Presentation to HCQ Forum 2016

Beyond a seat at the table

Co-presented by Neil Ryan and Pat Ryan, Carers

Introduction (Pat)

Good afternoon. We will start by painting a picture of who we are, where we live, the central role of caring in our lives, why we came to the table and where we go from here, finishing the session with a DVD of a care and consumer led event at the Empire Theatre in Toowoomba in Oct 2015.

We are both carers of family members. We live in the Southern Downs. I live in Killarney, just a few kilometres from the border with NSW. I provide back-up support and help with transport for my son Neil and daughter-in-law who live in Warwick, approx 35 klms distant. I served as Carer Representative on the Partners in Recovery Consortium for the Darling Downs and South West Qld from 2012-2015 and worked casually as the Capacity Building Project Officer for 15 hours per week.

I also support another family member with a physical disability who lives and works here in Brisbane. He undergoes periodic support during episodes of surgery and aftercare. So, a lot of travel and stay-overs involved.

Moving between caring for someone with a physical disability and someone with a mental illness I see the opportunities for working together to utilise the skills of one to address the physical and mental health needs of the other.

Introduction (Neil)

I live in Warwick and care full time for my wife who lives with severe and complex mental illness. In addition to the performing all the daily work of our household I also effectively fulfil the role of case manager for my wife who lives with complex mental illness.

I organise my wife's medication dosage for the week and note what scripts need to be written by the Dr and what scripts need to be filled. When adjustments are made by the psychiatrist to the type or the dosage of medication I observe any changes in mood, or overall wellbeing in my wife, and discuss the results with the doctor and the pharmacist.

I have developed a good working relationship with the local pharmacist who prepares my wife's medication and have found them to be very helpful to us in managing medications.

I organise my wife's appointments with the GP, Psychiatrist, Psychologist, PHAMS worker, etc. I make sure my wife showers every day, brushes her teeth, eats a healthy and balanced diet, gets exercise, etc.

Staff often have a simplistic view of recovery and see only how my wife presents in public. They do not see the daily struggle to maintain that life.

On top of that I try to organise my wife's day so that her focus is on positive things and not in yelling at the voices in her head or threatening self harm. These are aspects of my wife's illness that are rarely seen by mental health staff, especially since she was discharged from the AMHU and lost case management support.

I encourage my wife to interact with her PHAMS worker and help support her in maintaining contacts within the community. I organise her bills and pay them.

I am the linchpin in all interactions between the world and my wife and that world is getting more complex. With implementation of the NDIS in Qld I will need more targeted information, training and support in order to successfully navigate NDIS and gain the support package that she needs in order to lead a fulfilling life.

Overview of the local service scene (Neil)

I will quickly outline the local service scene so you get a picture of the context in which we operate and why we think partnerships between services, consumers and carers are so important.

The Southern Downs is an area of 7,120klms^2 stretched from the border with NSW to the Toowoomba region in the north and west to Goondiwindi with a diversity of age, gender, ethnicity and needs in the population.

There are limited health services in the Southern Downs and those services that do exist are stretched to provide emergency support to the local community.

Wherever family appear to be acting in a caring way they are largely unsupported by Adult Mental Health Unit which has implemented a practice of discharging people like my wife, effectively leaving all of their care to family.

There are no psychiatrists based in Warwick. There are a number of private psychologists in the region and most are heavily booked.

Community supports are underdeveloped, mainly provided by outreach from Toowoomba.

Carers Qld and ARAFMI are active in the area but many carers are unable to take up the opportunity for support groups and training they provide because there are no community based supports for people with severe mental illness.

We have yet to see an intersection at the practice level, between community based support and clinical support, that meets the needs of the consumer and incorporates the role of the carer.

Our immediate goal for our region is for the establishment of a Neighbourhood or Community centre which would provide much needed social and recreational support for a diversity of community needs.

Why we came to the table and where to from here (Pat):

We both became carer advisors on the Consortium for Partners in Recovery for the Darling Downs and South West Qld to work for better mental health services in the region.

