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PAPER

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Topic: Applying Person-Valuing & Self-Determining Approaches to Rehabilitation and Supported Living Services

Title: Ways to make care more collaborative, empowering, accountable and joyous

Background: This paper reports on the findings of a three year community-based participative action research (PAR) study, conducted among 60 multicultural participants living with intellectual disability (ID) and/or mental illness (MI) in greater Sydney, plus volunteer buddies and 'aunties & uncles'. It was established to explore options for more person-valuing, peer supported approaches to supported living and community-based rehabilitation. Participants and their non-blood 'aunties & uncles' shared responsibility for all planning and delivery of the project, modelling ways of improving rehabilitation and supported living services, by making them more engaged with and accountable to consumers and carers.

Method: The project began in May 2004 with a live-in weekend workshop where over 100 people gathered to share 'Stories with Friends', in a narrative therapeutic way. Creative, celebratory and contemplative processes were generated among the large group and smaller sub-groups over the weekend, and some people formed into buddy pairs, to go on keeping journals together of their feelings and experiences over the following year. One year later in June 2005 another weekend workshop was held, and the findings of the shared journey together were explored, plus more contemplative and communal time spent together, and creative and celebratory times. Subsequently members of this community of belonging, or 'open urban tribe', met on a regular, rhythmical basis, establishing the interactive framework for more person-valuing rehabilitation/supported living.

Results: Arising from this shared journey together, and the reflexive PAR accompanying it, were sets of qualitative evidence, including the researcher's ethnographic journal kept throughout, continual conversations recorded to assess progress, buddy pair journals reflecting on the process, plus a documentary film and photographic essay produced during the period. Resulting from these collated inputs was a set of strategies for improved supported living and community based rehabilitation approaches, including recommendations for more engaged and accountable management. Also, the All Fruits Theory was produced, arguing for more inclusive mixed consciousness 'communities of belonging', creating better ways of being together for healing, growth and development.

Implications: The project showed, through evidence based on the testimonies of consumers and carers, and their self-determining involvement in running the project (through management committees and continual decision-making sub-committee meetings), that consumers and carers want more hands-on involvement in the rehabilitation and supported living services offered to people living with ID and/or MI; and that they are capable of being the drivers from planning through to service delivery – if they are provided with respectful, equally empowering facilitation.

The Design

This Participative Action Research project followed the Supported Collaborative Inquiry approach (Heron & Reason) to bringing together people of difference. It was called 'Going Walkabout Together Through The Suburbs' (GW3TS), and it involved introducing more than 60 young adults (about 18-35 yrs) living with mental illness and/or intellectual disability, and peers living without those challenges. Over the space of a year these people formed an open urban tribe, which then went on meeting informally over the coming two years (ie. 2004–2006). Volunteer 'aunties and uncles' (in the indigenous sense of 'older, caring mentor'), plus the young adults living without these identified challenges (but as it turned out, with plenty of their own) made up the rest of the tribe.

Some buddy pairs kept journals of their feelings and experiences on average every fortnight or so for the twelve month period 2004–5. Some of the participants met and formed friendships with their partners at the first 'Stories With Friends' start-up bonding and introductory training workshop, held at the Salvation Army Collaroy Conference Centre, on the weekend of 28-30 May 2004. At this event more than 100 people, who were mostly strangers to each other, gathered to explore how such a group of strangers could begin forming a community of belonging, or open urban tribe. Some of these people did get together as buddies during this weekend, others found a partner separately, and some remained involved without finding a special buddy.

The tribe celebrated its first 12 months together at another weekend workshop on 3-4 June 2005, and had a Finale on 1 July 2006, at a documentary film & digital photo screening and get together. Peer support groups were slow to form and needed more active coordination than the project was able to provide. An Advisory Group oversaw the GW3TS project on behalf of 'consumers' (a concept this project rejected, but chose to conform to, in trying to encourage more trials like this within the system of public agencies), as well as carers, and assisted with ideas and awareness raising.

