

# **Collaborative and coordinated care: An investigation of the enablers and barriers for adults who experience mental ill-health in eastern Melbourne.**

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## **Abstract**

### **Aims**

Care Coordination is an important aspect of service provision for people with Mental Ill-Health and other complex issues. The Eastern Melbourne Mental Health Service Coordination Alliance (EMHSCA) has been supporting staff across eastern Melbourne to work together for the benefit of this cohort since 2007.

With disruptive changes to Mental Health (MH) and Alcohol and Other Drug (AOD) services, and the adoption of fee-for-service models across disability and primary health affecting collaboration, service providers need to discover new ways of working that may ameliorate effects arising from these extensive reforms. This study examines what works and does not work to support Care Coordination and ultimately provides impetus for effective systemic change.

### **Method**

A qualitative design was informed by a phenomenological approach. The sample included 59 participants in total, spanning 5 cohorts: Health and community service leaders (n=16); staff (n=19); Peer Support Workers (PSWs) (n=4); MH and AOD consumers (n=10); and MH and AOD carers (n=10). Thematic analysis from the subsequent 40 interviews and 7 focus groups was applied to data from each cohort and analysed for sub-themes. Data was analysed within and across cohorts, to identify overarching themes that describe the lived experience of current Care Coordination delivery.

### **Results/Discussion**

Themes confirmed Care Coordination is enabled by the development and sustainability of working relationships and knowledge across health and community services. Unnavigable service systems, stigmatisation, perceived power differentials, multiple and rapid service reforms, and fee-for-service models provide significant barriers to Care Coordination.

### **Conclusions**

Recommendations for system reform are provided and include the need for centralised service navigation, gentler service environments for consumers, a stable workforce, standardisation of knowledge across sectors, funding attached to Care Coordination, and a return to block funding of MH services, as part of a raft of potential changes.

## Acknowledgement

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## Chapter 1: Introduction

There are approximately 150,00 Victorians who experience severe mental ill-health (MIH) each year (Mental Health Victoria 2018). More than 60% of these people require care coordination to manage the multiple services involved, both clinical and non-clinical, such as Mental Health (MH), Primary Health (PH), homelessness services, Alcohol and Other Drug (AOD) services, family services, employment and forensic services (Mental Health Coordinating Council (MHCC) 2011, p.4; Victorian government 2009, p.54). Health policy has supported a coordinated approach to service provision for decades (Commonwealth government 2001), but uptake has been fraught by a lack of structural support (Shergold 2013, p.8-10).

An integrated approach to health care can reduce overall costs and improve service access for people with complex needs (Shergold 2013; Benzer et al 2015) by reducing duplication of effort and addressing service system gaps (Coffey et al, 2017). In a large multi-state Australian study of integration of MH, AOD and Homelessness services, Flatau et al (2013) found that integrated services, ideally those that are co-located, lead to positive consumer outcomes.

With organisations having limited capacity for integrated service provision, external Care Coordination (CC) has gained importance (Gittell & Weiss 2004). CC is by nature complex (Ehrlich et al 2009; Hubertus 2019; MHCC 2011, p.5), requiring adaptive and creative solutions (Hubertus 2019). The phenomenon of CC requires multi-level support and analysis (Ehrlich et al 2009, p.626; Gittell & Weiss 2004). Our challenge is to understand how it works, for whom, and when it should be employed as a strategy (Hubertus 2019, p.4). This current study examines these elements with a solutions focus.

Accordingly as background, it is necessary to provide context to the subject of CC by outlining the policy context, relevant service delivery frameworks, the local service coordination alliance that is central to the study, and the changing landscape that appears to be affecting its good work.

## **Policy context**

Collaborative and coordinated care and support for people who experience Mental ill-health (MIH) is listed as a key aim in numerous health and community service policy documents, beginning in Victoria with the First and Second National MH Plans in 1992 and 1998 respectively. This is where recognition was given to the need for partnership between Mental Health (MH) services and the Primary Health (PH) sector during the de-institutionalisation of MH care (Commonwealth Government 2001).

The 2009-2019 Victorian MH policy document 'Because MH matters' included a high-level strategy to improve CC, including alignment of the public and private sectors and funding for specific CC roles attached to brokerage (Victorian Government 2015, pp.105-107). Victoria's current 10-year MH plan also acknowledges the complexity of the service system and aims to support improved system integration to make accessing services easier and more streamlined (Victorian Government 2015).

Despite these efforts, it is evident health and community service providers experience a range of obstacles to delivering a seamless and holistic approach to care and support (EMHSCA 2017a; Grace et al 2015; Groenkjaer et al 2017, p.21; Shergold 2013).

## **Recovery Oriented Practice and Service coordination**

In the National Standards for MH Services (Commonwealth of Australia 2010, p.20), Standard 9 states that the MH service must develop internal and external partnerships to support "coordinated and integrated services for consumers and carers", and criteria 5 states that formal processes should be developed. This same document contains an outline of recovery-oriented MH practice which lists 'partnership and communication' as the fifth of five principles (Commonwealth of Australia 2010, pp. 42-43).

Recovery Oriented Practice (ROP) is a holistic, collaborative, person-centred approach to care relating to all 10 Mental Health Standards (Commonwealth Department of Health 2013, p.6; Commonwealth of Australia 2010; PCP Victoria, 2012). The National Recovery Framework occurring nationally across MH services provides detailed and specific capabilities in relation to CC and collaboration for organisations and their staff to implement ROP and includes: shared care; referral pathways; discharge planning and cross-service

communication; as well as the need to maintain knowledge of other services and build processes and policy to support service coordination and partnerships (Commonwealth Department of Health 2013, pp.56-69). Figure 1 demonstrates the centrality of the consumer in relation to the national framework for recovery-oriented MH practice (Commonwealth Government 2013, p.12).