The Consortium provides us with a seat at the table and the value of this to us cannot be overstated. It provides us with an opportunity for our experiences to be heard first hand and for the lessons from those experiences to be incorporated into service delivery.

It also gives us good insight into the complexities faced by service providers trying to balance budgets, set priorities and meet a myriad of needs. in other words, it gives us a ringside seat view into each other's world and increases mutual understanding which, in turn, helps us to find solutions to problems we share in common.

We would like to see this model of community dialogue extended across the health and community sectors since both have a vital role in supporting community wellbeing. For example, why not have a health sector manager at the same table as a community development worker, a consumer and a carer when it comes to planning integrated health and community support?

We are delighted to see that carers are recognised in legislation at State and Federal levels and there is now more support for inclusion and involvement of carers although Implementation of these provisions is sometimes lagging at the service delivery end because the provisions do not yet have full statutory authority. If you don't have to do something chances are you won't.

There is scope for more training in this area so staff know how to include and involve carers, particularly in the area of respecting the information that accrues to a carer from living with the consumer. We need to develop mechanisms that allow this to happen without further impinging on staff time that should be spent with the consumer.

We believe the time is right to recognise that carers form part of a home based workforce that provides necessary daily living support. This role will be further extended by the implementation of the NDIS. It is NDIS policy to involve carers in discussions with service providers to secure support for family living with disability or mental illness.

As the health system works towards the goal of fewer hospital admissions and a greater emphasis is placed on consumer and carer involvement in maintaining good health, we see the need to move beyond a seat at the table to greater involvement in shaping and delivering service.

There are some challenges to fully appreciating the work done by carers. Some of it arises from the nature of the work itself and the inherent difficulties society has in properly valuing voluntary and home based work. Shades of the child care debate here.

A word about the challenges ahead...

Some challenges arise from Commonwealth initiatives such as the Cashless Welfare Card which means that people of working age on income support, including carers and disability support pensioners, can access only 20% of their payment in cash.

The card was sold to the public and the media as a way to stop alcohol and substance abuse and gambling but targets everyone of working age on an income support pension including carers and disability support pensioners. It might be ok to pay wave in suburban Canberra or Brisbane but try it at country markets where cash still applies and see how far you get.

Local markets make sense for people on low incomes and very valuable to small local emerging economies. The Cashless Welfare Card is counterintuitive to greater individual choice and control and its economic impact could really reduce the participation rates of consumers and carers in Forums such as this.

Finally we need to re-think the language of the sector, moving away from 19th century concepts of charity, welfare or philanthropy that trap carers and consumers in the role of passive recipients of charity, towards a new lexicon that recognises carers as active agents for change in their own lives and the lives of their families and communities.

There has to be mutual respect if we are to progress the idea of inclusion and involvement to the fullest. Can we foresee the inclusion of carers as co-workers in flexible, work-from-home, part-time or casual roles that values the carer to the fullest?

Introduction to Big ideas Big Night Out partnership (Pat)

We would like to share a DVD with you. It is an example of a partnership between carers, consumers and four partner organisations -Lifeline Darling Downs and South West Qld, Mental Illness Fellowship Qld, Toowoomba Clubhouse, Richmond Fellowship Qld which culminated in a community carnival and Q&A on mental health, staged at the Empire Theatre in Toowoomba during Mental Health Week in Oct 2015. The result was Big Ideas Big Night Out. The evening featured Associate Professor John Mendoza, Qld Mental Health Commissioner Dr Lesley van Schoubroeck, the Mayor of Toowoomba Regional Council, the Qld NDIS Ambassador Karni Liddell, local consumers and carers in a debate about future directions for mental health care. Big Ideas Big Night Out attracted an audience of 350 people from around the Darling Downs. It showcased the creativity and diverse talent to be found among people living with mental illness who enlivened the evening with live performances, art work, sign making and catering. Here is Big Ideas Big Night Out.