The research was about recording feelings and experiences for about 18 months (during 2004-2006), including the self-reflexive thoughts of the researcher, and experimenting with the vitalising dynamic of forming and cyclically meeting in an open urban tribe. Within this gathering of people everyone was free to openly share their feelings and experiences, and get feedback and assistance with life growth and development. This was to show that people living with mental illness, or with intellectual disability, are quite capable of exercising self awareness and having a managing say in how their lives are organised.

Because GW3TS honoured the difference and diversity in consciousness of its participants, each equal to the other, and as teachers for each other in the exchange of 'Working The Business of Life' (WTBOL), the project nurtured mutual respect and learning among all participants. This feedback was as shared by almost everyone involved over the project's life. The journaling was based on a set of prompts designed to help balance self awareness, which the researcher had developed through an earlier research project in cultural inquiry, for a Masters Honours project through UWS (Lloyd 2003).

The Questions Investigated

1. What are the active attributes of consciousness, among those living with intellectual disability and/or mental illness, which can be acknowledged, nurtured and developed, to strengthen their balanced self awareness, and assist them to take more responsibility for their lives? (Plus those people who share this investigation with them).
2. How can these aspects of self awareness, of thoughts, feelings and experiences, be used to inform improved individual and group empowerment for these two groups, and improved rehabilitation practice, in communities of inter-subjective relationship and belonging?

3. By exploring collaborative engagement with 'the system' which serves these two groups, how can they be more effectively empowered, with appropriate support and resources, to manage the planning, policies, programs and service delivery, which largely determine their quality of life? And how can this sort of person valuing approach be applied in self-help, peer-supported, community-based rehabilitation within the system?

Method and Procedures

The two main approaches taken to engaging with participants throughout this project were Person Valuing cf. System Valuing, and Self Determining cf. System Determining approaches. Participants (consumers, carers, buddies and 'aunties & uncles') were all welcomed as equals, and treated each other as equals throughout. While not policed, this expectation became obvious to all involved, as soon as they took part in any of the project gatherings. It showed, in the way people listened and spoke to each other, and the way people waited for individuals to contribute at their own speed, in their own way. Respect for difference in consciousness was a foundation element in the process.

- **Making Care More Collaborative**

From the beginning of the project the Advisory Committee comprised representatives of all the varied participant sub-groups: people living with mental illness, people living with intellectual disability, carers of both these groups, volunteer buddies, and 'aunties & uncles' (ie. in the indigenous sense, of older mentors, with wide experience and often personal involvement as carers themselves).

Discussion occurred over meals in the researcher's home, or at others' homes, and the mood was always personally engaging and mutually valuing. All voices were equal, and this led to changes in plans whenever someone added new perspectives that may have been previously unheard – such as when events were being planned (eg. Christmas in Centennial Park in 2004), or activities for workshops and filming sessions were prioritised (eg. Filming at Lewisham Public School and then Rozelle Hospital grounds); the emphasis was on finding consensus but also going with one person's passion if that carried the feeling of the meeting.

Collaboration meant shared giving, and not always having 'the most sensible decision' dominate, as against eg. support for one person's most enthusiastic moment in the project. This way the tribe bonded into a deeper engagement with mutual purpose and intention, by joining forces to realise different members' dreams at different times.

- **Empowering**

Sometimes people would be encouraged to take leadership of activities they were scared of, and this would lead to feelings of achievement and success when those activities went off well. Even when they may have had some problems, the experience led to increased sense of self-worth and confidence to try another scary project next time.

'Performance' was literally a key learning area, as those living with Down Syndrome had little problem jumping onto the dance floor and leading the way for their peers living with mental illness. It was a liberating experience for many tribe members, including the volunteer buddies and the aunties and uncles. Many of them had had their own issues with lacking confidence in some of these aspects of life, and those had been hidden away for decades in some cases.