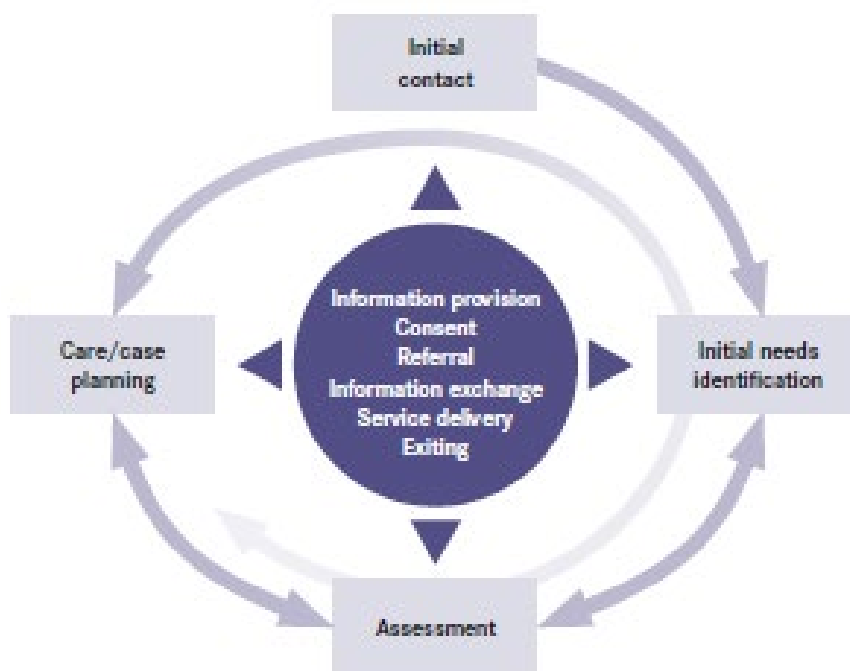
Figure 1: The concept of Recovery as depicted in the National framework for recovery-oriented mental health services (Commonwealth Government 2013, p.12)



Similarly, service coordination places the person at the centre of their care (PCP Victoria, 2012, p.7). Developed by the Victorian PCPs, the aim of the Service Coordination Framework (SCF) was to improve organisational ability to implement service coordination practices and monitor and revise processes to optimise the coordination of supports for people accessing services (PCP Victoria, 2012). This framework states that the professional duty of care extends to service providers taking responsibility for the needs of consumers, to communicate in an accurate and timely way with carers and other support providers and facilitate referrals (PCP Victoria, 2012, p.2).

The SCF is depicted in Figure 2, showing that the elements of CC apply to all aspects of the care process starting with initial contact.

Figure 2: Service coordination elements as depicted in the Victorian Service Coordination Practice Manual 2012 ( p.5)



Care planning is an essential aspect of service coordination. The YES survey data indicated that just over 62.5% of tertiary MH service consumer participants self-report having a care-plan that considered all their needs (Victorian Government 2018, p.66). From these results, there is much to be done in promoting the need for cross-sector knowledge and coordination of services. This current study is located around a local alliance that aligns with the SCF to promote ROP and support better integration at a service level.

### **The Eastern Mental Health Service Coordination Alliance**

The Eastern Mental Health Service Coordination Alliance (EMHSCA) is a more than 10-year partnership that aims to support MH service coordination, collaboration and system integration across the inner- and outer- Eastern areas of Melbourne to improve outcomes for consumers, and with respect to the needs of carers (Moreton 2018, p.18; EMHSCA



2018b). An Australian study by King et al (2013, p.5) focussed on the key factors in sustaining MH networks and found that they require dedicated coordination roles with funding attached to enable the continuation of these useful vehicles for collaborative practice. A project coordinator is funded by the Department of Health and Human Services (DHHS), the Eastern Melbourne PHN (EMPHN) and Eastern Health to support EMHSCA (EMHSCA 2018b). EMHSCA includes stakeholders such as MH, AOD, homelessness & housing, family services, family violence services, Aboriginal services, community health services, and Centrelink and is supported by the member endorsed 'Shared care protocol' (EMHSCA 2018a; Moreton 2018).

The EMHSCA Shared care protocol was developed in 2007 as an enabler to support effective shared care by addressing potential barriers of communication between health and community services (2018a). An implementation strategy was developed and included an extensive annual file audit (2014-2017), partner and consumer surveys, and targeted workshops that have been delivered to staff across the region between 2011 and 2018 (EMHSCA 2018b). Although the mechanisms for CC were made clear by the protocol, the barriers to implementation needed to be understood, and workshop attendees were supported to seek their own solutions to encourage ownership of the work. The non-identified results of discussions regarding barriers and solutions to collaborative care from these workshops have been collated and are available for comparison with the current study data (EMHSCA 2017a), however a complete comparative analysis is beyond the purview of this thesis. Therefore, the current study is a condensed version of these potential enablers and perceived barriers with greater depth of perspective.

### **The changing landscape**

Service reforms have become the expectation for health and community services in the past decade. In 2013 the Victorian AOD sector reform occurred simultaneously with the community MH supports reform, causing significant disruption to consumers, families and service providers (Aspex consulting 2015; Tandem 2015; Vicserv 2014). Currently across Australia, the Primary MH initiative known as Stepped care promises a more staged, coordinated and accessible system of supports for people with high prevalence MH issues (EMPHN 2019) and this is occurring at the same time as the National Disability Insurance

Scheme (NDIS) roll-out. Staff attrition is expected with each reform and formed relationships are lost. Consumers and carers are often caught in the middle trying to navigate the services, as worker changes necessitate the establishment of new and vital care connections, often with less experienced staff (Tandem 2015, p.8).

