Developing Effective Consumer Participation in Mental Health Services: The Lemon Tree Project (1997)[1]

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National Mental Health Strategy Innovative Grants Funding 1995

The Victorian Mental Illness Council (VMIAC) applied for and was successful in winning two significant grants from in the National Mental Health Strategy Innovative grants Program in 1995. These grants were to:

1. Research and document the most effective ways that consumers could participate in mental health services; and
2. Develop an effective consumer peer support program.

Both were highly successful. The first we called, The Lemon Tree Learning Project and the second was located in St Vincent's Place, Albert Park. It was called Vincent's.

The Lemon Tree Learning Project

The Lemon Tree Learning Project was all about the education of the mental health workforce. There are two significant parts of this project. Both are relevant to the educational aims. The definition of 'education' drawn in the Lemon Tree Learning Project took understanding of the role of consumer educators abruptly away from 'people who speak at other people' and 'trainers with expectations of instant educational gratification' to a much more sophisticated idea of what it truly means to be an educator. The two important aspects that will be described here do not adequately cover the breath of the endeavour but it is a start.

Concept One: The metaphor of the Lemon Tree

This metaphor was totally central to our thinking in relation to the education of clinicians. It had the following aspects that were significant:

1. The Lemon Tree in our concrete back yard at the then VMIAC HQ in Weston Street, Brunswick;
2. Our collectives feelings and reactions to the humble lemon;
3. The tree and its constituent parts: The roots; the trunk; the branches; and the leaves

The Lemon Tree in our back yard

The asphalt back yard of the small house which the VMIAC then called home was barren except for the Lemon Tree. This tree produced lemons and was green and protected us from the sun. We saw it as symbolic of life and possibilities for consumer power in institutional spaces.

Lemons: We had all sorts of associations with lemons. Nothing like a good brainstorm with consumers! Read the book. It'll tell all. However, some had to do with not protecting clinicians from sour educational experiences as the product, if they hang in there, could be sweet and wonderful. Others had to do with Lemmings – a bit farfetched but there you go…

The Tree Metaphor: This was of great significance to this project which had as its central goal of building change into institutions of psychiatry through consumer interventions – education defined broadly and focusing on the education of the institution through large and small scale intrusion of consumers into places we had never before been allowed to enter. Therefore it is unsurprising that we started with the roots.

Roots: Root work is about putting sufficient energy and time into nourishing the growth and

[1] Esptein, M and Shaw, J. (1997) *Developing effective consumer participation in mental health services: the report of the Lemon Tree Learning Project*. Victorian Mental Illness Awareness Council, Brunswick, Victoria.

development of an infrastructure for institutional change. It's deep, deep, slow and deliberate work with the institutions that maintain and control staff behaviours and attitudes – attitudes, values and behaviours we wished to change.

Root work is both the most important and the most difficult educational work we had to do. It was also the most difficult to describe, substantiate and, unsurprisingly, get funded. Convincing everyone of its fundamental purpose and promise is a major part of what we, as educators, must do. After several years of careful work we were convinced that without due respect for root work other educational interventions often do not achieve their potential.

Root education is not a discreet thing that can be neatly packaged then shared, sold, copied and branded. Rather, it is about the growth and nurturance of a new way for the organisation and staff to think about their practice. It necessitates organisations and practitioners reflecting on their practice **in** collaboration with consumers.

From the beginning, root work requires a critical mass of local consumers – not just a couple of tagged educators from outside (although we have our uses too). It is imperative, both ethically and in terms of changing the power dynamic, that local consumers need to be paid, and need to be paid respectfully. It will always include opportunities for **deep dialogue** and culture carriers.

Learning will take place over a period of time – it will be slow.

Trunk: The trunk is the substance of educational interventions. At the time the Lemon Tree Report was being written there was nothing that could match the extraordinarily detailed research undertaken by the consumers working with the U&I Project. It did have a leaning towards acute units because of the nature of the funding but there is a logic towards focusing intervention education on the area that arguably has the capacity to do the most harm. See the U&I tenets below.

Branches: The branch work is about building onto and supplementing existing skills, knowledge and attitudes around consumer participation in all aspects of institutional change including ways and means of changing institutional attitudes and individual attitudes, values and behaviour of clinicians through consumer intervention.

Leaves: Unfortunately leaf work is the most common. Sometimes it takes the form of people telling their stories, sometimes not. But we mustn't fall into the trap of thinking that the use of story is confined to leaf work. Telling and retelling stories, particularly stories of bad practice and bad outcomes, is also fundamental to root work. Leaf work is about one offs! It includes one off talks. They are potentially useless ways to make change come true. They are discrete events that might be plucked by a service, waft around and fall to the ground in any number of unpredictable ways totally unconnected to the amount of emotion expressed at the time. Educationally leaves are the least effective.

Concept Two: the eleven important components of the Understanding & Involvement built-in Consumer Consultant Plan

The Lemon tree Learning Project chose to utilise the significant findings of the Understanding & Involvement (U&I) Project. The comprehensiveness of the model and the thoroughness of the research undertaken by consumers working on the U&I project seemed sufficiently rigorous to form the content trunk of The Lemon Tree. Our role was to adapt this learning to an educational framework.

The U&I Model [2] **(The substantial trunk of the Lemon Tree)**

It is important for as many consumer educators as possible have a chance to look at the U&I research. We can't do it justice here. However we can outline the very basics and simply encourage further study. One of the aims of the U&I Project was to explore how institutional practice can be improved through consumer led and staff collaborative commitment to changing the damaging institutions that control the behaviour, values, attitudes and conduct of services-service that are 'not good enough' for either consumers or staff.

