail of anything in the model. I knew nothing of any of the proposed components of the model until the meeting at WMHHS on 11 December 2013

Ms Adamson then tells Mr Mullins that she couldn't say who the parents were representing – she would have to refer back to their report, which completely contradicts what Ms Adamson told Mr Fitzpatrick.

#### 2. Stephen Stathis

In his evidence, Stephen Stathis ref	erred to the meeting with th	ie Director General in N	lovember	
2014. The background to this mee	ting was an appeal to the DG	after the	of a young	
person from Barrett . Stephen refe	rs to the concept of a 'thera	peutic community' for	the parents	
being brought up. Our meeting wit	th the DG was not about disc	cussing the therapeutic	community of	
the parents. The contact we had a	nd the communications we h	nad as parents, all revo	lved around	
sharing common experiences that	our children had struggled –	– as a result of	the closure,	
but with the firm objective of maki	ng sure the young people – o	our children, were getti	ing the right	
treatment and support. Had the pi	ocess been handled well, we	e probably would neve	r have come	
across each other, or might have m	et in early 2013 at an inform	nation session, or subse	equent	
consultations. There were	there that night that	t I had never had conta	ct with before.	
H	nad only recently had some o	contact with via text m	essage in	
relation to the ABC's story on 7.30	report. We didn't <u>establish</u> t	this 'community' for οι	ır own well-	
being. We ended up in contact with each other out of wanting to get the right support for our				
children. We did make reference to Qld Health providing a Mental Health first aid course for				
parents as we received no support, information or help from WMHHS or CHQ on how we might				
handle having our children transferred to other providers or home and the impact that might have				
on them and us. I, like other parent	s have paid for my own psyc	chological support in de	ealing with the	
issues presented by comp	olex presentation – all of	ife. I have never sough	t anything	
from the Public System. However	our major focus was very firr	nly on what had happe	ned to each of	
independently during	transition and since the clos	ure, and that included t	the	
the as their parent	s were in attendance at that	meeting. We were ve	ry clear on	
what we thought were the inadequ	acies of the capacity for trea	atment in the commun	ity for each of	
our children. When the community	y resources fail to improve th	າe mental health of yoເ	ır child, where	
do you turn? That is not necessarily a reflection on the quality of the resources, but the complexity				
of the child.				



We had so much we wanted to tell the DG yet such limited time – this was the first time he had spoken with parents. And really I believe it was not out of choice, but because the closure,

the Kotze report, the ABC 7.30 Report story, the report in the news that parents wanted to meet with him, emails from others in the community. I believe this issue had become so contentious that he didn't have any other choice <u>but</u> to meet with parents. Certainly at any other time in the process he could have exercised the choice to meet with parents, particularly when requested to in 2013 before Barrett closed – but he did not.

Stephen stated "- and I wanted to understand the level of pain and the complexities of the issues that they were going through, and the question of a therapeutic community mainly for the parents was brought up, and the advantages that the parents reported in relation to their interconnectedness." I completely reject his statement 'therapeutic community mainly for the parents interconnectedness' was our focus, or even concern as I have discussed. I am amazed that this seems to be the key thing that Stephen got out of this meeting.

Stephen then stated – "I was trying to work out how such a community would be supportive for young people in relation to the whole point of an admission, which is to then transition them back into – their local community." Unless I misunderstand Stephen, I am surprised at how he could think

the young people could not benefit from a sense of community and belonging – young people who are isolated and extremely unwell, who probably feel like they are alone in their experience. In another respect, they are still adolescents – social beings. All adolescents, all people, form friendships across a range of settings – school, sport, work, social club. Sometimes they are discreet friendship groups – there is no cross-over. Just like all of us. Having a friend in one group doesn't mean you necessarily arrange for the groups to cross-over. In some cases quite the opposite. A friend formed in a work group or support group may prefer to remain exclusively in that setting, for the understanding, confidentiality, support specific to the purpose of the group. These adolescents were no different. It didn't mean that they had to be best friends. And they could not – should not – be treated isolation.

With social media, it is very easy to maintain a sense of community after returning to their 'local community'. And the BAC young people have. Just as they would use social media to keep in contact with friends in their local community. Social media is the perfect vehicle for it. Or not – it would be up to the young person to decide whether they wanted to maintain any social connections. The BAC adolescents set up their own Facebook page and kept in touch. They would notify each other or people outside their Facebook group if they were concerned about one of the others. They looked out for each other. Does Stephen and any of the clinicians who report the negatives of extended inpatient treatment know this – or seen any research on this? This shows the capacity for care, compassion, concern – humanity, community. Why would these young people be any different just because they have complex mental ill health? They have organised themselves to meet up with BAC young people from regional areas who have come to Brisbane for a visit – they have met up at

on occasions.	keeps in contact with		
recently when was in Bri	sbane, and when we go to	for	r them
to meet up for lunch and go	to a movie. They keep in contact	in between via social media.	
has picked up o	on a couple of occasions to help	out. There are other connect	tions
and friendships – these are j	ust a couple of examples. I would	say that what they are doing is	very
normal and shows they have	great capacity to cope with the s	ense of community at BAC and	return
to their communities – wher	n they are well. The very confusin	g thing is that nobody asked th	<u>ne</u>
BACyoung people!!! It is ast	counding that this amazing resour	ce that could inform research, p	orocess
and practice, was ignored. A	gain, just like the parents, there w	as no consultation, notwithsta	nding
my respect for the contribut	ion of the consumer and carer rep	os. I would also ask if anyone as	sked
any young people how conn	ected they were to their 'local' co	mmunities <b>before</b> they came to	BAC –
had they had disconnected f	rom friends and social activities th	nan not. Certainly had i	none.

BAC young people had some involvement in the Redlands project process. No one talked to any of the BAC young people, before, during or after the closure or development of new models of care. This process happened to them, most directly, and yet know one sought their opinions, ideas, feelings, thoughts – nothing. I understand the sensitivity of asking them for their opinions, and the possible risks, but again I go back to if this process had been undertaken in a proper, timely, respectful, and well-managed and informed way, I believe that would have been entirely possible. The value of what these young people could contribute is immeasurable. The information invaluable. For those that wanted to be involved, and well enough to be involved, they could have had their own clinically facilitated working group that could have informed the process and the development of new services. Rather than feeling abandoned and that this was something done to them, they could have felt empowered and valued. That was all within the power of the people making the

decisions – WMHHS and Qld Health. They created the very thing they are critical of. They pursued bureaucratic agendas rather than the very genuine ideal of how they could best support these young people through the process of developing a new model of care, that would result in the one place that had given them hope and health. I am not idealising BAC. But for the most part, certainly situation, it was our last hope, and gave the most progress until the announcement of the closure.

The cross-section of opinions, backgrounds and experiences of these young people would give great insight – they were from metropolitan and regional areas; ranged in ages; engaged with public and private care systems; various education levels and experiences; at different stages of their treatment; ranges of disorders, comorbidities, severities and complexities within the range of severe and complex; different stages of recovery and rehabilitation; day patients, inpatients, outpatients. For those in the 'establishment' that claim lack of evidence, there was a virtually endless pool of evidence within BAC – all they had to do was ask. But no one did. Despite their debilitating mental ill-health, and perhaps even because of it, these young people are intelligent, creative, thoughtful, insightful and could have provided the most valuable information of all.

I have some experience in working with young people in groups and some training in group processes/dynamics. I designed and ran an exchange program for disadvantaged long-term unemployed young people. One of the premises upon which the program was based, is that peer influence can be used in a positive way - that people in a group can often be engaged to do things they wouldn't do if on their own. Just as peer pressure can have a negative influence on young people, so can peer influence be used for positive purposes. The young people on this exchange would participate because the others participated, even when they might not really want to, but when they did they enjoyed a positive experience they would have otherwise missed out on. This positive experience then allowed the young person to have a more positive attitude and be more inclined to initiate their own involvement rather than join in because of the influence of the group. It allowed the young person to connect with positive feelings and experiences. I believe BAC was the same. For I know was reluctant to join in early in admission. But with encouragement from others, a sense of camaraderie, friendship – whatever name you give it, joined in and began enjoying the experience of participating alongside peers. Just as at times, when a couple of the young people didn't want to do an activity, the rest often refused also. That is adolescents being adolescents. Much has been made of the negatives of putting these young people together – in fact it was the focus of so much of the evidence given to the Inquiry – Bill Kingswell's characterisation of the 'violent and very difficult' environment of BAC cast it in an awful light. These young people deserve to have fun, feel a sense of belonging, feel part of something just like any other young person. It is healthy to have that and it can promote a positive outlook. I reiterate, the sense of community, if managed properly, could be extremely powerful and healing for young people with severe and complex mental health problems, as I believe it was in the main, for the young people at BAC. It is about the skills of the people and the framework in which they operate that allows that.

