

Hume PIR Systems Change Projects

Brief Summary and Overview of Outcomes to June 30, 2016

1. Background:

A key component of the PIR program is 'to improve the system response to, and outcomes for, people with severe and persistent mental illness who have complex needs'. Hume PIR commenced addressing this by developing a systems change 'discussion paper'¹ and then a further paper clarifying and defining systems change.²

Systems Issue: A system issue occurs when an element of a system fails to deliver the outcomes for which it was intended or there are unexpected outcomes which have a negative impact on the population it was designed to help.

2. Addressing Systems Issues:

Initially evidence of the need for systems change was gathered through the observation of Consortium partners, and the information gathered by Support Facilitators. As PIR developed and the CIMS was developed and utilised, particularly for producing reports, a further body of evidence was gathered through the data generated on the CIMS. In early 2015 a consumer carer forum was held which resulted in additional evidence from consumers which complemented all of the other sources of information. At this point the Consortium requested and were provided with a summary of the emerging systems issues and relevant evidence.³

Hume PIR undertook a number of small and large systems change projects between commencement and June 30th 2016. These projects can be divided into four main categories:

- 1) Support Facilitator Organisation Led Projects
- 2) Consortium driven projects
- 3) PIR lead agency driven projects
- 4) Innovation Grant projects

An overview of each project and the outcomes it produced is provided below.

3. Projects:

Regardless of who was undertaking the project to address systems change, there were basic expectations within all grant contracts. These were:

- The project would be overseen by a reference group or steering committee which must include a consumer and wherever possible clinical MH service provider(s) and non-mental health service providers (as well as community MH providers who were often the project lead).
- An evaluation plan must be provided and implemented.
- Outcomes must be identified and reported.

¹ HUME PIR Consortium 'Discussion Starter: Systems Issues'

² Hume PIR System Change Framework (revised July 2015)

³ Discussion Paper – Systems Change Priorities and evidence Sept 2015

Support Facilitator Organisation Led Projects

To ensure that support facilitators were able to be involved in not just identifying but also addressing systems issues locally, each host organisation was expected to identify an issue which they believed they could address at a local level.

I. **ACSO intake:**

This project sought to ensure that the new system to access MHCSS in Victoria did not leave people on a waiting list when they could be eligible to access other services ‘..that the person at that entry point needs to ensure that people are referred on to appropriate services and not just placed on the wait list for MHCSS..’

The SF involved advocated to ACSO with little response. The Hume and LMM PIR managers also advocated at a state-wide level, which included negotiating with ACSO’s state clinical services manager; delivering training to ACSO state-wide intake staff and advocating locally with ACSO service officers.

Outcomes: Some acknowledgement of options for referral other than MHCSS by individual intake workers, but not through any systematic approach. Increased referrals to PIR.

II. **Connecting to Culture**

It was identified through consultation with Aboriginal and Torres Strait Islander people that living with mental health issues can lead to a disconnect from community and that disconnection further exacerbates the mental health issue.

Staff at the Albury Wodonga Aboriginal Health Service were provided with Aboriginal and Torres Strait Islander Mental Health First Aid. Two groups (men and women) were established to focus on a mixture of cultural activities, and Aboriginal and Torres Strait Islander people with MH issues encouraged to attend.

Outcomes: Increased awareness on how to assist community members and the stigma associated with mental health issues. Increased engagement and connection of individuals participating in group programs.

III. **Project Mindful**

There were no options for access to therapeutic interventions for people with a borderline personality disorder diagnosis in Albury, if those people were not clients of community mental health. Coupled with this it was often very difficult to access Community mental health with such a diagnosis. Project Mindful provided access to training in Acceptance and Commitment Therapy for twenty staff in five local organisations all of whom signed an MOU committing to delivering ACT in a range of geographic locations across the PIR catchment.