However, consumers in developing the conclusions of the U&I argue that institutional malaise profoundly affects the **'done to'** (consumers) and that therefore they must be the educational leaders in the education of the **'doers'** (clinicians)[3]. The assumptions of the U&I model match the assumptions of the Lemon Tree. They are securely based on building new ways of thinking into the institutional assumptions that breed and support practice – both good and bad.

The 12 'musts' from the U&I project. Consumers who worked for three years (and a bit) developed a comprehensive and really useful model which outlined the essential needs, including educational needs, of any institution introducing paid consumer staff. The U&I consumer team called these brand new positions staff-consumer consultants. The hyphenation of the staff was to indicate that consumer work was not to do jobs that belonged to paid clinicians but rather to indicate to clinicians work that the institution must now find staff to action. The Lemon Tree Learning Project liked the comprehensiveness of this model and we made it the substantive trunk of the learning tree. The 12 parts of the U&I model are listed below and can be found in more detail both in the Lemon Tree Learning Book and in The Essential U&I pp 189—198. Consumer activity must be:

1. **Built in to the services and never an add-on.** It must be part of the quality assurance/quality improvement framework;
2. **It must never be seen as just eliciting local consumer feedback** and we shouldn't be enticed by fancy looking tick-the-box feedback forms or the promise of greater clout with professionally prepared feedback material. Rather, it has to be about a conversation between consumers using the services and other consumers – two-way dialogue will teach us heaps more than ticking the box. This also applies to conversations between staff and consumers who have used services provided it is safe.
3. **Consumer led education for staff must be comprehensive and systemic.** These must never be leaves. At the very least it needs to be built into the educational calendar for the service;
4. **Consumer participation for change in psychiatric institutions must be robust and 'built in';**
5. **To achieve institutional culture shift consumers must be supported to become and help enable supportive staff to become the carriers of a new consumer-respecting culture.** The support for this is crucial because it's a very difficult task and needs the development of a critical mass of like-minded consumers and staff;
6. **Multiple consumer feedback methods and 'mechanisms'.** Nothing will change with one off

[2] Wadsworth Y. *The Essential U&I -a one-volume presentation of the findings of a lengthy grounded study of whole systems change towards staff-consumer collaboration for enhancing mental health services*, Victorian Health Promotion Foundation, Melbourne 2001, p.18

[3] Culture carriers are staff or/and consumers working in services dedicated to carrying the 'message' of consumers on to as many other staff within the organisation as possible. It's a pretty hard job particularly if the carrier has little status.

lectures from consumers or one exit survey, or…. There are dozens of different ways the institution can be told about our experiences – ways for people who want their feedback to be confidential AND for those who want their names emblazoned. All have a right to speak back in the way that works best for them;

7. **Three 'sites':** These sites are essential: consumer-only places where we work out strategies, get confident and make our own decisions, decision-making sites (like meetings and the like) and, crucially, non-decision-making consumer/staff sites such as opportunities for deep dialogue.
8. **Centred on the acute unit and other high risk settings:** Partially this was because of the nature of funding for this project but much more importantly this is because the Acute Unit, Accident & Emergency Departments and other key spots are the most likely sites for harm to be experienced.
9. **Consumers as staff:** after three years of careful, methodical research by consumers we realised that if we weren't actually there to drive clinicians to fulfil their new commitment to 'listening to consumers in different ways', to finding every possible way to get feedback and, not just feedback, but real conversations with consumers about what is going wrong' etc, nothing would happen. Consumers needed to be on board within the organisation to drive change. However, without the other 10 support structures we knew this central but difficult task of consumers employed as the carriers of a new culture would be risky and hard.
10. **Consumers support resources infrastructure:** Consumers working with the U&I project needed a raft of supports built in from day one. Consumers participating in discussion and those on acute units who were able to have conversations-forchange also needed a bundle of support structures. These are explored more in the U&I and the Lemon Tree texts but there was no way we would have recommended employing consumer consultants without very specific, built-in supports including supervision from consumer leaders (or other trusted supporters) from Day1.
11. **Consumer driven and staff collaborative:** This was an important aspect of this highly developed package. The U&I Project was about staff changing their views, values, attitude so that:
    - priority might start to be given to those aspects of practice that consumers identify,
    - getting feedback and having constructed conversations about service, safety, 'care', 'treatment' etc gained institutional status;
    - and so on.

    In this model these exchanges are not about 'sharing opinions', 'educating consumers', 'working out our differences (glibly said without taking on board huge differences in power). Rather they are driven by consumers (who are not paid to be patients in hospitals) supported by consumer consultants. But staff are expected to play their part collaboratively. They are expected to listen to consumers in new ways and with respect, ask questions, clarify missed meanings, ask consumers for examples of good practice and any number of ways they need to operate to take a large chunk of the load for changing what can be a damaging mental health system.
12. **At all levels of all relevant organisations:** Consumers know about powerlessness. Consumer researchers know what it feels like to be talking what makes perfect sense to us but which seems totally incomprehensible to those who have the real power to make the important decisions, stall, or play bureaucratic games. The U&I model sort to make sure consumers held positions throughout all levels in organisations and within the overriding bureaucracy to enable consumer-sense to be spread especially into the most senior places.