

The Case Against the Yooralla Mental Health Research Project

Introduction

The Yooralla Mental Health Research Project, as recently advised, is challenged on a number of grounds. These are as detailed below and cover:

- Factual Avoidance, Evasive Terminology and Lack of Appropriateness
- Individual Rights and Customer Decision Making Ability
- The Nature of the Project, Ethics and Authorisation
- Project Design and Monitoring
- Funding, Core Business and Service Contradictions

Further, the writers highlight that Yooralla has been independently assessed as not yet having “*embedded*” or “*optimised*” their performance in four of seven identified focus areas. Critically, these four focus areas are key in ensuring the provision of customer support and wellbeing as part of their core business.

The writers therefore submit that this project must be stopped.

Note:

The use of the word ‘customer’ throughout this paper is based on Yooralla’s use of the word ‘customer’ as applying to people who use their various services. In this particular case it applies to people with disabilities who live in Yooralla’s residential houses.

1. Factual Avoidance, Evasive Terminology and Lack of Appropriateness

(i) The Customer Consent Form

This form contains a number of significant deficits either by way of exclusion of critical detail, or a lack of substantiation, or by misleading advice, or by the use of evasive terminology. Specifically these include:

- **The Project Title** – The title makes reference to “*Explore wellbeing (holistic care).*” Yet, this is inconsistent with the Project Aims as detailed in the Customer Information Sheet, where it is stated the aim is to “*Explore the **needs and supports** of mental health care.*” Exploring well being and supporting “*mental health care*” are not one and the same.
- Essentially, when considered in the context of the other documents circulated to families and customers, the project title as described in the Consent Form is inconsistent with other descriptors used for the project. In particular, it is inconsistent with the statement in the PowerPoint handout as being a “*Mental Health Project*”.
- This difference in terminology must be considered to be significant. As such it is reasonable to conclude that the writer of the documents, who in fact represents Yooralla, is seeking to divert attention from the reality that this not a Wellbeing Project as such but it is in fact a research project associated with the mental health of Yooralla customers.
- **Reference to “Researchers”** – The project Researchers is identified as Ms Lin LI only.
 - Despite having informed a Yooralla parent that she has “*nursing qualifications*” and is “*an expert in communicating with people with disabilities*”, no advice is provided in any of the documents detailing the project as to Ms LI’s formal qualifications and experience.
 - This includes a failure to detail any formal qualifications in communications, or her experience in working with people with disabilities.
- **Point 1** – This point targets the customer by reference to that person as the person consenting.

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- Despite this, no explanation is given anywhere on this form or indeed elsewhere in the documents provided as to the process to be applied in relation to those customers who do not have the capacity to consent; or, even with significant levels of support, to be able to adequately interpret whatever explanation is provided and however the 'written summary' is designed.
- This therefore raises the question of whether or not the individual customer is actually giving **informed consent**.
- **Point 2** - Makes reference to the customer signing the Consent Form and then receiving a copy of the signed Consent Form. It totally ignores the issue of those customers who do not have the capacity to 'sign' or, as noted above, be fully cognisant of what they are signing for, even if they can sign.
- **Point 3** - Is difficult to interpret, in that it states, *"I understand that my participation in the project will involve my staff team being record for context at different times throughout the day and participating in standardised assessments."*
 - This could be taken to mean that customers will be the subjects of standardised assessments or that staff will be the subject of standardised assessments.
 - Further, there is no reference to the 'context' and no reference to what is meant by *"different times throughout the day"*
- **Point 4a** - Although this point makes reference to participation being *"voluntary"* the statement seems to assume that all customers will fully understand what the term *"voluntary"* truly means.
 - Apart from this, however, it is also significant to note that the form and this particular point do not allow for what might be called an **Opt-out** provision.
 - Therefore, the question arises as to how the organisation will determine this and how they will deal with the possibility that a customer may indeed sign the form, albeit he or she has no wish to participate.
- **Point 4b** - This point also assumes that the customer has the capacity to fully understand what being *"free to withdraw from the program"* actually means; and what *"unprocessed data"* actually means.
- **Point 4c** - This point contains three quite complex concepts, these being *'confidentiality'*, *'safeguarded'* and *'legal requirements'*.
 - Again, it assumes the customer has capacity, even with some level of communication support, to fully understand these terms.
- **Point 4d** - The reference in this point as to the possible publication of the *"research findings"* supports the contention that this project goes beyond what it purports to be.
 - In other words, it is more than an in-house project aimed at exploring 'wellbeing'. On the balance of probabilities, it must be concluded that it also has a research objective and all that research entails and infers.
- **The two boxes acknowledging acceptance or non-acceptance of the file review:** Again, this assumes that the customer fully understands what a *"file review"* means.
 - In relation to this, it also raises the question as to why a choice is given when indeed this is a Customer Consent Form and the project requires a forensic examination of individual customer files.