Outcome: The commitment of 5 local organisations to deliver accessible Acceptance and Commitment Therapy programs to people with a diagnosis of Borderline Personality Disorder across the catchment area.

IV. **Mansfield Mates**

Sought to specifically address the issue of community inclusion, and create an environment where volunteers are used to assist those people in our community experiencing mental health challenges to access daytime activities and increase their social connectedness to their community.

Outcomes: Adult education, local government, community mental health, carer, PIR participant and the host organization (Wellways) have met regularly and engaged in discussions about community inclusion. Four volunteers have been trained and registered

to provide support and three people with MH issues have registered to be 'matched' with a mate.

V. Volunteer Visiting service Wangaratta

Develop a bank of volunteers that participants can access to facilitate normalising social inclusion. Build up the capacity of the volunteers by educating them in mental ill health and therefore enabling them to be able to respond to the needs of the participant as required. Another element of the Volunteer Program is community education. The volunteers would also generate community awareness about mental illness.

Outcomes: Consumers have reported feeling more socially connected and attributed this to being able to participate in normal social outings. Support and training needs clarified for volunteer roles of this type more broadly.

VI. Questioning the Service Response to people with a Borderline Personality Disorder

Provide a review (research) into service access and response to participants diagnosed with Borderline Personality Disorder (BPD) within the Hume region. By conducting a review into service access and response, it will give a more accurate picture of what the system currently does vs. what services are funded to provide within the Hume region.

Outcomes: The nature of this project was such that outcomes are in fact recommendations:

- The steering committee recommend and are committed to a launch of the research report – celebration, distribute and promote information;
- Develop a booklet of individual stories, de identified honouring people's stories and informing the sector.
- Continue to seek opportunities to present the project keeping the conversation current and providing the research to inform practice and ideally implement change. For example application to present at the Australian Rural and Remote Mental Health Symposium 2016 has been submitted.
- Steering committee suggestion to nominate research project for TheMHS award.

VII. Addressing Hoarding and Squalor Behaviours

To identify and implement strategies to effect changes in the way hoarding and squalor behaviours are viewed and addressed, particularly from the perspective of local government.

Outcomes:

- Consumer involvement and contribution to the project led to a better understanding of hoarding through the mind of the individual with lived experience.
- Interest and support from Local Government to intervene and seek community mental health assessment before enforcement.
- A draft policy was produced by Berrigan Shire '*Local Government – Hume PIR Hoarding Project Diversion Policy (Hoarding Disorder)*' and was distributed to MLHD Deputy Director, Albury-Wodonga Health, the SFs and staff within Berrigan and Greater Hume Shires for comment. This revised policy will be presented to BSC and GHSC at their October Council meetings and the intention is that this can be adapted by and utilised as appropriate within other shires.
- A community brochure, explaining hoarding and squalor behaviours has been developed and will be available for wide distribution shortly.

Consortium Driven Projects

Initially the Consortium utilising their own observations identified two key systems issues on which to focus. 'Accommodation; Pathways through the Jungle'; and the 'Interface between community and in-patient facilities'. With the increasing amount of evidence available as PIR developed, the Interface Project grew and developed further. By early 2015 the issue of Stigma was recognised as a massive contributor to systems issues and the Consortium directed that along with the 'Interface between community and in-patient facilities' which was by then referred to as the 'Supportive Discharge project', Stigma would be a priority for Hume PIR.

I. Accommodation: Pathways through the jungle to housing and accommodation

A small working group was established to explore what accommodation options were available for people with a severe and persistent mental illness, how they were accessed, what gaps or blockages existed and how they could be fixed.

