

The Understanding & Involvement Project (U&I): 1991 -2001¹

-By Merinda Epstein for Our Consumer Place.

What is/was the Understanding & Involvement (U&I) Project?

The U&I was a path breaking project that came out of a series of booklets put together by consumers from the Victorian Mental Illness Awareness Council (VMIAC) in the early 1990s. The particular trajectory that led to development of this special resource was publication of 'Unlocking the System,' (by Di Otto) then 'Understanding, Anytime,' (by Maggie McGuiness and Yoland Wadsworth) and then the huge commitment by many consumers into the "Understanding & Involvement (U&I)" project.

U&I was primarily a Participatory Action Research (PAR) Project that produced five volumes of work plus newsletters which were designed to inform and keep up to date the several hundred consumers and staff who were actively involved in the project. For me, it was one of those projects that seemed so comprehensive that I was confused. It was nothing like any other research project I had ever been involved in. In the first years, particularly, no matter how much I learnt about spirals of change I still wanted an hypothesis, the collection of data, analysis and some sort of encouraging end (report?).

Now I have a renewed regard for this amazing project. I recommend the books to everyone. I think the VMIAC still has a few copies if you get in quick. It is with hindsight that I realise just how brilliant this project was. The collection of data is incredibly thorough, fundamentally consumer perspective in its origin, and absolutely comprehensive. At some points where I know I was confused I now go back to the texts to find we were collecting, experimenting, feeling out, enticing staff participation and, at times, being bloody obstinate because that is what the situation called for. Re-reading this material has been heartbreaking in one sense – because it has not been utilised to its full and real potential; but also inspiring because they're treasures that can be retrieved that are as relevant today as they were a decade and more ago. The U&I material is being used for the education of clinicians around the world. It is regarded with enormous respect.

The political climate

The Understanding & Involvement project emerged from a completely localised, grounded, response from a consumer organisation's demand that 'something must be done to change acute services' and that this must be driven by consumers. At almost exactly the same time Brian Howe (Health Minister in the Keating Government) drove forward the First National Mental Health

¹ McGuiness, M and Wadsworth, Y. (1991) *'Understanding Anytime' – a consumer evaluation of an acute psychiatric hospital*, Victorian Mental illness Awareness Council, Melbourne;
Epstein, M. And Wadsworth, Y. (1994) *Understanding and Involvement (U&I) –Consumer Evaluation of Acute Psychiatric Hospital Practice: A Project's Beginning...*, (Vol.1), Victorian Mental Illness Awareness Council, Melbourne;
Wadsworth, Y. And Epstein, M. (1994) *Understanding and Involvement (U&I) –Consumer Evaluation of Acute Psychiatric Hospital Practice: A Project Unfolds...*, (Vol.2), Victorian Mental Illness Awareness Council, Melbourne;
Wadsworth, Y. And Epstein, M. (1994) *Understanding and Involvement (U&I) –Consumer Evaluation of Acute Psychiatric Hospital Practice: A Project Concludes...*, (Vol.3), Victorian Mental Illness Awareness Council, Melbourne;
Wadsworth, Y. (2001) *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*, Vic Health.

Strategy (which included consumer participation for the first time in this country at this level of policy) and the National Human Rights Commission published the damning National Inquiry into the Human Rights of People with Mental Illness (Burdekin Report). In Victoria, the politics collided in a way it had never before. The same messages from consumers were coming both from the top down and from the bottom up through projects such as the influential U&I. It ignited into action and the U&I project was a major player in this movement towards change.

Education of the Clinical Workforce

In many ways the U&I was always both a research project and a clinical education project. Unlike traditional research PAR research has a remit to delve into crannies and poke heads around the many corners of mental health practice. In its era every single interaction we had with clinicians was an example of education. We were pioneering the concept of consumers-as-insiders within institutions designed to 'treat' outsiders. Of course this was an education for all. If you look through the booklets you'll find many examples of educational praxis explored by the project. I recommend everyone read it. However I want to mention just two more discrete examples:

The "Communication Snake"

This method was originally used as a research technique in 'Understanding Anytime' 1991 p. 7. The concept involves the consumer/researcher or consumer/educator acting as a conduit between two groups where they are presently great misunderstandings. In the beginning we used the concept to bring the opinions of consumers about acute hospital experiences to clinicians. Always starting with consumers, we'd ask them what they would like to tell or query clinicians. We asked them to be as specific as possible. For example, "why are seclusion rooms still used?" We'd then take the consumer question to staff and get a response which may be something like, "because sometimes people are a danger to themselves or others" (for example) and we'd take this back to the consumers... this would go on, back and forward, till attitudes had shifted. Sometimes they had shifted enough for both groups to feel safe enough to talk together in the one room.

