

# THE ROAD WAY: A BOTTOM UP COLLABORATIVE APPROACH TO CONNECTING YOUNG PEOPLE AND THEIR FAMILIES TO EARLY PSYCHOSIS SERVICES IN NORTH QUEENSLAND

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## ABSTRACT

*Intervention in early psychosis has gained momentum over the past decade, with a growing body of literature focussing on best-practice principles and models of service (Herman-Doig et al 2003). The potential benefits of early intervention include reduced morbidity, more rapid recovery, better prognosis, preservation of psychosocial skills, preservation of family and social supports, and decreased need for hospitalisation (Edwards and McGorry 2002).*

*In Australia the majority of service development and research comes from large metropolitan services with access to early psychosis specialists, infrastructure and resources that are often out of the reach of regional centres.*

*Recovery of Attitudes and Dreams (R.O.A.D) is a partnership between Mental Illness Fellowship of North Queensland and Townsville Integrated Mental Health Service that reaches out and responds to the unique challenges of early psychosis intervention. It provides best-practice social, psychological and biological treatment for young people and their families in a regional setting, with efficacy that is comparable to larger programs in major service centres.*

*This paper explores the evolution of ROADS. It will demonstrate that with creativity, connection, collaboration, and a clinician-driven bottom-up approach, regional service centres can provide a best-practice EP service that mirrors those in major metropolitan centres.*

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When we come to conferences like TheMhs, we are made aware of just how many innovative programs are developed in response to local service needs. This array of services reflects the drive and initiative of many who work in the sector to improve the way that services are delivered. Sometimes these programs are successfully ingrained into mainstream practice but sometimes they lose impetus and disappear when resources, both human and monetary, are withdrawn or different priorities are identified. In talking about our program, The Recovery of Attitudes and Dreams (ROAD) program, we are looking at a program that has survived and grown within our regional setting. What we want to share with you today are some of those aspects of our program, that have firstly guaranteed its place within this district's service delivery, and secondly that have ensured that we can offer a viable and effective early intervention service that is responsive to our local community.

The ROAD "way" is a term that we coined that looks at the collaboration of two mental health organizations within our region. It is the "lived experience" of ROAD. Our experiences are not unique, but our bottom up approach has worked to keep the practice of early intervention and integrated individual and family practice firmly on the agenda in Townsville.

This program, as our title suggests, is a specialist early intervention program for individuals and their families experiencing their first episode of psychosis.

It is a formal partnership between Mental Illness Fellowship of North Queensland (MIFNQ) and Townsville District Institute of Mental Health Services (TDIMHS) .

The program comprises of a number of components, which are offered as an adjunct to standard care. Families are offered a six week psychoeducation program along with timely and flexible information and support, access to support groups and opportunities for peer support and social activities. This part of the program is facilitated by the Fellowship with referral and support from TDIMHS. TDIMHS in turn, takes responsibility for the young person's component where young people can be involved in a four week group based psychoeducation program or individual psychoeducation and support.

Specialist clinical care and group based, regular social activities are also offered. Within this program ongoing training and liaison is available to the local community (MH, primary health care and community).

We believe that the ROAD program represents an alternative way of offering a sustainable mental health service. What makes it different is...

The program, as a working partnership between the government and non-government sector, has its foundation in both clinical and non-clinical practice. We know that working within an early psychosis framework it is imperative that the psychosocial perspectives of recovery for the young person and their family have equal weighting with clinical care. For the families and individuals involved in the ROAD program this has translated in to actual opportunities for community linkage for things like low cost accommodation, employment services and social and recreational activities. The Fellowship has active links with other NGO's and maintains a number of residential properties.

Very often it this has meant alternative access points in times of stress. Family members often make contact just to check or to manage their own fears and anxieties.

For us as workers it has been about valuing and learning from the expertise of each member of the team. That is, the workers, the families and the young people working together in this very complex area.

In the ROAD family education program, clinical staff have contact with families in an education role. This activity breaks down barriers in communication and builds a context around the young person being treated. The education process ensures that families feel valued and included in their young person's care. Having this happen outside the clinical setting creates a place of respite for the family where their needs are met and they have access to their own support and information.

Our program evolved and continues its development from those actually working with young people and their families. It has been a response to identified need without any initial allocation of resources. This will be elaborated on a bit later but essentially individual workers stepped outside their usual practice worked, and continue to work, creatively and collaboratively to build this service.

The program is based on "best practice models" and integrates individual and family interventions using clinical and community based resources. In our program we have modelled our practice on the EPPIC model but have integrated other family models such as Robert Bland's model for family support and the principles of the World Schizophrenia Fellowship for providing services to families. The delivery of family support is based on a 20-year history of extending services in this area. Our young person's program was developed again through this partnership. It draws on the principles of the family program but obviously differs radically in its language and delivery. Whilst it has a clinical focus it embraces the notions of understanding and recovering from the experience of psychosis within the same framework as the family program.

Those first initiatives to offer family psychoeducation have evolved into model of service delivery that started as a bottom-up approach but have begun to develop into a successful bottom-up, top-down service model. It now has the support of district management together with involvement and ownership by those providing the services and the individuals and families its supports.

#### **ROAD Bottom-up Approach**



To examine the lived experience of the ROAD program we need to look at this model in terms of the influence it has had to maintain and grow the program

In the beginning and throughout the growing stages the program has relied on key people. These have been the people with the vision and motivation to work outside their given roles and seek out others with the same attitudes.