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- **Customer signing**
 - In one line reference is made to the “*Customer’s name*” then in the line immediately following reference is made to the “*Participant signature*”.
 - While it may be reasonable to assume that these are one and the same, the failure to standardise the terminology brings into question the lack of professional rigour in terms of the Consent Form.
- **Signing on behalf of a customer** - This section of the form provides for someone else to sign on behalf of a customer.
 - No indication is provided as to who has the authority to sign, and therefore it is assumed that the person who does sign is automatically accepted as being appropriate to approving or consenting to the customer’s participation in the project.
 - Further on this point, it is noted that this undesignated person is required to “*Print*” his or her name.
 - By contrast, no such direction is given in relation to where the customer’s name is to be supplied.
 - While this may be considered by some to be a minor point, it does raise the question in relation to where the customer signs as to whether the customer has actually completed the form.
- **On the matter of the provision of a summary report and the provision of an email or home address** - It seems reasonable to conclude this is targeted at the party who is signing on behalf of the customer.
 - However, the positioning of this statement can be taken to mean that no such option is given to the customer if it is he or she who signs the Consent Form.
- **An overall assessment** – Given the many deficits identified above it must be concluded that the customer Consent Form must immediately be withdrawn.

(ii) The Customer Information Sheet

- This form is highly subjective and lacks descriptive rigour as detailed below.
 - The statement that “*In Australia, around 1 in 5 adults are affected by a mental health disorder every year*” is not substantiated by any reference as to its source.
 - The claim that chemical restraint has been used as a matter of course with people with intellectual disability, and therefore inferring that in some way challenging behaviour, which is a prime reason for chemical restraint, is associated with a mental health disorder, is not substantiated.
 - Reference to “*A report*” without naming the particular report is a serious omission.
 - Claims about a lack of connection between mental health services and disability services and comments on the training of support workers stands as an unsubstantiated statement.
 - Despite the serious contentions underlying each of these statements, none of the claims is substantiated in any way.
- In the absence of detailed reference support for the above claims, it must be determined that this part of the Customer Information Sheet lacks intellectual rigour and professional integrity.
 - Therefore, given the significance of the project with particular reference to “*well being*” and “*research*” such sloppy documentation, and as providing the basis for the project, must not be countenanced.
- Under the project aims the Information Sheet advises that the aim is to “*explore the needs and supports of mental health care for our customers in order to improve the service for our customers’ wellbeing and quality of life*”.

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- As previously noted above, this statement clearly defines that the focus will be on “*mental health care*”. Yet the question of the qualifications of direct service staff who will by this definition operate as mental health practitioners must be seriously questioned.
- Interestingly, this gives emphasis to the statement made under the Background heading that there is “*poor training of support workers*”. Yet no reference is made anywhere in any of the documents of what formal training and qualifications staff already have or will be given in mental health before launching the project.
- **Focus** - In relation to the points under this heading, reference is made to “*providing quality of support in relation to the treatment*”.
 - Clearly, by the use of the word “*treatment*” this extends the residential services to being one of a mental health based treatment service. This clearly goes beyond that of a residential service to one of a medical model, where Yooralla is intending to institute some form of mental health “*treatment*”.
 - Further in regards to the dot points under the heading Focus, the use of the word “*exploring*” tends to paint the customer as a road map to be played with at the will of the organisation.
 - Further in relation to “*exploring*”, in the context of “*appropriate advocating for our customers’ treatment*”, this assumes that those advocating, whether it be staff or managers, have the necessary qualifications and experience to know what treatment is required for each individual customer in terms of his or her mental health.
- **The role of the Project Facilitator** - The role can be argued to be all encompassing and therefore a stand-alone role. This must be considered dangerous in what at times is described as a “*research project*”.
- **Referrals refer to** – Under this heading reference is made to the progress of the project being tracked for its duration via “*assessment and feedback*” and this then being “*provided to customers*”. No advice is provided as to the duration the project is likely to take. It also fails to identify in what form the feedback will be provided.
 - Under this heading it is also stated that the project “*may be presented as a research paper*”. No reference is made as to who will take ownership of the research, to whom it may be presented and the efficacy of the research
 - As such, given the highly questionable professional integrity in relation to this project, there is a significant potential for reputational damage to be done to the organisation.