The NDIS provides the most significant reform of community MH services and is marked by disruption to collaborative care for people who experience MH and cooccurring issues (MH Council of Australia 2013; MH Victoria 2018; Hancock et al 2018). With a shift away from block funding to a fee-for-service (FFS) model, the NDIS has necessitated a competitive community MH service environment to emerge (Green et al 2018; Office of Parliamentary Counsel 2013). The lower pricing for supports under NDIS have meant that pre-transition staff are leaving the sector and a new, less skilled and experienced workforce is emerging with limited capacity to attend care team and linkage meetings and capacity building activities such as cross-sector workshops (Hancock et al 2018, p.9; Mavromaras et al 2018, pp.263-268; MH Victoria 2018, p.18). For inner- and outer-eastern Melbourne there was a 50% reduction in staff attendance at EMHSCA forums and meetings in 2018 (EMHSCA 2017c).

EMHSCA has participated in an annual audit of their collaborative care practices since 2014 with steady improvement noted until 2017 as the NDIS was about to roll out in the region and the data showed the first decline in CC (EMHSCA 2016a; 2017b). It is important that we understand the reasons for this, as collaboration is essential to ensure service access and safety issues are effectively managed (MACNI 2009). With disruptive changes affecting collaboration, service providers need to discover more effective ways of partnering to stem the effects arising from multiple system reforms.

## Chapter 2: Literature Review

To examine this topic further and to identify relevant knowledge gaps, a targeted review was conducted sourcing published literature relevant to Care Coordination. This review commenced with a Deakin online library database search.

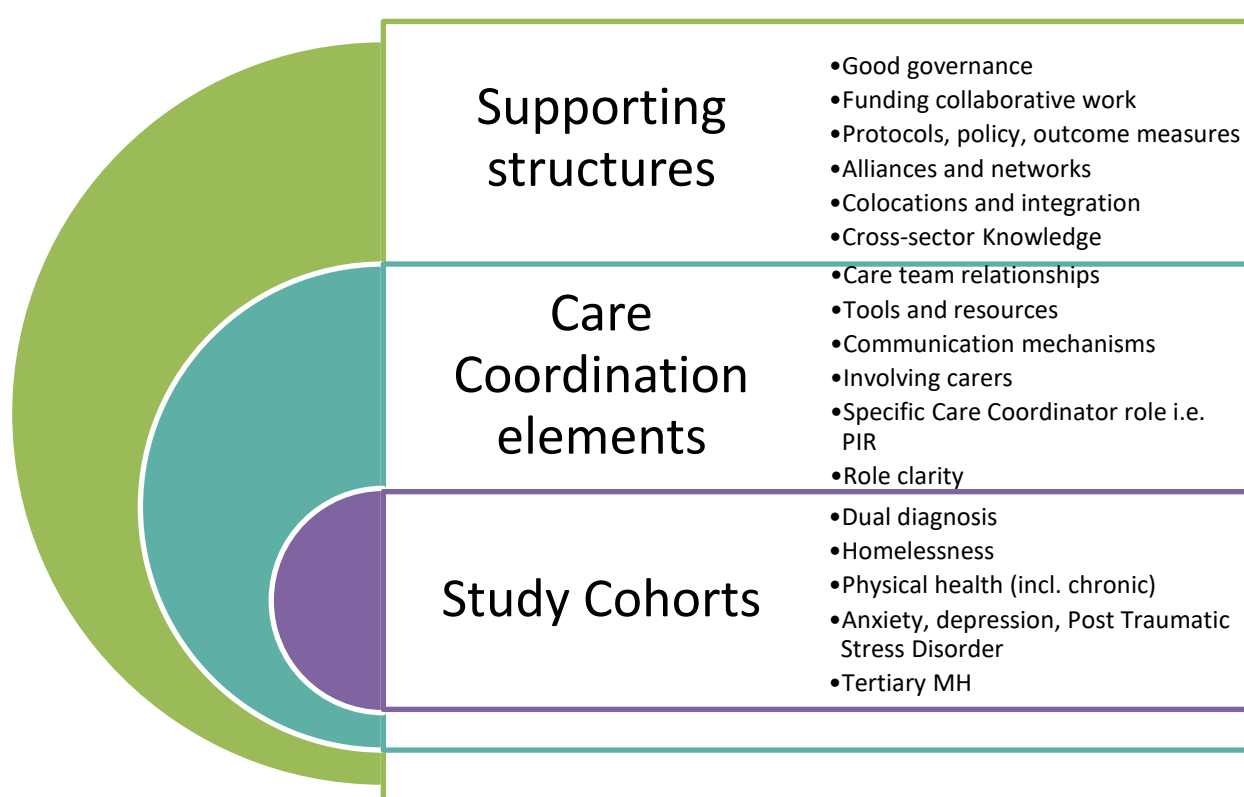
Table 1: Literature review search strategy

Data Bases	Embase, PubMed, Psycinfo, ProQuest, Medline. CINAHL
Inclusive search terms	"collaborative care" OR Collaborat* OR "shared care" OR "coordinated care" OR coordinat*, AND "mental health" or "mental illness" or "mental disorder" or "psychiatric illness" OR "psychiatric disorder" OR "behavioural health" OR “Mentally unwell” OR “Mental ill-health” OR psychiatr*, AND enablers or facilitators or factors, barriers or obstacles or challenges or difficulties or issues, AND Australia*,
Exclusion terms	NOT "aged care" OR youth OR child* OR "under 18" OR cancer OR palliative OR dent* OR oral
Search refined	By dates: 2012-2018 and restricted to peer reviewed articles 51 articles retrieved and analysed for relevance. 32 articles selected for critical appraisal.