Outcomes: The group developed recommendations which were provided broadly across the MH and Housing sector:

- Better and more synchronised data recording in the mental health and the housing/accommodation sectors.
- Crisis focused mental health training for homelessness workers.
- Tenancy training for mental health workers.
- Interim arrangements between accommodation providers, homelessness workers and mental health workers when supporting people with a mental illness in housing crisis.
- Increased access to 'tenancy saving' housing programs as secondary supports to mental health workers.
- Understanding how and why to make referrals to other sectors

II. Interface between in-patient and community

This project has been discussed in an ongoing way for over two years. Whilst everyone agreed it was an issue it initially failed to gain any traction with Albury Wodonga Health, the provider of in-patient services across the catchment. Further evidence was gathered, particularly through consultation with consumers and carers and the momentum to address this, particularly in relation to discharge planning grew slowly. After many discussions and sharing of data the 'Supportive Discharge Project' was initiated and led through Albury Wodonga Health and Hume PIR Consortium member agencies. AWH are now firmly committed and engaged partners. This project is developing systems and procedures to ensure a recovery focussed discharge process exists which supports people with severe and persistent mental illness who access the Albury Campus of AW Health, particularly Nolan House.

Outcomes: This project will continue to ensure referral pathways identified and supported through its activities provide supportive discharge and include reference to the NDIS

III. Reducing Stigma

This was a multi-faceted, multi strategy approach developed jointly by Hume and LMM PIR with Murray PHN as the lead agency. Consumers identified a key issue in accessing support to be stigma, and specifically stigma that manifested in the mental health service system.

In Hume, the approach utilised the following strategies:

- Three forums jointly referred to as 'Exploding the Myths' which were developed in response to consumer's suggestions and initially supported in a project officer capacity by a person with a lived experience:

- Focussed on the diagnoses of Bipolar Disorder; Schizophrenia; and Borderline Personality Disorder.
- Coordinated jointly by PIR staff, consumers and relevant stakeholders.
- Providing stories of hope and recovery, of successfully living with such diagnoses.
- Providing accurate information about the diagnosis from respected professionals alongside people with the lived experience.

Outcomes: The forums had a significant impact upon those who attended and participated and a positive message in relation to mental health has been spread into the broader community. The forums were positive experiences in relation to mental health and highlights “contradictions to diagnosis”. The forums were an example of collaboration between services and consumers and this facilitated a shared learning that hadn’t been accessed before.

- Inviting submissions for ‘Reducing Stigma’ activities utilising grants to organisations for amounts up to \$5000.00

- Pharmacy Guild provided Mental Health 1st Aid training to pharmacists across the PIR catchment in Victoria

Outcome: Participants reported a strong endorsement and recognition of the value of the training and the support that PHN/PIR are providing to increase awareness and reduce the stigma of mental health issues in regional areas.

- Gateway Health – two phase community development project utilising theatre as a vehicle for social change. In this case the development of, and then performance, which reflects participant’s experience of ‘Hearing Voices’. The ‘opening night’ formed part of one of the forums in the ‘Exploding the Myths’ series.

Outcome: Participants felt empowered and learnt about themselves from the process of sharing their experiences. The impact on the community more broadly was a shared understanding and empathy for people who hear voices and an increased desire to listen more and judge less. Further opportunities for sharing the performance and its messages in other regional communities are now available as a result of the project.

- Men Shedding Stigma – a project utilising the Stigma Charter and assertive ‘in-reach’ to reduce barriers to accessing the Men’s Shed program in rural areas for men with a diagnosis of mental illness. To support Men’s sheds to operate free of stigma and be a welcoming/supportive space for all men with or without mental illness.

Outcome: The project has allowed open dialogue and a framework to address stigma. The Sigma Charter is being implemented into current practices and policies of the organisation with progress monitored through monthly meetings. One participant with a lived experience of mental illness indicated that since the project began, the Men’s Shed has started to display posters and material aimed at breaking down the stigma of mental illness and that he felt more comfortable being a member with that information in the public arena.

- Contributing to the development and promotion an organisational charter to ‘Stop Mental Illness Stigma’

- Organisational Charter and resources developed and distributed. Consortium organisations and other partners invited to sign up. Active promotion of the Charter and resources through PIR Network.