Later we used this same technique for overtly educational purposes. An example was the Vignetter dialogue (p.117 in The Essential U&I). This involved consumers creating a vignette which generally implicated staff communicating or behaving in ways that hurt. We wanted them to be subtle rather than dramatically bad. Clinicians were asked by consumer educator how they could change the way the story went by changing the actions of the clinicians. They were not allowed to suggest changes to the way the consumer/s in the vignette acted or responded. The staff's suggestions were taken back to the consumers who made further comment and, if necessary, this comment was taken back to the staff. The Communication Snake wondering back and forward between consumers and clinicians minimises confrontation and enabling consumers to be free from their assumed role of placating staff; and staff to be able to react if they needed before concentrating on finding a solution to issues consumers have identified as important.

The Collaborative Committee (From 'The Chocolate Cake factor'

http://www.takver.com/epstein/articles/chocolate_cake_factor.htm)

In the U&I Project we first became interested in deep dialogue (see separate pieces on Deep Dialogue) through what came to be known as the Collaborative Committee. Our committee was different. In putting together the committee we wanted and needed around us and around the project we deliberately invited people who were vitally interested in consumer participation in service delivery. We did not select people because of their authority or position within the organisation and we did not select consumers who were necessarily representative of a

constituency. We said, “we are doing this project, who would like to join us.” Invariably what ended up happening was that we attracted both consumers and staff who had witnessed or experienced things within the culture of acute psychiatric hospital practice that needed to be changed. We described this method of attracting people as ‘organic’. It grew out of the soil of the project.

Secondly, we knew that there would have to be equal numbers of consumers as there were professionals at each meeting. The consumer voice would, we knew, be reduced to tokenism if this was not prioritised.

Instead of taking minutes we taped and transcribed each meeting because we accepted that the meeting itself was a microcosm of what happened in the real life relationships that play themselves out in a psychiatric unit. The taping of the meetings slowed down the thinking and forced all members of the collaborative committee to think about their language, to talk about their relationships with one another and to reflect collaboratively on their practice. So rather than a Steering Committee or a traditional research committee which would take on a management role for the project we developed as safe a place as possible that would also be a crucible for the fundamental issues that determine acute psychiatric hospital life.

In this collaborative committee we had an opportunity to:

...discuss the kinds of topics which at present rarely happen. You know when a committee gets into a very rare discussion about fundamental values, philosophy, purpose, and ‘what we’re all here for’... and everyone says, “Gee we never have this kind of discussion, this is really good, why don’t we do this more often?” And then the chairperson calls the meeting back by saying, “ Well I’m afraid we have to get back to the real business of the meeting – the staff’s leave provisions, the auditor’s report, the productivity savings the funder wants, and the quarterly statistics.

Our meetings operated more as ‘think tank’-type sessions about deep issues like:

- Stigma, dignity, respect and power,
- Ethics and ‘real’ consent,
- Consumer exclusion from the life of the hospital,
- What constituted personal experience of good practice,
- The pros and cons of psychiatric medicalisation,
- Relativist definitions of mental illness from the point of view of psychiatrists, police, policy makers, therapists, consumers etc.
- Fear and violence, and
- The impact of legislation

The taping and transcribing enabled this precious material to be used for later teaching.

Several highly successful projects grew out of the U&I project:

- Do you mind? The Ultimate Exit Survey (
- The Deep Dialogue Project
- The Lemon Tree Learning Project and
- The Lemon Looning Board game.

U&I won two national awards.

-**1995**: THEMHS (The Mental Health Services Conference) Partnership in Consumer Category Gold Award

-**1999**: Australasian Evaluation Society Caulley-Tulloch Prize for Innovation in Evaluation