Articles were selected for their relevance to severe MIH and co-occurring issues, care coordination, collaborative practices and service integration. Some international literature was included, however Australian studies were preferred for contextual reasons. Searches were performed in the period from August 2018 and May 2019. Additionally, contemporary articles on NDIS as it relates to psychosocial disability were located via Deakin library search and 3 were selected for relevance to this study and reviewed.

Papers were critically appraised using the relevant Critical Appraisal Skills Programme tools and results tabulated (CASP 2018). Methodology, results and conclusions were examined for strengths and weaknesses, potential applicability to this project's research questions, and for future research recommendations. Six key papers were identified via this process (Aveyard 2014, pp. 143-156), with an analysis of principal findings depicted in the following diagram. Enablers and barriers to CC were captured in the process.

Figure 2: Themes arising from a review of the literature



### Definition of Care Coordination

It is a view commonly held by researchers that the concept of CC has been ill-defined and that this has resulted in poor translation to practice (Banfield et al 2012; Flatau et al 2013;

Jones & Delaney 2014). In policy, the concepts attached to CC are complex and include; a person-centred approach, information sharing with a particular focus on confidentiality, networking and partnership, and knowledge transfer (Ehrlich et al 2009, p.626).

‘Shared care’, ‘coordinated care’, ‘integrated care’ and ‘collaborative care’ are used interchangeably throughout the literature, although pedantic definitions are arbitrarily applied by some, and ‘collaborative care’ may be seen as the precursor to ‘coordinated care’ (Holmwood, Groom & Nicholson 2001, p.15; Jones & Delaney 2014; WHO 2016). Flatau et al (2013, pp.14-18) provide a detailed discussion of terminology and propose that ‘integrated care’ can be divided into 2 distinct types: system level integration, involving cross-sector governance and supporting interventions; and service level integration, which is the coordinated cross-sector provision of supports and may be more about local efforts to address system complexity.

For the purposes of this current study ‘care coordination’ (CC) is the preferred term in relation to practicalities of service delivery. The term ‘collaboration’ was commonly used by research participants to frame their experiences working with other providers at all levels and with consumers and carers. ‘Service coordination’ is also used in this study and is considered an overarching term used to describe partnership and working relationships between services to support people with multiple and complex needs (PCP Victoria 2012).

## **Study cohorts**

### *Primary Health*

Much of the literature depicting elements of CC centred around people with cooccurring primary MH and physical health issues (Benzer et al 2015; Cranwell et al 2017; Fuller et al 2011; Henderson & Fuller 2011; Lewis et al 2014; Roberge et al 2016; Rogers et al 2018; Overbeck et al 2016; Thomas et al 2016). PH is seen as pivotal to the integration of care, as it is the most common entry point to treatment for people with cooccurring MH and physical health concerns (Durbin et al 2013, p.128; Groom & Nicholson 2001, p.14; Holmwood, Groom & Nicholson 2001,).

### *Dual Diagnosis*

Dual Diagnosis (co-occurring MH and AOD issues) is a common comorbidity with as many as 75% of people who access MH treatment and up to 85% of people who access AOD treatment experiencing both disorders (Croton 2011, p. 14). Four papers regarding this cohort were selected for this review, all having a focus on integration of services as the ideal framework for CC (Deedy et al 2013, pp.8-11; Groenkjaer et al 2017; Durbin et al 2016; Lewis et al 2014). For people with a Dual Diagnosis, Australian research has found that services are difficult to access and are not supported by policy or funded to manage the complexities involved in care (Groenkjaer et al 2017, p.23; Flatau et al 2013).

### *Consumers*

Flatau et al's (2013, p.94) large mixed methods study cohort included MH, AOD and homelessness service consumers, whose views were held as central to the results, and found that they prefer services to work together, share information and reduce the burden on them to tell their story multiple times, as well as navigate the complex service system.

### *Carers*

One significant and recent Australian study involved 19 MH carers in focus groups to examine carer perspectives on working with services to support their loved ones and feel lost in the gap between services, holding the care and struggling to navigate the complexities of supports (Olasoji et al 2017). Recommendations from this study included the need for work with MH carers to be core business for service providers, and that MH crisis needs to be better defined across sectors and conveyed to the community to enable more effective system navigation (Olasoji et al 2017. P.410).

### *Service providers*

Flatau et al's (2013, p.94) service provider cohort demonstrated an understanding of CC that included a holistic and person centred 'no wrong door' approach where consumers are comprehensively assessed and warmly referred to appropriate services that are well connected.

Research papers focussed on broader MH related service coordination were less prevalent than those in relation to PH cohorts and there was a noticeable shift towards Partners In Recovery (PIR) in studies from 2015 to 2018. Fifty-one PIR teams were introduced across

Australia at that time to improve CC for people with MIH and complex issues (Banfield & Forbes 2018). PIR studies will be discussed in the following section.

### **Care Coordination elements**

Although used interchangeably, CC and care planning for people with complex needs are, by implication, two different yet complimentary processes (Coffey et al 2017). Care planning is an expectation of health and community services however it is often done poorly, possibly due to resourcing issues and in many cases, it has become an output measure in itself (Coffey et al 2017). Case management (CM) appears to imply CC, however tertiary MH models of CM tend to lack resourcing to engage in CC activities (Brophy et al 2014, p.398).