Empowerment came from mutual risk-taking, where our tribe's general 'can do' attitude gave many people permission to 'let loose' and give things a go that they would otherwise not have been game to undertake. By sharing the fear and the apprehension, all levels of

ability and types of personality had things to teach each other, about 'how to be with life's uncertain moments'. The decision to move away from overzealous focus on 'duty of care', that too often creates cautionary environments and stagnation, paid off in multiple ways, and no irresponsible circumstances occurred throughout the three years of the core journey together (2004–6).

- **Accountable**

Participants knew they could always voice their worries or concerns, and that the project was answerable to them. Whenever 'consumers or carers' came up with problem, the project would focus on those and decided quickly on how to adapt. This occurred from the very first weekend workshop in May 2004, when our first afternoon/evening sessions felt quite fraught. The strangeness of this whole experience, and the high level of concern everyone had to make sure everything went right, led to anxiety among all of us.

Debriefings were happening all over the community on the first night, and then after breakfast on the second day, the aunties and uncles and some volunteer buddies met to have a quick feedback/input session. There was some concern we were 'losing it', ie. not engaging enough with some participants from both major groups (ie. those living with mental illness, and/or those living with intellectual disability).

After half an hour of various views, the research/coordinator asked for 'one more go' at the way we were 'letting it flow' ('trusting the process'), and then we'd have another meeting after lunch, to review whether we needed a major shift in plans. The result was that everything came together 'like magic' (one of our most frequently used expressions about the whole project, and especially the 'vibe within the tribe'). Everyone then relaxed another notch, and we proceeded to plan from then to the end – 'leaving it loose'.

So the accountability factor was about ensuring we were applying the group wisdom to our 'Working The Business Of Life' (WTBOL), not that we kept preventing things from happening in the interests of 'risk management'. Accountability was through group conscience and staying open to the most silent voices, who could feel comfortable to express their discomfort at any time.

- **Joyous**

Because of the very relaxed atmosphere and openness in the tribe, people felt good about being together and this generated spontaneity on many occasions. That had a snowball effect, and things would get on a roll before we knew it. Celebrating, hugging, crying together when moved by others' sharing, holding arms and hands, it was a form of interaction that bred 'the magic' through open-heartedness.

Often we had no idea why it felt so good, because the very mysterious nature of our shared gifts to each other didn't fit any clear definitions. It was our metaphorical presence of being there for each other, one-on-one and in small groups, that built up the joy factor. Sometimes we would be struck by the wonder of it all – how a bunch of total strangers could come together, share love, and feel great. Joy was a definite outcome and a sustaining aspect of our embracing risk, and mystery and wonder.

Self Determining Approaches

The project was not based on any particular model. Its combination of participants and facilitators meant there was a lot of spontaneous decision-making. While the overall framing technique was to use creative expression, narrative witnessing and testimony, and shared

experience of filming and photography as a recording process, there were many sub-angles to this story.

Individual participants paired off with different aunts and uncles, and began forming relationships of mutual support. Different volunteer buddies formed into sub-tribes, to share their amazement at what was taking place in the company of their peers, living with different life challenges and different consciousness.

The process unfolded organically, as links were made between hearts, minds and souls. And so that led to feedback that changed the direction of some events, and influenced further gatherings. The self-determining nature of the tribe went through an almost respiratory process – breathing its thoughts in and out, and reflecting on what the group conscience wanted to do with this experience.

Ultimately the Advisory Group would oversee the large directions of the project, but day-by-day things were being assessed and changed among sub-groups to suit their own dynamic. The result of this self-determination was a vitality and dynamism that fuelled us all throughout the whole experience. It augured well for system–application at a later time.