Their participation and vision goes way back to 1996 and the first Early Psychosis Conference in Melbourne. Attendance at this conference by key workers prompted a local response and a community forum was held in 1998 to identify local issues. Following on from this, two workers from MIFNQ and TDMHS started work on developing a specialised family psychoeducation program. This program has been delivered faithfully a number of times each year since that time. Some workplaces changes and the recruitment of others who were interested saw the expansion of the program to provide individual and group based specialised programs for the young person. Again it was key workers who drove this development.

The success of the program measured through program evaluation saw the program accepted as a quality activity for TDIMHS and the appointment of an Early Psychosis Co-ordinator.

Along with that came the allocation of some funding to buy resources and fund social activities.

Within the EPC role and with the backing of the ROAD steering committee (where both organizations are represented) referral systems, data collection, standardising of programs, practice manuals, policies and procedures were developed.

All this has led to the entrenchment of the ROAD program within the TDIMHS service framework and the support of clinical directors and service co-ordinators.

One of those interesting by-products of our program, developed through a bottom-up community collaboration, is that it has also circumvented (almost inadvertently) some of the barriers that impede service delivery to families and young people. Our framework in being able to separate out family and their young persons issues within an integrated service, accounts for many of the problems encountered by other services such as the

- allocation of clinician and administration time. In ROAD this is a shared responsibility.
- providing flexible ongoing support in the time frames that the family and young person can accept it.
- standardising practice and program delivery through stability of staff and facilitators.
- being mindful of and responsive to the local organisational issues and community cultures within our region (Dixon, 2000).

What I'd like to do today is present a four step formula for perfect collaboration. Unfortunately however, no such thing exists. If you are here and have one, please see me afterwards- together we can be very rich. It's only after five or six years of actually living it that we can look back with careful reflection at the influences that were helpful for collaboration, and those that weren't. What I'd like to do over the next few minutes is present four influences of collaboration that stand out in our own experience. And while they come from our experience they can be easily generalised to other mental health settings- so hopefully you'll walk away with something, at best inspiring or at least useful from our experience.

### **Born out of Frustration**

The first dynamic is that it was a partnership **born out of frustration**. It was the late nineteen nineties a body of early psychosis literature was growing. Stories were emanating from the south about creative interventions with great efficacy for young people and their families. But here in Townsville our capacity was already stretched to the limit. On the one hand we really didn't have the space for proactivity and creativity, but it remained obvious that as a service we weren't providing a best practice response for young people and particularly their families.

There was a real **groundswell of frustration** among clinicians, NGO's, family members and consumers that would later prove invaluable to the success of this program.

While many top down programs find their genesis in a new policy, priority, trend or even damaging headline, a bottom up collaboration often begins with a groundswell of anger at the coalface.

### **For Building Capacity**

From this frustration it became clear that if we were to provide best practice care for young people and their families, we were going to need to undertake considerable **capacity building**. With no additional resources to initiate the programs, the obvious solution was to collaborate with the NGO sector - to engage in an almost unprecedented level of cooperation and coordination. The Fellowship had always done family work- and they were good at it. The Government had always provided clinical care...but never had we aligned so closely as part of a single treatment package equally focussed on equipping the consumer and building capacity within their family. The collaboration provided instant improvement in our capacity to work creatively, proactively and deliberately.

Where many programs from the top down begin with an instant injection of funding, programs developed from the bottom up are often left to muster every inch of capacity by strategically reorganising already existing resources.

### **Widespread support and goodwill**

With widespread frustration now harnessed and service capacity increased the third consideration in our experience was the widespread support and goodwill. In practical terms this meant clinical staff volunteering to accrue TOIL in return for after hours group facilitation, the team agreeing to release a clinician from case management for the coordinators role, managers providing administrative support, stationary supplies, use of vehicles, and some money for barbecues and sporting equipment.

The bottom up development of the ROADS program, without any executive mandate, priority or resources, may have been the reason it was once described by a senior manager as a 'sexy fad'. Indeed early psychosis intervention can be sexy- sexier at least than chronicity.

### **Mutually beneficial**

So how does a government agency and a community organisation, with their vastly different philosophy, resource base and culture, who more often bang heads together than put their heads together, actually manage to coordinate care? The answer has been to focus on what is mutually beneficial. Both organisations have benefited from better working relationships, opportunities for PD and training, promotion and funding, the ability to rise above resource gaps and of course a greater capacity to reduce the burden of mental illness on young people and their families. Sure, there have been differences in philosophy and treatment approach along the way, but a continual focus on the mutual benefits of the collaboration has ensured a good working harmony.

### **Then later... formalisation**

Finally, consistent with bottom up development, the formalisation of the programs, positions and partnership within ROADS occurred some two and a half years after the service had evolved. Of course, there are risks involved with running things informally for such a long time. Without the creation of permanent positions, partnership agreements or program manuals, any initiative runs the risk of becoming a distant memory. For us it was about growth and sustainability. Roads had come to a point of acknowledging that now we have a working and established intervention, let's consolidate and make it a permanent part of the service. This took the form of the coordinator going 'off-line' for six months to document and evaluate the program, and make a set of recommendations for its future development. Management has so far remained committed to these recommendations.

In Summary- collaboration was once described as something that "enhancing the capacity of the other partner for mutual benefit and common purpose" and as something that "requires each partner to give up part of their turf to the other agency to create a better or more seamless service system." This is the ROADS partnership in a nutshell.

Thankyou for baring with us this afternoon...we will now answer any questions from the audience.