#### *A relational approach with Partners In Recovery (PIR)*

Key elements of successful CC models have been identified in a literature review by Brophy et al (2014) and commonly include taking a relational approach to consumer care with this factor being key to informed decision making and self-management (Brophy et al 2014, p. 397). The PIR initiative provided a relational model of CC, with Support Facilitators (SF) taking a person-centred approach and working closely with consumers (Banfield & Forbes 2018, p.2).

Banfield and Forbes (2018) used mixed methods involving 25 consumers and 14 service providers (both PIR and non-PIR), with questionnaires that sought to evaluate their experiences of the program. These were followed up with semi-structured interviews with a selected group of 6 consumers, 2 carers and 4 staff, and results concluded that successful CC models rely on 'relational continuity' (Banfield & Forbes 2018, p.10).

PIR was viewed positively by study participants and concern was raised regarding the sustainability of the PIR model, providing some validation for the importance of a dedicated care coordinator to facilitate CC (Banfield & Forbes 2018, p.10). Empowerment of consumers was achieved by PIR Support Facilitators (SF) as a function of the Recovery Oriented Practice (ROP) of navigating services and connecting supports (Banfield & Forbes 2018, p.10). This was in contrast with findings from a study conducted by Smith-Merry et al (2015, p.12) when PIR was newly introduced, that suggested ROP was not articulated by SFs at that time.

## Supporting structures

Groenkjaer et al (2013) examined the enablers and barriers to Dual Diagnosis collaborative care in South Australia with 20 semi-structured interviews of MH and AOD staff. They found that insecure funding models led to staff attrition and decreased quality of care due to stress and high staff turn-over. Stability of funding is linked to continuity of care and consistency of services for consumers (Banfield et al 2012, p.156; Cranwell 2017; Groenkjaer et al 2013).

## Outcome measures

A number of studies conclude that outcome measures are required to evaluate various CC efforts (Banfield et al 2012; Ehrlich et al 2009; Flatau et al 2013; Frost et al 2017). In concluding their description of a service-wide Integrated Recovery-oriented Model (IRM) with collaboration as one of its core principals, Frost et al (2017, pp.13-14) recommend evaluation mechanisms be implemented and provide some suggestions regarding suitable strategies.

## *Fee-for-service models as barriers*

An Australian study with a qualitative design by Green et al (2018) investigated the changes to service relationships with the roll-out of the NDIS and showed that the historical relationships formed between services remain intact, at least in the early stages of the transition to the new model, however more research is required to understand how organisations can negotiate information sharing in a competitive environment and what types of partnerships will best support this (Green et al 2018, p. 14). With no way to bill for collaborative activities or networking, it is difficult to imagine how such practices can survive under a fee-for service model (Fleury et al 2012, p.87; Meltzer et al 2016, in Green et al 2018, p.13).

An Australian study surveyed 33 MH service providers in the Australian Capital Territory (ACT) regarding the NDIS for psychosocial support (Furst, Salinas-Perez & Salvador-Carulla 2018, p.593) and found that the FFS model has negatively impacted on the stability and competence of the workforce. The authors agree with Green et al (2018) that the



competitive environment is affecting CC and collaboration (Furst, Salinas-Perez & Salvador-Carulla 2018, p.593)

### **Approaches to research topic**

Following an analysis of various theoretical frameworks applied to the study of CC, Van Houdt et al (2013, p.7) recommend a multi-level research framework that addresses a range of factors including supporting structures, external and cultural factors, the quality of relationships and patient outcomes, operational processes, staff knowledge, clarity of roles, and inter-sectoral communication (Van Houdt et al 2013).

Qualitative methodology has commonly been employed to investigate perceptions of enablers and barriers to CC and collaboration and included the use of focus groups (Cranwell et al 2017; Olasoji et al 2017; King et al 2013) or semi-structured interviews (Benzer et al 2015; Broadbent & Moxham 2014; Chong et al 2013; Crotty, Henderson & Fuller 2012; Green et al 2018; Groenkjaer et al 2017; Jones & Delaney 2014; Overbeck et al 2016; Rollins et al 2017; Smith-Merry et al 2015). Mixed methods approaches were less common and often involved the use of a survey followed up with individual interviews or focussed group discussions (Banfield & Forbes 2018; Flatau et al 2013; Fleury et al 2012; Lewis et al 2014; Roberge et al 2016).

### **Limitations of previous studies**

Among the extant literature it appears studies have focussed on two sectors, physical health and MH; or MH and AOD, rather than the broader range required to address more complex problems such as those targeted by service coordination efforts. Consumer and carer views were seldom sought, with service providers making up the majority of research participants. It was recommended by Banfield et al (2012, p.156) that consumers be included in future studies on the subject of CC.

Green et al's (2018, p.14) qualitative study examining the early impacts of NDIS on inter-service relationships recommended that further research will be required when the roll-out of the scheme has progressed. There is a demonstrated need to investigate strategies that can be used by organisations to preserve collaborative practices and partnerships in a reforming MH system (Green et al 2018, p.14).

## **Research aims**

Given the above and the identified knowledge gaps, this study is an investigation of the enablers and barriers for service providers, consumers and carers to achieve collaborative and coordinated care. Specifically, it aims to extend understanding about what is required to connect the 'care team' and avoid preventable gaps in service provision. As such, this study will provide a multi-level, cross-sector perspective on collaborative and coordinated care and give voice to consumer and carer experiences. The ultimate goal is to provide impetus for effective systemic change, including improved funding models and supporting structures. As the research was conducted with study cohorts from EMHSCA member organisations, the results are to be presented to the alliance with the intention of informing future work across inner and outer-eastern Melbourne. It is imperative that we create a joined-up service system of accessible and navigable supports to reduce the toll on consumers and their families.