Outcomes: Clearer understanding of stigma and evidence based strategies to address in the PIR organisations and greater networks. Nearly half of Hume PIR consortium organisations have signed the Charter at the time of writing.

- Build consumers capacity to use their own stories to create change:
 - Storytelling Training developed and run by the Health Issues Centre was offered to interested consumers and carers. The training was accompanied by support and information to access a range of speaker's bureaus for people with a lived experience of mental illness.
 - Stop Stigma Ambassadors proposal – in response to consumer interest a proposal to involve consumers as ambassadors for the Stop Stigma Charter was developed. The proposal will be considered at the upcoming Murray PHN Stop Stigma Working Group.

Lead Agency Driven Project

Family Connections Project

In tandem with the other two projects which were seeking to impact the access of people with a Borderline Personality Disorder to support and information, the Hume PIR Intake Triage Clinician in partnership with a carer delivered the 'Family Connections' course to carers of people with a BPD diagnosis.

Outcome: Participants indicated that the program increased their knowledge and understanding of the diagnosis which has in turn enabled them to better respond to the person in their care, and so increase their own well-being. The project also enabled the voices of carers to be heard in developing solutions in related projects, namely, reducing stigma and access to support and information.

Innovation Grant projects

Innovation grants were also offered to the broader community to address systems change, as a result four projects were undertaken:

I. Unfogging the Future 2

Unfogging the future is a parenting program for targeting parents who have a mental illness. It had been in existence for some years and was identified as deficits based and not reflective of recovery practice. The project, a partnership between Charles Sturt University and Gateway Health, sought to re-develop the program to be more practical, strengths based and with a recovery focus.

Outcomes: The pilot reinforced the need for flexible delivery of a parenting intervention for people with a mental illness. The feedback from participants was that the group provided a non-threatening environment that promoted parenting strengths despite the struggles associated with mental illness. The participants stated that they felt listened to and that their struggles with mental illness did not reflect their ability to parent. All who participated in the pilot are still engaged with Gateway Health services with 2 participants (1 participant was the consumer rep on the working group) looking at volunteer roles rather than as service users. The need to continue to develop the program was reinforced as the content was not as appropriate for parents of children

of all ages (needed more specific modules). The modules in the pilot were strength based and Recovery focussed, and although this was recognised as crucial to the engagement and personal outcomes, the participants wanted more specific information about Mental Illness and where to find supports. The program is continuing to be developed and modified to reflect and contain the feedback, and ongoing evaluation and consumer feedback will be essential to the final outcome.

II. Bhutanese Young Carers

Gateway Health currently offer a program to young people who are carers of parents with a mental illness (Paying Attention to Self - PATS). In Wodonga there is a growing Bhutanese community. Many of these have a refugee background and are living with a mental illness. They have often lived in camps for over 20 years and have a poor understanding of western mental health care. Their children often find themselves in a carer role. This project sought to develop a young carers program similar to the PATS program but modified to meet the unique cultural differences of the young Bhutanese carers.

Outcomes: Participants developed a greater understanding of stigma, impacts of being a young carer; of own self-care and factors that influence their own well-being. Partnerships between Bhutanese community leaders and services are ongoing and will influence future planning. One of the key findings from the evaluation was that the young people were able to develop a shared understanding of what it's like to not only be a young carer; but to also manage the pressures of their families cultural understanding of mental illness and how this impacts on treatment options. The group program will be looking to source other funding to provide this group in the African community.

III. CALD Mental Health Connections Project

The CALD Mental Health Connections project was a pilot project designed to address the lack of culturally appropriate service provision and responses to the specific mental health needs of Culturally and Linguistically Diverse (CALD) people in the Rural City of Wangaratta.