It is greatly disappointing that Stephen and other witnesses could not see the positives that were gained by young people being treated at BAC, and that any new model may discount the value of young people being engaged in a 'micro' community in which they can learn, practice and develop their skills and rediscover their interest in social engagement because there is 'no evidence'. The

evidence is there – no one has looked for it and examined it in a project. That is precisely why I put so much emphasis on the research component of any new model, so that research can be gathered to properly inform new services.

#### 3. Lesley Van Schoubroek - Mental Health Commissioner 15 February 2016

In her evidence, Ms van Schoebroek stated in relation to information to parents regarding the closure: "My overriding concern there was to make parents who clearly thought when the Commission was established it would be able to change a decision which was imminent." I wanted did not think the Commissioner could change the to make it clear that decision. What we were very clearly asking her was to assist with the process. The document we supplied to her on 11 September 2013 clearly outlined our many issues with closure, but we very clearly articulated in this document that something she could do was to ask for the process to be delayed: "The Commissioner's role in the future of Queensland's mental healthcare provision is a key one and the reassurance of her significant involvement and her openness to recommending a delay to the closure to ensure that services to this group of adolescents can be consistently maintained throughout any change of model would provide the stability that has, unfortunately, been lacking in recent months."(In support of Barrett document). I very clearly remember asking Ms van Schoebroek about flexibility around the closing date, to allow more time and stability for the young people and if she could assist with trying to make that happen. Her response was that she believed the process (towards closure) was "too far along" for that to happen.

#### 4. Sub-Acute Beds

I had a brief discussion last week with about the Inquiry. The issue of the sub-acute beds came up. He made a comment that in talks with other clinicians and the comment has been made that they don't know how you get access to the sub-acute beds, that if they have client they don't know how to get them into the beds. When I heard the stats for the sub-acute beds, these questions came to mind.

- 1. Who actually knows about the sub-acute beds what promotion as a service has been done since the closure of BAC how clearly has their purpose been explained?
- 2. Do clinicians who have patients who could go there decide not to pursue an admission because they are located in the acute ward?
- 3. Do clinicians try to make referrals and they are talked out of it encouraged to seek other community options by those in charge of the sub-acute beds how motivated are they to actually provide the sub-acute service given that everything in the environment in which they are is about acute care the staffing, the rosters, the support services.
- 4. Has anyone followed up the that were in the beds how long were they there for, what has happened to them, how did they find their experience of being in there?
- 5. I know the school have come across young people that they believe need the admission but the young people can't get in if someone from the commission could contact them Debbie Rankin (principal) and ask about their perspective.

6. How could you get a longer term admission if all the acute beds are full – is LCCH not offering those beds because they know the demand for acute beds requires them to be available for that – and how do you turn away an acute patient? The whole location of the sub-acute beds in the acute ward is problematic for so many reasons.

7. In his evidence, Stephen Stathis said there was no funding for the sub-acute beds. If there was someone wanting an admission, does that mean funding comes from the acute ward's budget? Are referrals being discouraged because of the inability to fund the beds?

Subsequent to writing the above, I looked on the LCHHS website to see what was written about the beds. The following is copied from the website:

"The subacute beds are available for adolescents who require medium-term, intensive treatment and rehabilitation services 24 hours a day, seven days a week, in a safe, secure and structured environment. This highest level of mental health care is aimed at the small group of young people with severe and complex mental health issues, whose needs cannot be safely and effectively met through alternative services. Subacute beds are available at the Lady Cilento Children's Hospital. Referrals to this service are made via a CYMHS Community Clinic.

#### How to access our services?

To access our services, referrals are generally made by a secondary source, such as a guidance officer, general practitioner, other health professional, to one of our CYMHS Community Clinics. Adolescents can also self-refer. Our community clinics have a comprehensive understanding of CYMHS services and other support agencies, and will ensure that all children and young people are offered the most appropriate service for their current circumstances"

#### Further questions arise:

- 1. How long does someone wait for an assessment by CYMHS, for their eligibility level of severity and complexity?
- 2. How long do they wait for an answer as to whether they are 'eligible' to be admitted to the bed?
- 3. Will CYMHS accept the assessment of the treating clinician the clinician who knows the patient as sufficient for admission?
- 4. Does the young person have to see a CYMHS clinician in person or does CYMHS assess the patients file/discuss with referring clinician?
- 5. What do they do, and how long do they wait if the ward is full of acute patients? Stephen stated in evidence that the acute beds were full.
- 6. Are acute patients given priority over those that would occupy a sub-acute bed?
- 7. What support is in place if the young person has to wait for a bed to become available or are they expected to persist with the treatment and support that has been ineffective?
- 8. Which of the acute admissions if any had been waiting for a sub-acute admission

How long does a private clinician or NGO wait to get a young person into a sub-acute bed, particularly if the delay is in the initial phase of waiting for an assessment by CYMHS, before trying to find other options? Are there other options?

Since Stephen Stathis stated that it would be speculation to say that lower admissions were the result of AMYOS or the 'full continuum of care' being responsible for that, I think it would be an **urgent** matter to research and study the referral pathways and referral thresholds for the sub-acute beds:

- where the referrals are coming from
- why people aren't referring
- why does an admission not result
- has the length of time in for acute admissions increased
- are patients staying longer in acute ending up as a pseudo-subacute patient
- are any acute patients transferred to the sub-acute beds if not why not

## 5. Risks associated with being treated in the Community, for young people with Severe and Complex Mental Health Conditions.

Much has been made of the risks associated with young people being treated in extended treatment inpatient environments such as exposure to other young people who are self-harming, allegations of losing skills due to institutionalisation and disconnecting from the community. Are these all symptoms of extended inpatient treatment per se, or extended inpatient treatment in extenuating, less than ideal circumstances – the lack of a purpose built facility with multiple accommodations/campuses that would allow young people to be better separated depending on issues like self-harm, aggression, level of wellness; inadequately staffed that prevents the appropriate amount of OT and other allied health input with young people to facilitate the development of skills; inadequately designed facility that doesn't allow for more independent type living (doing own washing, cooking etc); longer than ideal inpatient times due to lack of appropriate services and accommodation to which young people could transition. How would these risks and perceived 'downsides' be mitigated in a purpose built facility, with a stable, highly skilled and experienced workforce across all disciplines, with adequate and purpose designed integrated services for accommodation and other support for transition from inpatient into the community? Potentially very well. We wouldn't know as there is no evidence, as no such places really exist. But it doesn't mean they aren't an appropriate model of care.

In the community, there are risks also, particularly for this cohort of adolescents. And some of these risks may mean that adolescents end up in the cohort, when they may not have needed to.

1. <u>Turn over of Staff</u>: it is difficult enough locating experienced staff, however anecdotally I am aware of the high turnover of staff in NGO's and CYMHS. Who has studied the rates of turnover in youth mental health organisations and the impact this has on young people? I have heard of one young person who is now on their fifth staff member in a CYMHS. How can this be conducive to consistent, productive care of the young person, when they have the therapeutic relationship interrupted so often – having to tell their story over and over again, and learning to trust someone new with their story and develop meaningful communication with that person?

2. Attracting appropriately qualified and experienced staff: Everyone has to start somewhere, but the place to start is not with an adolescent in this cohort. They need expert clinicians. Not expert in dealing with the average young person with mental health problems, but expert in treating the cohort. Where are those clinicians? With the push to treatment in the community, this is falling more and more to NGOs. It is generally regarded that wages in the public sector are usually lower than in government employment, with career options often limited as well. This compounds the issue of NGOs finding suitable qualified staff and contributing to staff turnover. And we have heard in the Commission that it took nearly 2 years to fully staff an AMYOS team. If the government is having this difficulty attracting staff, what chance do the NGOs have? Are there relaxations to qualifications or experience in order to fill positions in a service? What limits or expectations are there for NGOs to maintain a certain qualification level for staff – particularly those working with this cohort. I am not anti NGOs. They fulfil a very important role within the system. I am just very aware of the limits on them, and the need of this cohort to have experienced, skilled staff to work with them.

The other issue with attracting staff is in the regions. For anyone wanting experience and professional and career development, metropolitan areas are where this is happens. This is somewhat countered by the opportunities for video-conferencing and other technology-based communications but that does not account for the lifestyle and isolation – personal and professional – that can occur being in a regional or rural area. The mere population distribution in Queensland means the majority of this cohort will be in south-east Queensland. Whilst a clinician may obtain some general experience in adolescent psychiatry, psychology or allied health fields, it will still be limited to a small proportion of their caseload in non-metropolitan areas.