## **Research questions**

Accordingly, based on the need to understand the current situation arising out of multiple and simultaneous system reforms, and noticeable disruptions to collaborative work in the inner and outer-eastern regions of Melbourne, the following questions guide this research:

1. What are the perceptions and experiences among a) health and community service staff, and b) their leaders, regarding the enablers and barriers to collaborative and coordinated care and support for people with MH and cooccurring issues at this time?
2. What are the perceptions and experiences of MH consumers and carers in relation to collaboration with and between services?
3. What has changed, for better or for worse in the past year?
4. What perceived future changes are required to preserve and improve cross sectoral and collaborative practices and CC?

The following chapter will describe the qualitative methods applied to answer these questions.

## Chapter 3: Methods

### 3.1 Research design

Care Coordination is a complex and ill-defined phenomenon which can be interpreted in a variety of ways (Van Houdt et al 2013). An inductive phenomenological approach was chosen to gain deeper understanding regarding the lived experiences of health and community service users and providers in relation to MIH in the inner and outer-eastern regions of Melbourne. Quantitative data is limited to applying a numerical value to the aspects of coordinated care whereas qualitative research looks beyond the numbers to identify the beliefs, knowledge and experiences driving quantitative outcomes.

### 3.2 Research methodology

#### **Rationale for use of method**

A previous attempt to conduct a co-designed and peer delivered survey about consumer experiences of CC revealed some issues with the complex nature of the study topic (EMHSCA 2015). For this reason, a semi-structured interview format was chosen for the current study to allow for exploration of concepts and encourage dialogue around the experiences of participants.

Focus groups were initially offered as a primary format for data capture. However, they were found to be less popular for a variety of reasons including the participants desire for privacy, convenience, and the poor MH of some participants. Ultimately, a series of 6 open ended questions were provided to participants prior to engaging in the interviews and focus groups (refer to Appendix 3). The same questions were used for both activities.

#### **Ethical considerations**

The research proposal was provided to the Eastern Health Office of Research and Ethics and a Low-Risk Application was recommended due to the nature of the research and being considered reflective of a quality assurance activity. This project has been approved by the Eastern Health Ethics Committee (Approval No. LR72/2018) (see Appendix 4) and secondarily by the Deakin University ethics committee (Approval No. 2018 – 361) (see Appendix 5).

A requirement for recruitment of consumer participants was that they be engaged with a MH service during the study and immediately following participation in the focus group or interview. For this study all participants were assessed by their MH service providers for their ability to provide informed consent. Patterson et al (2010) warn that clinicians may exclude potential participants due to concern for their lack of capacity to participate. For this reason, posters were placed in services and waiting areas to enable consumers to elect to participate apart from their clinician's assessment. Guidelines defined by Roper et al. (2018) were implemented to prevent any possibility of coercion (Pope 2012, p.253).

Ulivi, Reilly and Atkinson (2009, p.162) support the view that people should be assumed to have capacity to consent as the default position and briefed appropriately prior to undertaking research. Pope (2012, p. 253) advises that capacity to give informed consent relies on a person's ability to understand the study and weigh up potential risks before making a decision to participate in research. Accordingly, plain language statements were provided to potential participants, including a verbal explanation of information, and a comprehension check was made by the researcher at the commencement of interviews and focus groups.

### **Sampling**

Purposive sampling methods were applied and involved. These steps included: 1. Defining the sample universe; 2. Deciding upon sample size; 3. Selecting a sampling strategy; 4. Sample sourcing; as described by Robinson (2014, pp. 25-38).

### *Inclusion criteria*

The sample universe for this study included the following demographic, geographical and psychological homogeneity: aged between 18- and 64-years; accessing, supporting people who are accessing, or currently employed by health and community services located in the inner- and outer-eastern areas of Melbourne; experiencing or supporting someone experiencing MIH and co-occurring concerns such as substance use, homelessness, and family violence amongst others. Interest in this group was derived from the purpose of the research, being to build on previous EMHSCA data obtained from similar cohorts, and to provide a more in-depth understanding of the phenomena associated with CC, for the future use of EMHSCA service providers and healthcare policy makers.

Consumers and carers are rarely included in studies about Care coordination and their views are not captured adequately in the literature. Consumers and carers as participants in this research were sourced primarily from current clients of MH and AOD services in this region and are those who have a lived experience of MIH and cooccurring issues. As service recipients, consumers are considered experts by experience (Roper et al 2018). Since consumers are central to ROP and SCF, they are an important cohort to include in this conversation about the enablers and barriers to coordinated care. Carers are also intrinsic to the topic and should be considered key stakeholders and experts by experience of working with health and community services to get the best outcomes for the consumers they support (Victorian Government 2012).

#### *Exclusion criteria*

This study excluded adults over 65 years of age and children under 18 years of age, and age specific health and community services. This study excluded staff, staff leaders, consumers and carers who were not with inner or outer eastern Melbourne area health and community services and/or did not have the capacity to deliver collaborative care to people who experience MIH and cooccurring issues.