Outcomes: The project was a significant undertaking and has revealed some key concerns and areas for improvement regarding mental health service delivery to the CALD community, including:

- Stigma associated with mental health (MH) is compounded where there are cultural diversity issues. Understanding the potential impact that this stigma has for CALD people such as perhaps losing their visa or altering their status with authorities is a very real barrier to engaging with services.
- There is a lack of social inclusion opportunities that offer a soft entry point for CALD people to gain information at a very primary level. Actioning this would provide early intervention, rather than the current situation where CALD people tend to present with intermediate or clinically complex situations.
- The opportunity exists to use the North East Multicultural Association (NEMA) Cultural Advocate (CA) network to access the communities to provide early intervention through information and advice on available services.
- The further development of the local, ground level MH services pocket guide in a number of key relevant languages as well as English would be a worthwhile initiative, as many of the services highlighted in existing local literature are more aligned to state or federal services.
- Resistance to CALD engagement often lies at the worker level (e.g. "We don't do that here"). This could be due to no Cultural Diversity Training (CDT) being provided by the organisation, or the organisation does not communicate to its workers or train them in the services available for CALD people (e.g. interpreter services).

The project report has been distributed to all consortium member agencies, including the Murray PHN and to the Hume Goulburn Valley Mental Health and Housing Alliance for their consideration in mental health service planning.

4. Outcomes/Issues Overall:

- The steering committee structure did see many services around the table addressing systems issues for people with MH challenges who would not usually be involved. Notably education providers; local government and general health providers not only in attendance but engaged and equally enthusiastically seeking solutions to the issues. This was particularly so in Centacare's Addressing Hoarding and Squalor project; the 'Mansfield Mates' project; and the Wangaratta CALD project.
- The steering committees reported that they often played an integral role in the project informing many areas however engaging the right members and maintaining the commitment was challenging.
- The Exploding the Myths forums enabled consumers to take a lead role, and this resulted in an increased understanding from both consumers and service providers about each of their 'drivers', expectations and boundaries.
- Whilst the highest unmet need consistently recorded for Hume PIR participants is day activity and company, there were few projects addressing this. The biggest impact to these unmet needs would be expected to be the 'Reducing Stigma' initiative with all its strategies, but the impact of this work cannot be measured effectively in such a short timeframe.
- Systems change was (and for the most part, is still) not a concept well understood. Initially many of the proposals were for capacity building staff and organisations. Whilst capacity building may result in systems change the notion that in measuring the change simply providing the activity was not in and of itself an indicator that systems change had occurred.
- In many of the smaller projects organisers appeared reluctant or unable to engage a consumer for the steering group. It appears that engaging consumers jointly in developing services etc. is not generally occurring, although consultation following the establishment of new services and systems may be occurring. This became an issue and required continual oversight from the PIR Manager to ensure it occurred. That said in almost every project it did occur eventually.
- It was difficult to engage clinical (usually community mental health services) on smaller projects.
- Evaluation is not commonly 'practiced' in MH services and often not understood. Hume PIR provided access to training around evaluation including highlighting outcome not output evaluation. The consultant engaged to undertake the local evaluation of the Hume PIR program was also funded to provide training, advice, lead forums, and/or undertake simple evaluation strategies for all of the SF/Host organisation projects. This was taken up inconsistently and for the most part the quality of evaluation was poor. Particularly concerning was the poor understanding of outcome based evaluation. This will be an issue with NDIS roll out, and specifically with projects funded under the ILC component.
- Systems issues are complex and a timeframe of three years to produce sustainable outcomes was challenging.

Three years is a very short timeframe within which to measure sustainable systems change. What we do know is that the greatest systems change has occurred as a result of the activity of all of these projects whether they achieved their 'systems change' goals or not. The most recent Hume PIR Consortium reflection clearly identified that the key systems change is the increasingly 'shared' responsibility for, and commitment to, resolving these major issues. This shared responsibility:

- sits beyond one service and not even just mental health service providers,
- includes a recognition of the role of consumers and carers in problem solving, and
- acknowledges the importance of 'collective impact'.