#### 3. Recurrent Funding

One of the crucial issues for NGOs is funding. In September 2014, I read an article about a counselling service for adolescents in Rockhampton being ceased because the funding for the service had been withdrawn and redistributed to a service run by Anglicare. (see Attahcment 2). The service had successfully for many years, and had wide community support – it had helped many adolescents. They were a trusted and respected service with significant community connections. The description of their service is as follows:

Carinity Communities Wahroonga offers psychological support and counselling to young people aged 13 – 24 years, with the primary focus on suicide intervention and mental health; to deal with trauma to develop coping strategies for issues such as abuse, neglect, depression, anxiety, bullying, self harm, suicidal thoughts and family relationships. The counselling and therapy sessions assist young people to be better equipped to engage with their peers, their families and function within the community more effectively. Wahroonga staff will assist young people to access services through Medicare's Better Access to Mental Health Care initiative. A small contribution is appreciated but not mandatory to access services.

After reading the article I phoned the Centre and spoke to the psychologist (I cannot recall his name) who worked there. He told me that he was aware of the closure of BAC and was

concerned about similar risks to the young people that were being asked to move from his service to the Anglicare service. His problem was not that Anglicare wouldn't be a good service but that the young people were being expected to change the therapeutic relationships with their treating staff and be expected to develop them with staff at another service. He said the centre and its staff had changed lives and saved lives, yet with a redistribution of funding they were reduced to just being able to provide the services under the mental health care plans which subsidised 10 visits. Previously the service was free. Attachment 2 indicates the service is now subsisting on community contributions. In order to get psychology treatment then, the adolescent would have to go to a GP to get a mental health care plan, to then go to the service. That in itself is a daunting experience to a young person who may be seeking help independent of their parent/carer. He told me the service is well-known in the community, and young people would come there because they knew others who had been helped by the service.

Of great concern is that this is in a regional community – a sizeable one, but with significant youth problems and a limited range of services – no dedicated adolescent acute ward. There is a Headspace, but the psychologist told me they were struggling with the demand, and they too were limited to the 10 Medicare subsidised visits. This is one regional community. How many other places did this happen around Queensland in that funding round, where a successful, valued and respected service lost its funding. The psychologist and I discussed the fact that the funding went to Anglicare – a much larger NGO. We discussed the benefits to the government of rationalising the funding to community services – would there be administrative benefits = cost savings in having more services in that state run by fewer organisations? Only the government could explain that. Certainly there wasn't any explanation that he or I could come up with that warranted the removal of their funding.

It must be incumbent on those who determine funding to not only look at the bottom line when making funding decisions. There were young people whose lives would have been majorly affected by the cessation funding to the service. Yes they were given a 'transition' time, but did anyone follow up to see if they disengaged from treatment, did they continue and then drop out of Wahroonga when they used up their 10 Medicare visits? Did they present somewhere else? Were there any suicides of those clients? If no one did, why not? These are the very kind of questions that need to be asked – the research that needs to be done to determine if policy and practice is working and not detrimental to those it is supposed to help. These kinds of decisions have massive ramifications. The are like ripples in a pond – with potentially far-reaching consequences.

4.	<b>Frequency of Treatment</b> : By the time a yo	ung perso	n moves into th	ne severe and	d complex
	category, they need immediate and inten-	sive clinica	l input. It shou	ld be argued	that they
	required that before they got to that leve	of illness,	however there	are constrai	nts in the
	community that prevent that happening.		xample, of tryi	ng to access	
	CYMHS, whilst a little out of the ordinary	as were	e outside the se	rvice bounda	ary, once it
	was approved at executive level, which to	ok nearly 3	3 weeks, still on	ly resulted in	n an intake
	appointment over 2 weeks from approval		was having		was
	incredibly depressed, was having difficulty	talking to	psychiatrist	I didn't ex	pect special

CYMHS and other services on a normal basis. I know of one young person that has a 3 month wait for potential support from Open Minds. Then when these adolescents get an appointment, how frequent are they? The great benefit of BAC was that for these very unwell young people, the treatment and rehabilitation for them when an inpatient was 24/7. If there was a problem, a distress, any need, the support was there instantly. Even as a day patient, had the capacity to stay back on the ward to receive support or attend an outing. could have gone in on a weekend if wanted to or needed to. Unless treatment gains are consistently and regularly reinforced, particularly at difficult/crucial points in treatment, gains can be lost or compromised. For young people not in this cohort, the frequency of access to treatment and appointments needs to be examined, as complications and the worsening of their conditions could be due to the infrequency of their treatment.

Dr Graham Martin, in his evidence, described another aspect to the frequency of treatment and treatment in the community: time. A young person may get better accessing treatment in the community, but how long does it take? Does the cost of inpatient treatment offset or match the cost of what could take 2 years to achieve in the community? Not just the financial cost – the toll on families, the disruption to the young person's education, the stagnation of their development, the utilisation of other services. A comparison such as this should be made if a true examination and comparison of the merits or otherwise of treatment in the community is to be gauged. The risk of the disengagement of the adolescent form other aspects of their lives and their treatment must be considered in the time taken to treat and rehabilitate in the community.

5. Normative experiences: There was evidence given about the normative experience of adolescents, and that being an inpatient at BAC, attending BAC school was not regarded as a normative experience for the BAC cohort. It is normal for an adolescent to attend school, go out with friends to the movies or other social activities, play sport, go to the shops and any number of other normal activities. did none of those **BEFORE** he went to BAC. In my statement I detail the lack of any contact had with peers – none in over 18 months, and little for at least 6 months before that. was physically at school prior to home schooling, but experience there was not normative. had no social contact with peers outside school. Some other adolescents from BAC had similar isolating experiences. Spending nearly every waking moment in your room is not normative. Harming yourself is not normative. Having suicidal thoughts is not normative. Normative is relative. Nobody asked the BAC cohort about their feelings about being at BAC, amongst others like themselves. I'm sure all of the range of teenage behaviours were present: arguments, forming allegiances, isolating others, pushing boundaries – the good, the bad and the ugly. The difference is if not in BAC, most of these young people would not have had any social contact at all. It was about how it was managed. You cannot protect young people from everything, nor do you intentionally put them in harm's way. They will have positive and negative experiences in any environment – their normal school or home environment. It gave me the greatest joy to hear talk about things did with the other young

people at BAC – outings, activities, a joke someone told, a prank someone played on another. had something to talk about for the first time in nearly 2 years. was engaged, was participating. And so were the others. did and said things in exchanges with peers and staff that were wrong partly due to inexperience and lack of skills, and because was testing the limits of these new relationships. These situations were managed skilfully by the clinicians and staff who worked with was given skills, tested them in the group, was encouraged if it didn't work out well, was redirected if did something inappropriate and given another chance to engage appropriately. In a normal social group such as at school, may have been the target of bullying, exclusion or worse for the things said or did when was testing out functioning in a peer group, such as did at Barrett. There would have been no support or guidance for this until after the event, if at all, and the consequences of bullying or worse could have been further isolating or damaging. These young people have been so disconnected for so long that they have sometimes lost, or failed to develop the skills they need for basic social interaction, let alone to function in broader society.

BAC school was different to other schools in that it was co-located with a mental health treatment facility. The school supported some young people to transition back into a conventional school. That was the ideal. Others like needed to maintain their connection to their education via an individual program at BAC school. participated in the group activities run by the school such as camps, community visits, visits to employment and training options. So did many of the other BAC cohort. They were in this school because they could not access or function in the normal school environment due to their illness. To call that not 'normative' is too simplistic. Is that to say that a young person who attends a special education unit within the grounds of a 'normal' school, is not getting a 'normative' experience? Is the hospital school attended by an acutely ill young person a 'normative' experience — I would argue not. But the circumstances demand it — just as the circumstances of these young people demanded access to education in some form — in fact there is a legislative requirement for the Department of Education to provide for these young people, just as any others.

To just say that the experiences of young people in BAC was not normative is a gross over simplification, and fails to acknowledge the limitations that were placed on them by an

administration that didn't want them there, people within the Health system who were ideologically opposed to the model or judgemental about the kind of 'badly behaved' young person that was there and the fact that all other treatment options had been exhausted — there was nowhere else that could treat and rehabilitate them. I would ask any of those people to walk in the shoes of these young people and their parents, and then make such judgement on the lack of 'normative' experience at BAC, and the torturous lives they led before accessing BAC.