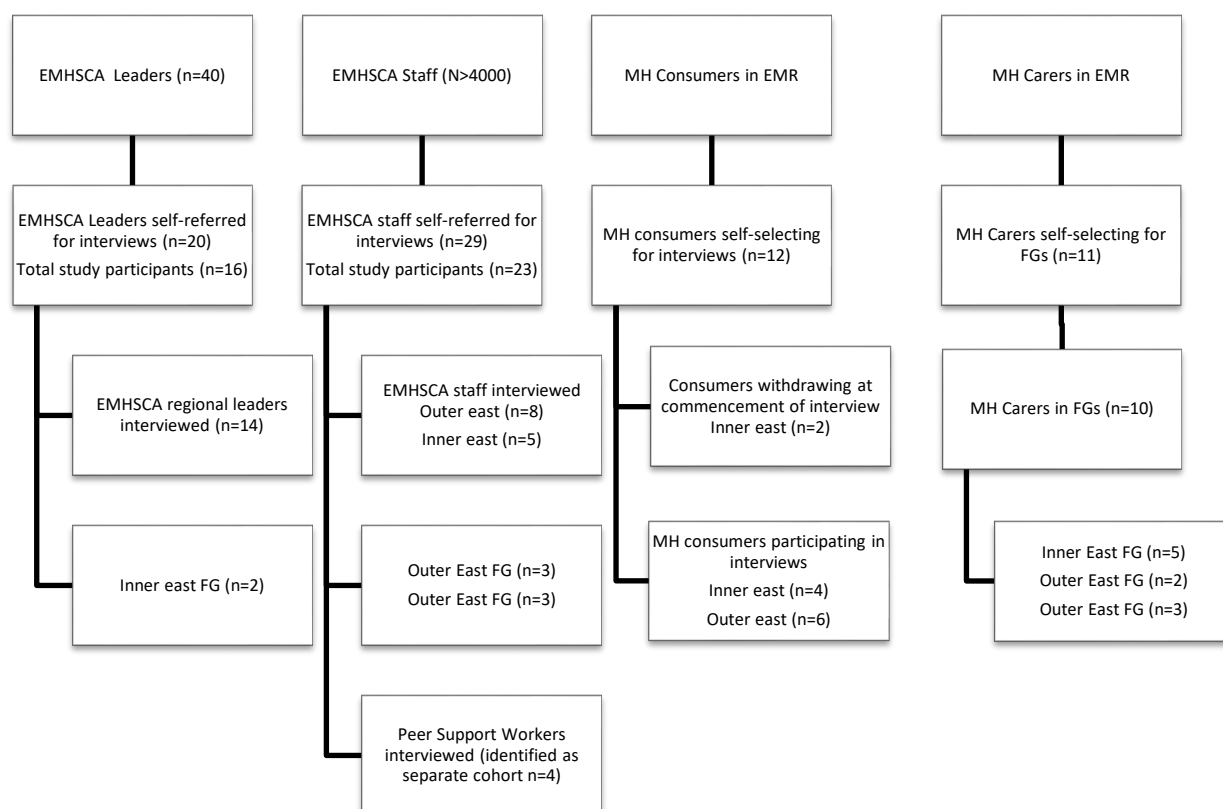
#### *Sample size*

Sample size was set at between 10 and 30 participants for each cohort in order to include a wide range of service sector perspectives, although Hagaman & Wutich (2016) have found that 16 or less interviews were sufficient to identify common themes in qualitative research. As generalisability was not a concern, sample size was based on the desire to reach a thick and rich description of the complex phenomenon under investigation, whilst maintaining patency regarding the voice of individual participants (Robinson 2014, p.29). Final participant numbers were dependent on 1. willingness of suitable subjects to take part and 2. time restrictions on data collection. Data saturation was achieved at different time points for different cohorts. The substantial sample size led to strong trends emerging over the course of the study. Straddling several cohorts, this study consisted of 5 smaller sub studies which were later aggregated to provide an overall picture of the phenomenon of CC (Robinson 2014, p.29).

#### *Sampling strategy*

A stratified purposeful sampling strategy was employed to ensure broad representation from key stakeholders, including service users and their families (Robinson 2014). Originally four cohorts were identified to be of interest; Consumers, Carers, Staff, and Leaders. A separate cohort was derived from the sample and labelled 'Peer Support Workers'(PSWs) as there appeared to be a clear overlap between staff and consumer views for these participants. A unique data set emerged from this small group of participants who identified themselves as staff employed for their lived experience of MIH. Final recruitment is represented in Figure 3 below.

Figure 3: Flow diagram of sampling qualitative study participants



## Recruitment and consent process

### *Staff and leaders*

Recruitment to the staff and staff leader interviews and focus groups was by written invitation emailed to all Eastern Melbourne Metropolitan Region health and community

services staff and promoted at the EMHSCA bi-monthly meetings held in October and December 2018.

### *Consumers and carers*

An invitation to participate in consumer and carer interviews or focus groups was offered to potential consumer and carer participants by the following process:

1. Poster invitations were placed in waiting rooms at Eastern Health MH and AOD services (see Appendix 6);
2. An email was sent to staff from Eastern Health MH services with a printable invitation that was to be provided to consumers and carers when attending their services;
3. The staff were advised not to discriminate in provision of the invitation to their client group. Individual barriers to consumer participation were identified by the staff, and advice was provided to the researcher as required to support inclusiveness;
4. The capacity to provide informed consent to participate was a prerequisite for interested participants;
5. Written and informed consent to participate in this research project was sought by the researcher prior to engagement in the interviews.

Similarly, a verbal and written invitation for carers to participate in a focus group was made by staff at participating organisations. Written and informed consent was sought prior to inclusion in carer focus groups. All sessions were recorded on a digital recording device to support accurate analysis of the data via transcription.

### **Description of Study Cohorts**

The following is a description of the 5 study cohorts including definitions, demographics, and examples of service affiliations.