Governance and Supported Management Delegation

- **Running the Project through an Advisory Group and Sub-Committees**

In the words of the system, this project showed that ‘consumers and carers’ want more hands-on involvement in ‘governance’. Their core role in running things for GW3TS was a crucial part of its success. While a plan and overall framework was there from the beginning, things kept being modelled by the group. Meeting about month in the first year, and then three-monthly after that for the next two years, the Advisory Group was the linchpin of the tribe.

The researcher, as key facilitator, was a resource for this group’s thinking and decision-making process. Then he would go off and make happen what they had confirmed as priorities. This showed itself to be a very effective model, and indicated that cost-effective coordination could happen by adapting such an approach within the system, if the over-bearing structures and reporting lines were removed from the foreground of community-based rehabilitation and supported living services.

- **More Engaged with and Accountable to Consumers and Carers**

While we had some glitches when people were unwell, the empowerment of consumers and carers created many more positives than negatives. When disagreements arose (as they often did in our ‘house meetings’) the process of allowing heated discussion and exchange of views and even prejudices led to deeper mutual respect in the long run.

Accountability meant a lot of reporting back and repeated discussions, when some couldn’t make meetings. But the ultimate effect was that agreement could be reached more easily, once the points of dispute had been aired, and then everyone wanted to ‘get on with the party’ of being together again. Engagement meant full involvement in decisions and faster achievement of the discerning view on behalf of the whole group – it felt very indigenous, in the ‘going round the circle’ way.

- **Shared Responsibility for all Planning and Delivery**

While the process may have slowed, the rewards from having our participants being the key players were so enriching. Activities that brought different players together (as caterers,

performers, recorders, or reporters from other meetings) led to new relationships and deeper understanding of our differences.

When one person fell out of the program, another would self-nominate to replace them. The organic nature of this tribal reflection generated its own sense of mutual responsibility, that often didn't get voiced, it just happened seamlessly. Meanwhile, buddy pairs were busy keeping journals and social engagements together, away from group events. It was a dynamic mix of different layers of engagement that created a deep impact when the whole group got together.

- **Risk-taking**

Trusting the people involved to know their limits, and to communicate their needs as things proceeded, showed itself to be a valuable philosophy and practice. The researcher's priority to invest in trust more than paranoid risk-management (akin to Patch Adams' approach to stimulating communities for health, Adams 1993) made some people nervous, but ultimately paid off. We had one major upset, when a male living with mental illness got over-attached to a younger female buddy participant and joint film project committee member.

In a moment of being peeved about the friendship not being closer, this male complained to the university ethics committee that he had been badly treated in the project. Two weeks later he had recovered and withdrew any complaint, and was feeling upset about having been upset. The young woman handled the incident admirably, and no hard feelings remained – but it had taken investment in a lot of facilitation and mutual discussion to work through this sort of inappropriate interaction. Such an approach seemed a small cost for having the benefit of much more freedom in the overall scheme of things, generating spontaneity and joyfulness across the tribe.

Person Valuing Approaches

- **The Structure of Feelings and Experience (SOFE) and MCRIDW**

From the researcher's earlier work (Lloyd 2003, Lloyd 2005), a framework for imagining the qualitative parameters of human consciousness had been developed. Described as the Structure of Feelings and Experience (SOFE), this framework was distilled from the analysis of culture and society, literature and art, by the two cultural theorists Raymond Williams and Bernard Smith.

The GW3TS project set out to explore how well participants could benefit from having the parameters of SOFE stimulated, in a setting of unconditional support and mutual respect. So various activities and stimuli were woven into the experiential weekend and other gatherings, to inspire expression of the six basic elements in this framework, summarised as 'MCRIDW':