6. The need to leave home: Dr Michelle Fryer gave evidence that she believed the BAC cohort could have been effectively treated in the community with the current suite of services, including in particular AMYOS. I am not a clinician, but from a parent's perspective, I honestly believe needed to leave the home environment in order to achieve changes behaviour and to get the kind of intensive experiential treatment and rehabilitation such as received at BAC. To have someone coming to the home to see only reinforce position to not leave the house. That is not to say that AMYOS would not be suitable for some young people. Maybe if AMYOS had been available earlier in deterioration, they might have been helpful, but it is a risky generalisation to make to say the service could have treated this cohort of young people in their own home. What about those outside the Brisbane metropolitan area? AMYOS is not an option yet for so many communities. What about waiting times, what happens when AMYOS says there is no more they can do for your child - what are the options then? I am not against AMYOS. I am completely behind early intervention and any services that can treat young people and prevent them from deteriorating into the realms of severe and complex conditions. But what is the contingency, the fall-back position? Where is the consultation with young people and families about what they want, what would help? It is the hardest thing to admit how much relief I felt when was finally admitted to BAC. Firstly because finally I felt would be getting the kind of treatment needed – that was my absolute priority area of concern. But I needed respite, and there was nowhere to get it. would not even go and stay at because of anxiety. I know and I know change would not have occurred had been treated from home.

For other young people they must leave their home environment because it may be the cause of their trauma – abuse, neglect or other extenuating circumstances, including lack of acceptance of and support for the young person's mental health condition. In smaller communities for example, everyone knows everyone. I know of a young person who was known as nd admissions to the acute ward. Young people can be cruel and judgemental and the stigma against mentall ill-health can be worst amongst peers who don't understand. To remain in that community would be subjecting that young person to the daily constant negative and destructive attitudes of her peers and the broader community and potentially undermine any positives from whatever treatment she was receiving. How do the current services available to young people address that issue?

#### 7. Medicare and the 10 visits under the GP Mental Health Care Plan

I am incredibly aware of the fact that we live in a society that has the kind of supports available such as the Mental Health Care Plan. The difficulty is that those 10 subsidised visits can be gone in 10 weeks. There are limits on what you can claim under private health insurance. That means in a relatively short space of time, there is no support to assist with the treatments for your child. I made this point very clearly to WMHHS before BAC closed; parents raised it with Stephen Stathis and the DG in their meeting. No response. I wish to make very clear, this is not about asking for handouts or expecting someone else to take responsibility for our children. This is a bigger issue than in the BAC community. Mental illhealth is, I believe, the only illness where there are limits put on the support you can get. If your child has cancer, the government does not say "we will fund you 5 chemo treatments for your child, then it's up to you to pay". Indeed, they would never have closed the cancer ward. Diabetes, Cystic Fibrosis – any number of other chronic illnesses, there is no limit on the hospitalisations you can have or the number of times you can see the specialist. I am talking about very, very unwell young people, who consider taking their lives - have taken their lives. Untreated, or not treated adequately, and the risk is that this level of mental unwellness will persist into adulthood. We are told to get treatment in the community – NGOs, CYHMHS, private clinicians. I do that. We tried CYMHS – I don't believe it was right It wasn't a personal aversion to the service – I found a clinician with specialist expertise in . . . CYMHS could not provide that for . . . Neither CYMHS nor other NGOs will be all things to all people. What do you do though when you when your child needs more than what the system allows for or that the system can supply?

I stated this was a bigger issue than just BAC. In one of my documents I quoted Sam Mostyn from the National Mental Health Commission who said one of her objectives was to get parity for mental health with the general health issues. Professor Patrick McGorry regularly raises this issue in relation to funding for mental health care. Medicare is a federally funded system. I understand that. But young people with other chronic health issues don't miss out on the level of treatment they need because the funding comes from a particular source. It is very easy for the government to say it's not their responsibility. In the meantime, young people and their families struggle. I couldn't count — wouldn't want to count — the thousands and thousands of dollars I have spent out of pocket. I do not have a welfare mentality. I have gone without plenty to afford to pay for the treatment and associated requirements needs. That's what you do as a parent. Some people would have less capacity than I to afford the treatment. And then it is more than about cost, it is about whether the treatment and supports are actually there.

The complexity of the Mental Health Care Plan (MHCP) is also an issue. Recently we asked for a new MHCP as it was the new year. I believed the plans were for calendar years. The number of visits are actually based on the calendar year, but the plans are based on 12 months from when the original plan was written. In order to generate the extra 4 visits after the initial 6 the plan provides for, you are required to do a review with the GP. We did this last year and got the extra 4 subsidised visits. At the beginning of this year, I arranged to get a new MHCP for The GP advised he couldn't write one because it was inside the 12

months based on the date of the original one. SO he did a review which generated 4 visits. I to get the new MHCP done - the GP couldn't do it because you can't have then took a new MHCP written inside 90 days of having a review. So another visit with the GP is required in April to get the new MHCP. This then will generate 6 subsidised visits. will then get no more as got 4 with the review at the beginning of the year, then the 6 will get with the new Plan will make 10 in total. That will mean that by mid year, is likely to require intensive exposure therapy that will subsidised visits will be up. require 2 psychology visits per week. That will mean those 6 subsidised in 3 weeks. Then they will be gone for the year. The recent worsening of condition means that if a place at the Resi becomes available, will be too unwell to take it up as has to have that intensive treatment. But along with that needs more OT. Now because of recent drastic weight loss because of needs a dietician. This week I took to get a GP extended care plan. This provides for 5 subsidised visits with allied health. We used the 5 visits for 5 sessions with an OT last year. When about to write out the plan the GP advised we could not have a new plan because we had used the 5 visits on the last plan. I again thought that it was based on calendar year. It was not. The plans are for 12 months from the date on the plan, even though there is an allocation for 5 visits in a calendar year. So they wrote up a review, in the hope that it would trigger 5 more visits, but that will still be all will be able to access in 2016. Which will leave nothing for OT treatment. How would pay for all of this if was independent of me? How long would wait to get access to psychiatry, OT, Dietician, Psychology, in the public system now is an adult, by age? The complexity must force some people to give up. Certainly

is not capable of managing any of this on own. Nor other young people I would

#### Example - Mater Kids in Mind - CYMHS

think.

I wish to provide a real example of seeking services. This is the experience of who has . I have permission to provide this example. In around 2013 rought to Brisbane to undergo through testing at Mater Kids in Mind. had Speech, OT, Psychology assessments. had very difficult behaviours as a result of comorbid conditions. where services are extremely limited, certainly for someone with presentation. They were already seeing a paediatrician in Brisbane at Kids in Mind who was responsible for medication. We took video of one of the 'meltdowns' in order to show the Psychologist what some of this behaviour looked like, as presented well – smiled nicely, was polite when engaged with adults. Most people could not behaving any other way. The psychologist viewed the video, said thought it looked like conduct disorder but was too young for that diagnosis. She told to go to . They would be able to do family support – visit home, help with behaviour and routines at home, provide the range of therapeutic support. thought this sounded amazing as they had struggled for so long with difficulties. They impacted significantly at home on the family and on education and peers. had a couple of meetings with a very nice lady at the CYMHS office. On the 1st meeting was so excited to meet with them, as said it was very rarely that someone walks through the

door actually searching for answers and help for their child. Normally people have been sent there

from the courts or the school has forced them to go there. On the second meeting didn't tick 2 boxe: being suicidal and wanting to hurt people. She was sorry but they
weren't able to help them, which really disappointed the lady because thought would have been an excellent case for team to work with. That is despite being shown a video that showed very distressing behaviours.
This highlights the referral thresholds that exist for services. I understand the need for these but this was struggling, as was family and extremely difficult to manage. And Kids in Mind thought that service could be provided. Yet could not get access to the service. I recall Peter Steer telling me that he had been considering a change to CYMHS where the service considered what they could do for the child, rather than the child fitting the criteria. Has this been done? Just because a service is there doesn't mean it is accessible. Even more crucial in regional areas, as there are such limited alternatives.
The Parental Experience
I haven't really referred to how condition has affected me as a parent. It's not something I
do readily, but for the sake of all parents in similar situations I believe it is important to discuss. As I
stated in my evidence, I believe there is a stigma associated with being the parent of a young person
with mental health problems (in this case severe and complex, however I believe it would apply to mental health problems generally). I have experienced it and most parents I have spoken to report
the same experience – not just parents from BAC. It seems the very immediate assumption that the
child's problems are a function of your failure or ineffectiveness in the role of parent in some way. I
have worked in child protection so I am very aware that abuse and neglect occurs in families, but it is
not the majority of families. I understand the need for it to be considered or ruled out. But it seems
the failures of the parent is the first port of call. I would never profess to be a perfect parent – far
from it. I don't know if there would be a harsher critic than the parent of a young person with
mental health problems. I remember saying to the paediatrician that diagnosed who was
astounded at my calmness in the initial interview, where was punching me, climbing on me,
trying to disrupt the consultation, that I was not like that always. That like anyone I had limits, and
some days I got angry about behaviour and yelled and got frustrated. He told me he was
glad to hear me say that, because I would not have been normal otherwise.
As a parent – you put your child first, above everything else. and I did everything we
could to minimise the impact of even more-so because had and
and other conditions. We spent every Christmas, Easter and some holidays
with other family until was around wasn't put in a position where
had to choose who would spend the time with or someone else decided who would spend
those times with. There was never an argument in front of and neither of us said negative
things about the other, for benefit. I always did everything that psychologist advised,
even if it was hard and went against my instincts as a parent: I didn't buy certain food for in
order that would be forced to go to the shop to get it if wanted it, as was so avoidant to developing independence. To then have clinicians insinuate or assume, that difficulties are a
function of your parenting is offensive, degrading, humiliating. No one actually asks how do the
, , , , , , , , , , , , , , , , , , , ,

difficulties that your child has affect you and the functioning of your family? That is not to blame my but to just state that the dynamic in a family is hugely affected by any illness – in this case it is

mental ill-health, with the added complexity of it occurring during your child's adolescence and all the issues and difficulties of that period of development compounded by the mental ill-health.