(iii) The Power Point Presentation

- This presentation consists of 14 slides.
- **Slide 3** – States “*All customers*” will participate and be involved in the project. This is most likely to be untrue as it assumes all customers will consent to being involved.
- **Slide 12** – Makes reference to a “*Literature Review*” without specifically referencing any specific literature that has been reviewed and in what context.
- **Slide 14** – This Project Procedure slide is critical for the following reasons:
 - It introduces the project as a Mental Health project to customers.
 - No advice is provided as to who will undertake the “*individual assessments*.”
 - Under the heading the “*Customers make decision*” and the schematic detailing where consent is not given, the question must be asked as to why the reference to “*Feedback and recommendation*” is included.

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- This slide also fails to provide any advice as to what project controls will be put in place, if indeed any. The assumption must therefore be that the control is maintained through the Project Facilitator only.
 - As noted under 3 (iii) below this seems to confirm that the project is not overseen by a Project Committee and has not been approved by an Ethics Committee.
- Given the content and format of the presentation it seems reasonable to conclude it has been designed to present to both staff and customers.
 - In terms of presentation to customers, it must be deemed to drift between naivety and simplification of complex matters to the point of being misleading.
 - In terms of presentation to staff, it is simplistic and therefore must be considered of questionable value.

2. Individual Rights and Customer Decision Making Ability

(i) Communication and Decision Making

- Significant question must be raised in relation to all individual customers having the capacity to fully understand the details of the project, whether by means of verbal, schematic or written communication provided to explain the research project.
- Further, while it may well be that there are a number of customers who do have the capacity to either independently or with the right level or type of support to make an informed decision, equally it seems reasonable to assume that there will be a number of customers who do not have such capacity.
- The important consideration in relation to those with limited capacity to make a truly informed decision in relation to their willingness to participate or not participate in the project, is that because it is a mental health research project it is invasive and the results have far greater significance than simply being about the wellbeing of the individual customer.
- In relation to the above, while the Consent Form talks about “*wellbeing and holistic care*” it seems reasonable to conclude that a major objective of the project could well be assumed to be about self-promotion, both of the entity and individual managers.
- Yooralla first and foremost is a disability service provider. It is funded and charged with the responsibility of providing services to meet the individual needs of its customer population.
- In relation to this project, it is specifically funded to provide residential services to those customers who have a residential placement with the organisation.
- It is critical to note that the Yooralla structure and service model does not establish it as either being a research establishment or having a research arm.

(ii) Distribution

- Associated with the Customer Consent Form and the provision for allowing another party to sign on behalf of the customer, there is no reference in any of the documentation as to the distribution of the documents.
- By way of explanation - Has it only been sent to customers? Has it only been sent to customers and families? Has it only been sent to customers and legally appointed guardians? Has it been sent to DHHS?

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3. The Nature of the Project, Ethics and Authorisation

(i) The Concept of Research

- Despite the mixed message as to the project's title and as referenced in the various documents provided by Yooralla, there can be no doubt the project is first and foremost a Mental Health Research Project.
- This is confirmed as per slide 14 of the Wellbeing Project Power Point slides titled Project procedure, the boxes under "*Information to Service manager*" and "*Attend Staff meeting*" defines the project as "*Mental Health Project.*" Further there is the oval that "*Staff introduce mental health project to customers*"
- Notwithstanding the title of the project, the clear and unambiguous evidence shows it to be a project directly associated with the mental health of individual customers in Yooralla's accommodation facilities.

(ii) A Yooralla Ethics Committee

- A project of this nature demands that it be considered and approved by an Ethics Committee. There is no evidence on the Yooralla website to suggest that such a committee exist at Yooralla.
- Additionally, there is no advice in the documents provided as to whom at Yooralla has authorised the project.
- There is no advice in the documents provided as to whether the project has been submitted to and authorised by the Department of Health and Human Services as an inclusion under Yooralla's Funding and Service Agreement.
- A project of this nature, where it is stated that "*The outcomes of this project may be presented as a research paper*" demands to be considered by an Ethics Committee and by the principal funder in order to determine whether it should or should not be approved.
- Given Yooralla's recent statements about family engagement, any such consideration of the project must involve wide-ranging elected family representation, whereby if consideration is to be given to the project, the review team must involve a majority of family members over staff nominees.