- **Mystery** – By inviting the unknown and unknowing into our experience, we open ourselves to greater knowing, and different ways of being; this was one key message of the GW3TS experience of different consciousness, among people living with mental illness and/or intellectual disability; so the project went about creating shared spaces among people of difference, to experience the poetics of this mysterious learning about how 'to be' ('dasein' Fealy 2007) more lovingly and openly (Irigaray 2002);
- **Conversation** – By sharing our feelings and experience in open conversation with each other we are realising our humanity, our being as people of story; the stories of our lives are telling us; and GW3TS gave everyone a vehicle to experience that way of being together; this combined narrative therapeutics (White 2007) and their externalising conversations, with the metaphors of play (Meares 2007) and the witnessing and

testimony necessary to give voice to those otherwise 'disabled' by society, and often by the very 'support services' meant to be 'supporting' them (Goggin & Newell 2004; Hallahan 2004);

- Relating – Humans are primarily social beings, beings of relationship (Jackson 1998), and when we actively care for, and share with, each other, we are healthier as a result; so GW3TS used the Alcoholics Anonymous Twelve Step Recovery program maxim, that “the best way to help yourself is to help someone else” (AA Big Book 1993), and encouraged active caring and sharing throughout;
- Imagining – The ‘social imaginary’ is our great resource of dreams, inspired intuitions and insights from the universal human unconscious (Lloyd 2003, 2005), this was a key element used to stimulate energy shared among the GW3TS tribe, encouraging all sorts of different creative and imaginative expressions, both in the moment and with some time to prepare;
- Discerning – Knowing we belong, and getting feedback about ‘how we are being’ together, are basic elements in human sociality (Lloyd 2003, 2005), and these were used to generate one of the main tools GW3TS applied to exercise engagement among all its members (see ‘WTBOL’ below); it equated to what Ethan Watters found among his ‘Urban Tribes’, that “my tribe helps me be the best me I can be” (Watters 2003);
- Wonder – Without a sense of wonder, and the humility it breeds, humans become ego-bloated and insensitive to others, so GW3TS incorporated this regular celebration of the value in contemplating wonder, and communing with the wonder of being alive together and in the world, to ground our process in an embodied, shared reality (Lloyd 2003, 2005).

- **Working The Business Of Life (WTBOL)**

Mirroring and Feedback are some of our strongest tools for active belonging in groups, so GW3TS combined the techniques of the International Clubhouse mental health rehabilitation movement, with person-valuing approaches used in the Down Syndrome community in NSW, along with indigenous ways of using humour and ‘taking the mickey’, to balance everyone’s sense of themselves in the group.

The sharing of our stories, as both Witnessing and Testimonies (in the legal sense of ‘evidence in court’), created an empowering sense of being heard and understood, both for personal valuing about also for social justice empowering; this led to mutual nurturing and more intentional sharing, and through discussing the ‘issues of the day’ a sort of Reciprocal Mirroring gave the Feeding back to each other that made GW3TS’s dynamic so relevant.

- **Relations of Care and Celebration**

Combining what the American poet Robert Frost called the ‘work of knowing’ (Poirier 1977) with person-valuing approaches to care and celebration made GW3TS a particularly personal tribe to be in; it was not always ‘warm fuzzy’ through, this sometimes required firm boundary setting and times of upset about not having everyone’s immediate desires met, while the group determined what was best for all; but usually it would not be long before we were all sharing a laugh, even some tears had been shed along the way;

These Peer Supported Approaches to supported living and community-based rehabilitation showed that GW3TS had developed a dynamic that could be ‘cloned’ in other settings, for use by all sorts of groups: from addiction recovery, to trauma recovery, preventive ageing support programs, to consumers and carers in most multicultural social settings.

Playing and celebrating showed up as major elements in the healing dynamic of GW3TS. This form of revitalising, energising sharing fits Ryan LaMothe's work on vitality in psychoanalysis (LaMothe 2005), which informed the GW3TS interpretive process.