was unlike some other young people who have mental ill-health appear in their teenage
years, after relatively normal childhood functioning. Having
behavioural difficulties were apparent from very young age. The majority of childhood was a very
difficult time, managing difficult behaviours and trying methods to improve functioning. The
period of time just before went into Barrett in February 2013 was one of the worst times of
my life. The life that was living was not 'life'. barely left the house, did nothing, had no
friends, could barely do schoolwork and was becoming increasingly agitated, distressed and
difficult to manage. The impact on my life was immense. I had stopped working in order for to
do home school. Instead of home being my retreat, my haven, it was my prison – as it was
prison. There were days I had to leave the house to retain the last scraps of my sanity. I say this in
no way to attract attention to myself, but to describe the toll it takes on a parent. I could only be
away for relatively short periods of time as I was concerned about behaviour, and I was
supervising homeschooling. I recall one bad day: I went to Indooroopilly, our local shopping
centre, and had to sit in the Library as I left the house quickly in tears and distress due to
behaviour and our situation. I could not face the increasingly frequent argument of starting
schoolwork for the day and associated complex avoidant behaviours surrounding the start
to the day. I grabbed my phone which was nearly flat, so I had to sit in the Library at Indooroopilly
before I could do anything else so I could charge it, because if became distressed, the plan
was always for him to phone me. Once it charged, I sat in tears in the Coffee Club because I didn't
want to go home and face what our lives had become. Other people would talk about their children
being anxious, or having difficulty getting organised – "all teenage" have difficulty with
organisation" – but none of it was at a level experienced by  The level of distress and
problems was beyond most people's experience, and whilst they commented to be sympathetic,
they could never understand the extremity of the problem and the 24 hr nature of being the parent
of a child with severe and complex mental health problems. And . Getting out of bed every
day was hard – I faced the same problems every morning. The problems lasted all day and didn't
stop until went to bed at night. Sometimes would come to me in the middle of the night with a
worry or distressed. I didn't sleep well, and sometimes the sleep I did get was disrupted. even
stopped going to for weekends due to anxiety about getting sick, so mostly I got little or no
respite. medication and strategies gave no little or no reprieve. It was like had
stalled, and the anxiety over-ran every element of thoughts and functioning.
It is extremely isolating . If you do have an invitation somewhere, the issue is whether you actually
have the energy or motivation to go. If was more unwell and it didn't feel safe leaving
for too long, that was another reason not to go out, or go for long. Every day is like groundhog day.
To feel like nothing was ever going to change; that was never going to improve is the most
depressing and distressing thing. To be constantly worried about future – what work will do, will ever work? Will ever have a friends – 1 friend? You learn to set your
expectations very, very low. How do you answer your child when they ask if things will always be
this bad, when at that time, you believe they will? You lose hope and despair for future. You see
other young people working in shops, with their riding their bikes, going to a movie –
everything that normal teenagers do. And your child is not doing it – can't do it. Again this is not
about me – it is about despair for What was missing out on. The fun wasn't having.

The growth and development that wasn't happening. I knew what life was like – it was awful and I wanted so much for to have so much more.

My thoughts on high school years were that I would consider it a success if made it through to the end of high school without having been bullied. If was happy and self-esteem was intact I would be happy beyond words. I only wanted to do best – whatever marks were, were enough. If ended up sweeping the streets for a job, but was happy, it was enough – and I would be happy for I had no expectations other than that had a go and tried best at whatever did. didn't make it past year 10 at school. In the circumstances we found ourselves in, was past trying. The anxiety had nearly completely incapacitated was miserable, depressed, frustrated, angry, desperate. The one thing I most wanted for — to be happy —

seemed unachievable. A simple hope. The grief I felt for and what I life had become weighed

heavy on me every minute of every day.

As a parent, you feel powerless. Angry. Frustrated. Like a failure. Hopeless. As a parent your job is to nurture your child; guide them through life; help them learn to navigate hurdles; sharing with them the joys of life; letting them experience all that life presents, the good and the bad. life had never really been like that, and before went into Barrett it was awful. To know you have brought a child into the world and they have found most of every day tough and challenging; found simple things difficult and things other kids take for granted out of their reach – and for their lives to get even worse, makes you feel guilty for bringing them into the world. The hardest thing is that you can't help – it's not a scratched knee you can put a bandaid on, or giving a cudde to ease hurt feelings or disappointment. There are things you shouldn't do, can't do, told not to do. You can't make it better. When clinicians can't assist – when they have exhausted their clinical bag of tricks, it is the most horrible feeling. To be told by 'the expert', they don't know what to do next. To see other clinicians, and feel like they think you are somehow responsible. All relationships are a dynamic, and no one is perfect all the time. But with mental ill-health, particularly when some of it is chemical, neurological in nature, there seems a particular lack of understanding or recognition of the demands, costs (physical, emotional, mental and monetary), tolls, effort that is put into their child by the majority of parents, the changes that take place in the household and the lifestyle to address the difficulties. I don't want recognition for anything I have done. It's the responsibility I assumed when I became a parent. I love my more than anything and I would do anything – have done whatever I can for I will continue to do whatever I can but there is a cost – something I bear willingly - but still a cost. The cost is enormous: my mental, emotional, physical health; my capacity to contribute to the community and work; limitations on my earning capacity, my super and therefore my capacity to be independent of welfare in my later life. That this is what comes with having a child with a such complex ongoing problems must be recognised by clinicians, the bureaucracy, the health system, the Government: I don't meant for me – I mean for all parents. Barrett gave the chance to have the right amount of intensive treatment and rehabilitation. It gave me respite and relief that there was something else that might help. I have never asked for handouts. I dislike asking for help - I am proud and independent. I don't like admitting failure - I am always looking for other ways things can be done. But my experience as a parent of someone whose mental ill-health is all-consuming, is often that I despair for future, just as many other parents do for their children.

I was painfully aware from very early on because	ause has	that one of my major r	esponsibilities
was to do whatever was necessary to allow	to reach	maximum potential	for functioning
in society. I have done everything I can to tr	y and prepare	and connect with	n the right
support so does not become welfare depe	endent, not only	for society's benefit, bu	ut for own
identity and sense of independence and self-	-esteem. is o	n a Disability Pension, a	nd the reality is
may never be completely independent of	the welfare syst	em. may in fact be	completely
reliant on the welfare system for the rest of	life. There is r	no shame in that, but it	will not be
because I did not try to give every oppor	rtunity. That brir	ngs with it the worries o	of how will
support into the future. It is my most	t desperate hope	that can conqu	ier OCD and
anxiety, or at least learn to manage it so it do	oes not complete	ely disrupt life. But	will always
have ASD and that will always impact life	to some degree	<ul> <li>I am hoping to a lesse</li> </ul>	r degree as
gets older, matures, and hopefully develops	the insight into h	now it affects and	interaction
with the world. As for any parent whose chil	ld has a disability	, your own mortality be	ecomes a very
prominent part of your thinking.			

So this is a parent's perspective – my perspective. I am painfully aware that this experience is common to other parents of young people with severe and complex mental health problems. I hope that in some way, sharing this information can help increase awareness of the impact on parents, carers and families.