(iii) The Role of the Department of Health and Human Services

- As the Department is the principal funder of Yooralla to an amount of at least \$60 - \$70 million per annum, it is critical and indeed necessary that the Department is involved in considering the project before it commences, if indeed it is to proceed.
- The Funding and Service Agreement that exists between the Department and Yooralla constitutes a contract. The proposed Mental Health Research Project must be considered in the context of this contract.

4. Project Design and Monitoring

(i) Project Design

- No advice is provided as to who was involved in the project's design. As a research project involving vulnerable people this must be considered as a major deficit.

(ii) Structural Controls and Monitoring

- The documents provided in relation to the project do not provide any information as to what, if any, structural controls will monitor the project.

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- A project of this type demands that there is Control Committee that monitors the implementation of the project.
- A project of this type demands that the monitoring body be suitably qualified and is capable of maintaining tight controls.
- A project of this types demands it must have the full approval of the Board and the Chief Executive Officer. There is no evidence to show this exists or has been granted.

5. Funding, Core Business and Service Contradictions

(i) Legislation, Funding and Core Business

- As is the case for all funded disability service providers, Yooralla operates under the Disability Act 2006 and is therefore subject to the provisions of that legislation.
- This Mental Health Project brings into serious question as to whether or not Yooralla is going beyond its legislated authority and obligations.

(ii) Funding and Service Agreement

- As a disability service provider funded through the public purse via the Department of Health and Human Services, Yooralla is subject to a Funding and Service Agreement. This agreement constitutes a formal contract.
- The establishment of the project as a Mental Health Research Project brings into serious question as to where the project fits within this agreement.

(iii) A Conflict between Core Business and a Mental Health Focus

- Associated with (i) and (ii) above, the establishment of this Mental Health Research Project brings into serious question whether or not Yooralla is straying from its core business.
- On this matter, it is essential to note that Yooralla is not registered as a mental health service provider.
- Further, it must reasonably be assumed on the balance of probabilities that the majority, if not all, of Yooralla's staff, and certainly those delivering direct residential services, do not have the necessary qualifications and expertise to undertake assessments, whether they be via observations or through a clinical assessment process to assess and deliver a mental health focus. This being whether or not it is considered to be part of "*holistic care*".
- This project sets a dangerous precedent in promoting a mental health focus which could well override the organisation's duty of care to provide disability services.

6. A Concluding Comment

No matter how this project is assessed, the finding must be that it is ill considered and ill conceived. At a time when the Yooralla organisation has been placed under scrutiny because of the failure of the organisation, at all levels, to address abuse and neglect, this project takes them on a tangent that is not in keeping with their core business.

It can be argued that there is an abuse of power and position where the project is sugar-coated to the degree that it ignores the fact that Yooralla is not a mental health service provider. It is not funded as such and it is not staffed as such.

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It is wrong that this project is being promoted when there are still outstanding critical deficits to be addressed in terms of Yooralla’s current performance status as directly applying to its customers and as assessed by the recently released DHHS report of the review conducted by KPMG.

Critically, of the seven focus areas assessed by the reviewers, and as summarised on page 60 of the report, three of the seven focus areas must be deemed to be platform activities associated with service delivery and customer wellbeing. Each of these three has been assessed as not yet being fully “*established*”, let alone being fully “*embedded*” or fully “*optimised*” as a practice delivery. A fourth - Information, education and training - while “*established*” is not yet “*embedded*” or “*optimised*”.

The “*maturity assessment*” summary for each of these four critical areas is as detailed as below and as extracted from the report.

Area of Focus	Non-Existent	Initial-Reactive	Emerging	Established	Embedded	Optimised
Safeguarding						
Information, education and training						
Supervision and support						
Customer planning and support						

The relationship of the above findings to the Mental Health Research Project

The significance of the assessment as above as related to the Mental Health Research project is that a time when Yooralla is still yet to fully optimise its performance in all key focus areas, it has not yet done so in those areas most critical to customer support and wellbeing.

Therefore, to now seek to enter a complex service area such as mental health defies logic, constitutes unethical behaviour and as such represents exceedingly poor judgment and decision-making. Further, it poses an unacceptable risk to those customers who are the subjects of this research project for the very reasons stated above, and particularly concerning the fact that the staff are disability workers and not mental health workers. They are neither trained nor experienced in such complex work.

Given the above, the Mental Health Research Project must therefore be stopped.

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Attachments:
Yooralla Customer Consent Form
Yooralla Customer Information Sheet
Yooralla PowerPoint Presentation

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