- **Interaction – I³R⁴C⁵**

One of the main findings of this work was that people get well, stay well and grow, when they can access rhythmical, interactive rituals of contemplation, communion and celebration. From the early work of Erving Goffman (1967) to later work by Randall Collins (2005), Interaction Ritual Chains have been shown to be part of natural human mutuality; the GW3TS tribe produced these rhythms 'without even trying', and they became a major indicator of ways to improve rehabilitation and supported living processes – through Interactive, Intentional, Intuitional, Rhythmical, Relational, Reciprocal Ritual Cycles of Contemplation, Companionship, Communion and Celebration (I³R⁴C⁵).

- **Meeting in the Circle – Interacting, encouraging Spontaneity (Intuitive)**

Every gathering involved participants forming into a circle and beginning with introductions and sharing around the circle. This led to follow-on anticipations and expectations from the last time people shared, and lots of cross talk, arising from news' about what may have happened with various life experiences that were evolving through the period of the project. The interaction was unforced, comfortable, often shy but quietly assertive, and frequently hilarious. Sometimes sad news came out and a shared sorrow or grieving would flow around the circle. There was an intuitive sense that people knew how to be with each other, and this energy of being became the major metaphorical experience that the project offered.

When the time came for Contemplating and Communing, it was as if we had formed into one combined heart–mind–soul unit; the group forming around the issues arising in people's lives, and sharing grief, joy, wonder and mystery; this led to stronger Companionship, so that the Friendships that formed kept evolving; some grew and parted, and others formed in their stead. It was a process of growth and development shared among all the tribe, and it provided a 'magic ingredient' to our gatherings that kept people coming back. The only thing that stopped our on-going connection was the researcher's need to go off and complete this sort of writing up of the process.

Results and Essential Findings

- Engaging with the active attributes of consciousness illustrated in GW3TS (SOFE, MCRIDW, WTBOL, I³R⁴C⁵) was critical to its success. Without a genuine relationship-based process, the project could have degenerated into another impression-management exercise like too many rehabilitation and supported living schemes to date. When participants felt acknowledged, nurtured and loved, they recovered, grew and developed. By strengthening their balanced self awareness, they were assisted in taking more responsibility for their lives. This then needed to be combined with management giving them an equal say in the management of their service policies, plans and delivery processes.
- These aspects of self awareness, of thoughts, feelings and experiences, informed improved individual and group empowerment for these two groups, by creating the GW3TS community-based, peer support, self help community of belonging (or open urban tribe). Such schemes would be easily repeatable, if managers of health and social services were willing to invest the trust and time that it takes, to build such mutual combinations of peer support among consumers and carers. If they did so, they would find that the 'energy of being' shared among participants

becomes the major metaphorical vitalising force behind successful rehabilitation, as the experience of GW3TS showed.

- By establishing mutually respectful collaborative engagement, between staff, consumers & carers of the supported living and rehabilitation systems, people living with difference can be more effectively empowered. GW3TS showed that they can play a role in managing the planning, policies, programs and service delivery, which largely determine their quality of life.

Strengths and Limitations

The project showed that one facilitator can effectively coordinate and bring to fruition the intentional gathering of an efficacious open urban tribe of 60 participants, over a two year period. This was mainly due to the equal sharing of management delegation about the way the project unfolded, in discussion among the participants and its Advisory Group. That very democratic approach gave the project its vitalising power and dynamic inspiration, shared among all the participants and their 'aunties & uncles'. No one felt disempowered, according to the evidence of their shared input throughout, or that they had to wait to be given permission – it was 'their project' and the facilitator was just enabling their own wishes to see it go on with this self-determining force.

However, the project was also limited by not having mainstream funding to support the Facilitation function. The researcher had to go on funding participants to attend events etc, because so many were living in poverty on the Disability Support Pension. And this was on top of having to work pretty well full time to afford to live and go on supporting the project, while trying to write a PhD about it.

The mode proved it could work in mainstream situations, if management allowed self-determining micro-management among the participants themselves, along with respectful and enabling facilitation, not the sort of patronising 'expert knows best' style that dominates disability support and mental health rehabilitation circles in Australia and other western nations.

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