#### **The Complexities of Co-morbid Conditions**

I give the following information aboutto you o	nly as an example for the Commission of how
complex conditions can become.	
We saw psychiatrist last week. is now bor	derline for a medical admission to hospital –
according to criteria for	not because has but because
h	as compromised physical condition
because it has reduced food intake. has now los	t more weight –
3weeks since our last visit. T	he psychiatrist said his has
now become secondary as we must focus on increasing	quickly or will need to go into
hospital to achieve that, potentially via a	This would be a general admission to an
ordinary hospital, not an adolescent acute ward. ph	nysical condition is now compromising
cognitive capacity so does not have the mental capa	acity to apply the strategies for addressing the
and the impact they are having on	functioning. I have been advised to now
engage a - I need to get an Extended GP Heal	th Care plan for that (which I have arranged),
and visit the GP weekly for	until next appointment with the
Psychiatrist on 12 April. That appointment time is only	a half hour appointment and we are waiting
to see if a cancellation comes up on 8 <sup>th</sup> April so	can have the regular hour-long appointment,
which is the psychiatrist's preference. So even in these	e circumstances we are really at the mercy of
appointment availability when it comes down to it, and	not when is the most appropriate time for
to have a consult. That is not a criticism of the	Psychiatrist. She has been excellent. It is a
statement of fact based on her availability and the nun	nber of patients she has to see.

would be currently too unwell to take up a place at the Youth Resi at

was to be offered a place. Regarding th		_		
application, and then how lon	ng it might	be before a place	was available for	is
dependent on a young person moving of	out of the	Resi, unless they h	nave a current vac	ancy. I am
extremely grateful for the possibility th	at	may be able to go	there, as my und	erstanding is a
young person normally needs to be a C	YMHS clie	nt.		
has not responded to the treati	ment h	as been getting fro	om the Psychologi	st and
Psychiatrist. That is not a criticism of or	reflection	on them in any w	ay – merely show	ing the
complexity presents as a young	g person w	ith a dual diagnosi	is —	
multiple mental health conditions:		) and the la	ck of other resour	ces available to
private clinicians who seek to help their	r complex	patients. As yet	still has had no r	elief/support
from medication – has now tried	l several –	and an extra med	ication has been a	dded in to try
and calm with	the added	d benefit that it wi	I increase appetite	e hopefully,
which should help try to		wants to tr	y and	at home rather
than a hospital admission. Obviously th	nat is the i	deal, and it keeps	control over what	happens to
with As a parent however, the	re is the co	onstant line you w	alk between want	ing your child to
maintain control over their circumstand	ces and tre	eatment, but know	ing that the very	nature of their
mental condition may not be optimal for	or them m	aking such decisio	ns, which I'm sure	clinicians
balance as well.				

#### Dr Anne Brennan's Supplementary Statement dated 22 February 2016

Re: Para 121 of Ann's statement she mentions I did not supply the emails between Justine Oxenham and myself. In preparation of my statement, I had not remembered the email exchange with Justine Oxenham. I understood the focus was on transition and my communications with WMHHS, CHQ, MHC, etc to show who I had contacted to advocate regarding the growing concerns around the transition and closure and focused on providing the detail surrounding that. The first I recalled of them was when Justine phoned me the night before she gave evidence to tell me she had included them in her evidence to the Commission. At the time they were personal emails, with Justine expressing her extreme concern about the transitions. I had great respect for Justine, her dedication to the young people at BAC and her professionalism, and the fact that she was contacting me regarding the transition issues told me that she was greatly concerned about the process. For the record, Justine never supplied me with the notes she made in the transition meetings. I never spoke of the information Justine gave me to others. I have been a state and commonwealth public servant and I very clearly understand the confidentiality requirements of employees. I had parents and others expressing the same concerns to me, and therefore the significance of Justine communicating those concerns to me. in particular, as their children were of the most difficult to place and finding options was extremely difficult, frequently passed details of their concerns and difficulties with the transition to me. Both of these people told me of their concerns and issues with Anne and the process, again which I treated in confidence, except where they gave their permission to use the details of their experience in the advocacy I did, to illustrate the real issues for parents and young people. I would imagine Anne may

even if he

have communicated her concerns to others in a personal manner, but not included those communications in her testimony.

Re: Para 122 of Anne's statement Anne questions my state to the AETRS committee and availability of options for the upon Dr Sadler's Upon reflection, I accept that it conversation she said that , but I stand by my very clear real Anne sometime after that, that she told me she hoped the because she didn't know where the young people would go to be so difficult if the person WMHHS replaced Trevor with the go, as I state in Para 42. This served to reinforce my contains the person with the per	e young people in our first conversation, it may not have been in that first ecollection in a phone conversation with e Committee came up with something go. I agreed with her and noted it was going ith didn't know where the kids were going
	to me as I state in Para 66 of my th Dr James McAuliffe , but I did say was contact with him in the adolescent acute
Re: Para 124 of Anne's statement regarding Leith Johnston statement and accept it could read as if I was claiming Leit talking about finding an OT and then Anne suggested Leit could case manage  I stand by my claim that Anne that with the suggestion that I could claim on the 10 subseman 52 of my statement, that would not be possible due. Anne. Anne added in this conversation she was struggling.	th Johnston was an OT. We had been h Johnston, who was a speech-therapist said she was expensive, as Anne followed idised Medicare visits for her. As I state in to using them for psychology, which I told
Re: Para 125 I stand by my claim that it was only the idea at that stage as on 30 October 2013 Anne emailed me to sector', and that NW CYMHS would be the relevant agent had mentioned of CYMHS. I clearly recall as I could not rea complex case and would need case management, yet all psychologist and psychiatrist – that was what we had before enough. That was why I had said that in the radio interview	say we could 'explore options in the public cy for that (JK19). This was the first Anne econcile Anne's comments that was a private ore he went to Barrett, and it had not been
afterwards it was not proposed again as a suitable place. ensured it would not be an option for socialisation. disorder is social difficulties. I am amazed that is a good thing, but in another, going to a completely unfaservice itself and not knowing the people, was an enormous thinks and the need to clarify arrangements a understanding, I could envisage a situation where mode of transport - but with not understanding that impletravelling with would have just assumed an consistent with the literal way a person with thinks, a expected to understand that situation. An adult a outings. was with	. A significant part of the en went without an escort, which in a way smiliar environment both the location, the east, if not impossible task. Knowing the eand instructions with to check said was happy to go on the train — as a fied it would be independent of an adult adult would go with That is eand consistent with how I would have always went with them for school or other as well and there was no option for
either of the if anything went wrong, which it did.	had no idea what the was like

or In an environment of distress at that time,	tolerance for further anxiety and
distress was already reduced. At that point in time	it would have been essential to ensure success
when attempting anything, particularly for	as once something doesn't work, there is
virtually no chance of convincing to give somet	thing a second go. I would have had no problem if
someone had taken them to and once they ha	
location and the environment, for to travel the	
visit. Anne states another patient went there and w	
and particular needs when doing somet	• •
and particular needs when doing somet	ining new.
Re: Para 128: I state travelled from	by train. Anne stated had
travelled to is on that	same line, so yes did travel to by
train.	
Re: Para 129 Anne states the effect of Dr Sadler's	and the closure on were
"unfortunately exacerbated by (my) constant critic	
closure." I reject that statement completely and the	e insinuation that I would compromise my
mental health and well-being. At no time did I eve	r criticise any staff in front of
<ul> <li>in fact I did my utmost to make sure that phone of</li> </ul>	conversations and any work I was doing relating to
the closure, such as emails, was done when was	at school or after went to bed. And at the
time of Dr Sadler's was still inpation	ent a couple of nights per week.
attitude about the closure was firmly fixed upon Dr	Sadler's removal and didn't like what was
happening. lost two friends as well as Dr Sadler	in that process and the discussions between
and the other adolescents and their direct experien	nce of it formed those feelings. There are notes in
file to indicate distress about Dr Sadle	_
served to make more angry – Mr Springborg's	
Barrett, knowing what appeared in the Media, and	
young people weren't silly – their belief was that the	-
	d at those beliefs and attitudes all by themselves.
	•
TO claim anything else is to try to minimise their ex	
	des in relation to the events. I could not afford
	t to go to Barrett. old me would say
everything was ok whenever staff asked, as was	
want to talk to anybody. This is reflected in many ${\mathfrak p}$	
concerns' and says is fine. That is why I	thought it was so crucial to inform Anne and
other staff about mental state and difficultie	es, because was not wanting to acknowledge
them to anyone at Barrett. The peoplemight ha	ve talked about feelings to were, Kate and
Kimmy – OT's, and a couple of school staff. But Kat	e and Kimmy left, and perception of the
circumstances under which that happened, as for n	nost of the young people, made very angry
about that. I had nothing to do with those events of	or attitudes towards them. They were
from direct experience. I was critical of WMHHS –	•
those criticisms were justified. I was critical of Ann	
	he engaged with me. I was critical about the
options given to other young people, as advised to	
Anne. But that was <b>NOT</b> to or in front of	
WMMHS. In fact I emailed Lesley Dwyer to ask if Ar	
vvivings. III lact i elitalieu teslev DWVel to ask II Al	ine nau Sumicient Support, in recognition of the

difficulties of maintaining treatment and developing transition plans. Anything I reported to WMHHS relating to Anne were only the facts of what was offered for transition. I can also support this with an example of expressing dislike and negativity towards Megan Hayes – who and the other adolescents perceived to have taken Kate or Kimmy's job. I told Megan had come back to help and she was doing whatever she could to assist the the young people transition process. I did not jeopardise mental health by engaging in the details of what I was doing or conversations I was having with people about the closure. would often ask me what could be done and could I help as was upset and worried and I told I was trying to do something to help. I gave as little detail as possible. I at least wanted to model that as a parent I friends when we believed something wrong was being done but I did would support nothing to undermine the standing of any of the staff. I stand by my actions in that regard. I was not actively engaging or reporting to he details of my actions – only sufficient to reassure I was trying. I would never put anything above well-being and best interests. I was critical of the actions and decisions of Sharon Kelly, Lesley Dwyer, and Anne as per details provided directly to me by other parents and staff, but these discussions were only between me and those people. As a result of the criticisms I heard, I advised parents to contact the Consumer advocate, the Children's Commissioner, write to the minister, sign the petition, and other similar action. I asked for help from Anne. I accepted the offer and attended the one on one meetings she arranged. I had been able to see functioning deteriorating for at least a couple of months and reported that fact regularly. I was very happy to see how Anne since the might be able to assist. I did not attend the last appointment on 12 December, as stated in Para 66 in my statement, due to my concern for the other young people, being the last week in school. I thought it was more important to have that hour of Anne's time available to them on the ward, as I was very aware it would be a difficult and stressful week for them all. I reject Anne's assertion that the emails from Justine had anything to do with how I approached the transition nor the capacity to establish a therapeutic alliance with Anne. Did Anne's opinion and criticism of what I was doing affect her interactions with me? I treated Anne respectfully as she did me. I asked questions and sought her clinical advice on the best way to handle difficulties. My primary concern was well-being. I had no difficulty separating my dealings with Anne regarding the bigger picture of the transition. My issue was that I knew that private psychiatry and psychology was never going to be enough for and my job as a parent I believe was to advocate for what needed. I did so respectfully through Anne and Lesley Dwyer, yet no arrangements or suggestions for case management or OT were put forward to me, aside from NW CYMHS, which was impractical, and it was Anne's suggestion that the location of the private clinicians would be an advantage for On 20 September I asked Jenny Rice what she thought about taking on Anne psychiatrist due to him having familiarity with her by the time Barrett closed Brennan as (Del 121), in order to ensure continuity of treatment for I believe this shows me being able needs as a priority. On 27 September I also emailed Lesley Dwyer asking if Anne had support to manage both treatment/Director role and that of finding alternative care for the young people, as I understood what a monumental job it would be to transition all of the young people (JK90). I treated all staff – nursing, education, Anne, Sharon Kelly, Lesley Dwyer politely and with respect. I never spoke harshly, was never rude or aggressive to any of them. I was always polite and respectful and tried to engage in a manner that could result in a positive outcome for the young people – that was my primary objective at all times and I challenge anyone to say I presented myself

in any different manner. I cried on the phone to Lesley Dwyer, told her what I had heard and
observed, often begged her to do something but I never did anything in front of or to sway
opinion. could see what was happening all for was living it.
Re: Para 131: I only reported what I had been told by It is no wonder didn't
'engage' with Ashleigh Trinder – didn't know her (in a familiar enough way to talk to as a
psychologist) and was angry and upset and didn't talk to anyone. also had difficulty
identifying and expressing and articulating emotions, which is another feature of It was
Anne who told me at that time there was not enough time to establish a therapeutic relationship.
<b>Re Para 132</b> : If much of the meeting focused on daily routine, it's because that is the
foundation of functioning. was returning to the state was in before went to
Barrett. I had spent 18 months virtually, with not leaving the house, unmotivated, unable to
attend to a small number of simple chores and limited independence, limited in acapacity to do
home schooling I was seeing return to that state. I had spent most of life with many
difficulties from with increasing anxiety and other problems the older got and the more
was expected of with age and the more aware became how different was from peers.
My concern was that if could not manage a simple home routine, how was going to manage in
a work environment or manage to maintain connection with school/education. was
increasingly late for school over that period as a result of decreasing functioning at home. If
stopped going to school, would be <b>absolutely</b> back where started before Barrett – completely
socially isolated, which would further stunt and delay development and capacity to rehabilitate
and recover, and engage in any transition options. And was being expected to transition out of
Barrett in a few months. I could not see that there was going to be the right support or level of
expertise for in the community. With regards to the suggestion of private psychologist and
psychiatrist initially, that is what we had before came to Barrett. It did not work.
deteriorated to the point where needed to go to Barrett.
Anne states started with Megan Hayes on 27 November 2013. By that stage I had been
expressing concern about difficulties transitioning home throughout all of October and up
to that date. I had contact with Kimmy Hoang (OT) at some point but she left. I have mentioned
difficulties with Megan Hayes, so it was perhaps never going to be a successful intervention
but I encouraged to be positive about engagement with Megan. I believe this is yet another
example of how the staffing issues during transition impacted on patients' treatment.
Re Para 134: I did not simply decline Case Management through CYMHS based on the 18 yr cut off.
The location of the service in was problematic and as I have said Anne encouraged the local
psychiatrist because could get there on own. For increasing independence,
CYMHS would have been completely unworkable, and extremely difficult to manage even if
I took to appointments. Anne had tried to arrange an OT but when that fell through, there was
no further offer of an alternative.
Re: Para 135: I don't recall reminders from Anne but I do recall her asking me if had an
appointment with Bradley Johnston, in the transition meeting 'family meeting' on 21 November
2013. It is after that I arranged appointment with Bradley, which by then had to be in the
new year.

Re: Para 139: No one arranged case management for and the psychological support came too late for to engage with, if the 1 meeting with Ashleigh Trinder is to what Anne refers.

That is despite weeks of emails and and expressions of concerns regarding deterioration. I know Anne was in a difficult position but she is correct in that I was not satisfied. That should not be a criticism of me, but of the process that was in place for and all of the young people. I ask any of the people from WMHHS or Anne, if it was there child, would they have accepted this process forced on their children, the distress and disruption that ensued from the decisions of WMHHS and Qld Health, and all the related bodies – CHQ, Mental Health Branch etc. I could see my deteriorating before my eyes and essentially I was powerless to do anything about it, despite desperately trying to influence the process for mine and other families. I maintain that what ended up with was inadequate, despite the fact that ended up with CYMHS, after I initiated that process.

Re: Para 142 I never received any resource or 'Community Contact List' from BAC. does not recall being given such a list. In terms of being given transition plans, that is in relation to the National Mental Health Standards requirements. Those plans are not merely where the young people went but relapse prevention, signs of relapse – information and guidance for what a parent – and/or receiving service would need so they could best support their child after the closure. As far as consulting other colleagues regarding giving transition plans, Anne said it was not 'usual practice'. I would suggest the closure of BAC and the subsequent removal of the associated treatment and rehabilitation supports was not a 'usual' situation.

Re Para 145: In relation to OT at CYMHS, I believe I made it clear that I would be seeking OT from CYMHS, with only the Psychiatry to be provided form Dr James McAuliffe. I stated that in the letter to Lesley Dwyer on 30 January 2014. I had been in contact with Liz Fourie throughout the weeks of waiting to find out if could access CYMHS, in the event that would not be granted access.

#### **ATTACHMENT 1**

Summary:

Steering Committee Mtg 4 November

It began with the Committee Chair reminding us of our 30 minute time limit - 20 to talk and 10 for them to ask questions of us. She also stated that whilst they were aware of the problems at Barrett, this wasn't the forum to voice our dissatisfaction.

and I told the Committee we would worked on the premise that they had read our submission.

1. presented account of how ended up at Barrett. It was very powerful and emotional but we wanted to make sure the Committee was left in no doubt for whom they were designing their model. We wanted them to hold that front and centre of their minds the whole time and also to realise the extremely trying and distressing process that young people and parents go through just to get to Barrett. And how many times the existing system fails young people and their families. drew attention to the fact that parents have been passed around when they ask questions - CHG, WMH, Minister etc: we are always told its someone else's area/responsibility. also told them there is nothing but private alternatives being offered to young people and their parents as transition options at this stage; that the alternatives outside Barrett are inadequate and there must be recognition of that - that's why is there in the first place;

2. I explained that my presentation focused on making the Committee aware that whilst they have a particular task to do, they are part of a bigger process and that I felt it was important that they were aware of what was happening at the same time as their work. I started by stating that the Committee's work started with and is based on the ECRG's recommendations; that initially the two processes - Barrett closing and a new model of care to replace Barrett - appeared to be linked: one closes, the other opens. It has been regularly stated the alternative would be available in early 2014. I quoted from letters and statements from WMH, the Minister etc to very that. I said that the further the process went on, there seemed to be a gap appearing between the two processes, to now when it seems like they are two completely independent events. I referred to Recommendation 3 that acknowledges the RISK if BAC closes before Tier 3 available: this recommendation states 'wrap-around care' "ESSENTIAL" and that The availability of BAC funds was a "significant benefit". At this stage, wrap-around care is non- existent, and risk is significant because of that.

I said that our respective presentations may be slightly outside what the Committee was expecting, but that I could not live with myself if I did not tell them of the concerns for the kids because of this process, in case one of them might have been able to do something about it. I gave them examples of some of the things that have happened to kids in this process (I had permission from respective parents to share this information- nothing identifying either parent or child).

I referred to poor consultation and stressed the need for consultation with young people and all stakeholders - the reason we were able to submit to the Committee and talk to it was because of processes initiated by us, not offered by WMH; the bad PR that Barrett has received from some people - describing what Barrett really does and how incredibly successful it has been and is!; how

important the school and its staff are to the whole treatment and rehabilitation process - so onsite schooling is crucial as per the ECRG recommendations; even though it wasn't their decision to close Barrett, to be aware that the decision to close - and the reason they are now charged with deciding on a new model - was not based on an analysis of the outcomes produced by Barrett and therefore there is no way of knowing if whatever they come up with will provide better outcomes. It did not start with 'how can we do better for these kids'. I told them Barrett is much more than the sum of its parts -it's the 'community' it provides and the power of the relationships the kids form with educators, nurses and other staff that makes rehabilitation and recovery possible.

The room was deafeningly quiet when we finished. There were no questions. We expressed our gratitude at being able to provide our perspectives to the Committee.

Afterwards and I met with Stephen Stathis (head of Children's Clinical Services Children's Health Queensland) for our 'debrief'. We had a very positive discussion with Stephen, again highlighting the gap that will be gaping wide when Barrett closes with no Tier 3 available. He was very interested in many aspects of our parent submission. was able to give Stephen a good regional perspective - lack of services, lack of coordination between existing services. We discussed the link between education and treatment: especially how both might be accessed and delivered in regional areas, the need for extended inpatient elsewhere, but at least in Brisbane as a minimum. The objective of providing care close to home is just not feasible for some young people (ie. they actually need to leave their home to escape abuse and/or stigma) or because of lack of resources (funding) mean only one could be provided but we made sure we clearly stated that there must be a Tier 3 service, and that must include onsite schooling. We raised the issue of unqualified/inexperienced staff, the difficulty attracting said staff to regional areas and the lack of continuity of care because of staff turn-over. We didn't solve anything, and Stephen couldn't provide anything specific for us, but I feel very certain that he is very clear on the issues, and keen to consider the concerns we raised in the Committee's work.

We didn't - and couldn't - expect solutions to the current issues of closure, but we made very certain all the Committee was aware of them, and that we put forward everything that we could think of that is relevant to being considered in the new model. It is very possible that Stephen will consult with us again, especially , to get the regional perspective.

The summary of the meeting with CHQ - Dr Peter Steer - CEO will follow soon.

#### Attachment 2

#### Carinity to tell teens that funding cuts will stress service

30th Sep 2014 12:00 PM

A QUEENSLAND Health spokesman yesterday explained why Carinity Wahroonga's funding was withdrawn.

"In 2013 the Queensland Centre for Mental Health Research (QCMHR) undertook a review of community managed (non-government) mental health services (CMMHS)," he said.

"The QCMHR review recommended the provision of funding for services targeted to individuals with severe mental illness, including those with persistent or episodic illness, and those with additional complex needs.

"Based on the findings of the QCMHR review, the recent Request for Offer (RFO) tender process for CMMHS did not provide specific funding to support young people under the age of 18 years.

"However, organisations who had previously provided programs designated to a younger age group were invited to include this age cohort in their Offer, and provide a rationale for inclusion."

The spokesman said Carinity Wahroonga's submission included targeting people in the 18 to 64 years age group in the Central Queensland Hospital and Health Service area and providing statewide services for people with eating disorders.

"Carinity's offer in the RFO was unsuccessful and funding has been provided to Anglicare to provide community managed mental health services in Central Queensland HHS.

"FCMU provided transitional funding to Carinity for 1 July 2014 to 30 September 2014 to enable transition of existing clients to other services and to provide for a period to conclude counselling sessions for clients not requiring ongoing support.

"Additionally, the Commonwealth Government has increased its commitment to the mental health needs of young people. In January 2014, a Headspace Centre opened in Rockhampton, funded by the Commonwealth Department of Health.

"This program supports young people in the 12-24 age group dealing with issues such as abuse, neglect, depression, anxiety, bullying, self-harm and suicidal ideation, and provides a confidential service delivered by qualified professionals.

"Approximately \$1,054,640 (GST inclusive) in annual funding has been allocated to Anglicare Central Queensland as the sole CMMHS provider for the Central Queensland HHS."



http://www.themorningbulletin.com.au/news/carinity-will-tell-teens-that-funding-cuts-will-st/2403593/

Carinity Wahroonga

**About Us** 

## **About Us**

Carinity Communities Wahroonga offers psychological support and counselling to young people aged 13 – 24 years, with the primary focus on suicide intervention and mental health; to deal with trauma to develop coping strategies for issues such as abuse, neglect, depression, anxiety,

bullying, self harm, suicidal thoughts and family relationships. The counselling and therapy sessions assist young people to be better equipped to engage with their peers, their families and function within the community more effectively. Wahroonga staff will assist young people to access services through Medicare's Better Access to Mental Health Care initiative. A small contribution is appreciated but not mandatory to access services.

# 12 months after funding cuts community still rallying around Wahroonga

Home / Media / News / 12 months after funding cuts community still rallying around Wahroonga This time last year, the future of Carinity Communities – Wahroonga was in jeopardy after vital funding was cut from the Adolescent Wellness Program which provides free counselling and psychology services to young people aged 10 – 24 years.

Despite the funding not being restored to the service, the Rockhampton community continues to rally around the service with the Inner Wheel Club of Rockhampton Sunset raising over \$12,500 for the service.

Carinity Communities – Wahroonga Program Manager Kaylene Paradine said the service continued to provide assistance to young people in need.

"This year has been rough, we have been operating on a much smaller budget and the donations by the community have been the reason we have been able to continue," She said.

"We are incredibly blessed to have the ladies of the Inner Wheel Club who organised the wonderful Capricorn Christmas Trail as a fundraiser."

"Christmas is a critical time for many young people and we see an increased demand for our services. As seen by the recent announced changes to the mental health system, being able to access affordable and consistent mental health services is a major barrier to treatment."

"With continued donations, we are able to provide **free counselling services** to young people in the Rockhampton region."

The Inner Wheel Club of Rockhampton Sunset President, Glenda Ireland said Wahroonga's services were vital to the community.

"The region has a higher than average youth disengagement and unemployment. We want to see the region's youth thrive and counselling services to assist youth in crisis is important to this," she said.

"One of our members, Everil Curd wanted to raise funds for Wahroonga and advocated the idea of the Christmas Trail to the rest of the club. We are all absolutely ecstatic with its success."

https://www.carinity.org.au/12-months-after-funding-cuts-community-still-rallying-around-wahroonga

Carinity Communities - Wahroonga

#### Wahroonga's Adolescent Wellness Program

Wahroonga's Adolescent Wellness Program is a **free** youth mental health initiative of Carinity Communities providing high-quality, specialist counselling and psychology services to preteens, teenagers and young adults aged 10 – 24 years.

Wahroonga's adolescent program has been operating in the Rockhampton community for 12 years and provides help for young people and their families who are having trouble coping, have emotional, behavioural or mental health concerns, or who may be at risk of self-harm or suicide.

All our services are provided by experienced registered psychologists with many years of practice working with young people.

#### How to access the program

Any concerned adult, including parents, teachers or others involved with young people can refer to our service directly. Youth can also contact Wahroonga themselves.

A General Practitioner (GP) or Pediatrician can also refer a young person to Wahroonga's adolescent program under a Mental Health Treatment Plan.

Enquiries or referrals can be made by phoning or visiting us at 114 Fitzroy Street (Corner Fitzroy & Murray Streets), Rockhampton.