Table 2: Study subjects and characteristics

<b><i>Cohort</i></b>	<b>Age range</b>	<b>Sex</b>	<b>Examples of Service sectors</b>
<i>Consumers</i> <i>n= 10</i>	21-55	7F; 3M	Tertiary subacute MH residential services and Community care teams; NDIS; AOD; Primary

			health
<i>Carers</i> <i>N=7</i>	45-55	5F; 2M	Tertiary and Community MH; AOD; Dual Diagnosis; Homelessness/Housing; NDIS; Centrelink; Stepped care; Primary health
<i>Carer Consultants</i> <i>N=3</i>	26-50	2F;1M	Tertiary MH
<i>Peer Support Workers</i> <i>N=4</i>	35-45	2F; 2M	3 Tertiary MH; 1 AOD
<i>Staff</i> <i>N=19</i>	26-65	11F; 8M	AOD; Community Health; Subacute MH residential; Tertiary MH Triage; Stepped care; Specialist Family Violence; PIR; Dual Diagnosis Service; Homelessness/Housing; Community MH Rehabilitation; NDIS
<i>Leaders</i> <i>N=16</i>	30-65	8F; 8M	AOD; Family Violence; Housing /Homelessness; Tertiary MH Triage; Community Health; Dual Diagnosis service; DHHS; Primary MH; Youth MH rehabilitation; NDIS; Community MH; Tertiary subacute MH residential services.

### *Consumers*

In MH services a person receiving care and support is called a consumer, rather than a patient or client (Victorian Government 2014, p.3). The term 'consumer' implies that the service would not exist without them (Mental Health Consumer 2019). The consumer cohort for this study was sourced from current clients of MH services in inner- and outer- eastern Melbourne.

PARC consumers were invited to participate by staff who had learned about the study. People who reside in PARC facilities are usually experiencing severe MIH and require support either to prevent further deterioration leading to hospital admission or to assist



with transition from the MH Inpatient unit back to the community. All subjects were individually interviewed as a result.

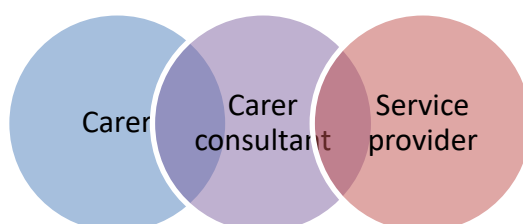
### *Carers*

The term carer refers to a person who provides care and support for someone, and that person is not their child under the age of 16 years (Victorian Government 2012, p.2). The carer cohort for this study were invited to participate by staff who had been briefed through the EMHSCA meetings. All carer participants had provided support to someone who had experienced MIH and cooccurring concerns and had accessed services in the inner - and outer-eastern areas of Melbourne.

### *Carer consultants*

A carer consultant has a lived experience of caring for someone who experiences MIH and is employed to provide carer perspectives and promote the improvement of service quality (Bell et al 2014). They may also provide direct support to other carers as part of their role, as depicted in Figure 4 below.

Figure 4: Depiction of the relationship between Carers, Carer consultants and service



providers. The Carer consultant provides the conduit between the carer and the service.

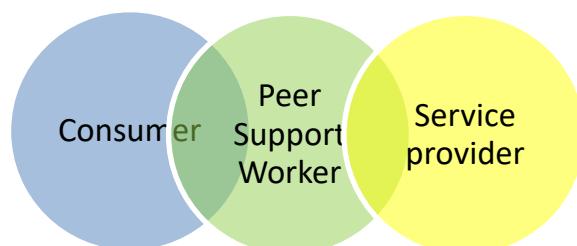
All 3 Carer consultants participating in this research were employed as such to work within the Eastern Health MH program. Their participation in a focus group was with 2 other carers, who were not Carer consultants.

### *Peer Support Workers*

A Peer Support Worker (PSW) is a person who uses their lived experience to support others who are experiencing similar issues (Centre of excellence in peer support 2011). In the context of MH, a PSW is employed by a MH service to use their lived experience to provide

support to consumers who are using the MH service. An AOD PSW is a person who is employed by an AOD service in a similar way. The PSW provides the conduit between the consumer and the service. Overlap between stakeholders is represented in Figure 5 below.

Figure 5: Depiction of the relationship between consumers, PSWs and service providers.



Three PSW participants were from MH services and one was from an AOD service. The AOD Peer Support Worker participated as part of a focus group with 4 other staff. All MH PSWs have been working in Post-discharge peer support roles attached to MH inpatient settings and were interviewed individually.

#### *Staff*

For the purposes of this study the term 'staff' refers to people who are employed to work in health and community services in the inner- and outer-eastern Melbourne, not in a leadership or peer workforce role.

#### *Leaders*

For the purposes of this study the term 'leader' refers to someone in a leadership role and working with health and community services located in the inner- and outer-eastern areas of Melbourne. Leadership roles included in this study were program and team leaders, area and general managers, program directors and coordinators.

### **3.3 Data collection**

#### **Style and setting**

Data was collected via 40 interviews and 7 focus groups with a total of 59 health and community service staff, PSWs, MH consumers and carers (refer to Figure 3). The interviews and focus groups took place in a setting that was convenient to the participants. The settings

included, service sites, a public library, and private homes. The sessions were semi-structured, and participants were provided with a list of questions and a list of services in the region prior to commencement (refer to Appendix 3). This assisted the researcher to contain the scope of the data gathered and provided clarity to the participants about the research.

### **Interview/ Focus Group questions**

Participants were asked about their experiences of collaborative and coordinated service provision, any changes noticed in the past year, and recommendations they may have for improvements to support better collaboration. The interview questions had similar aims but were tailored for service providers and for service users (see Appendix 2). Interviews and focus groups each lasted an average of 1 hour.

The first question aimed to focus attention on the topic of the research, as participants were asked to look at the service list and name any services that they had some experience with. To encourage the narrative, they were then asked to talk about anything that stood out in relation to those experiences. Next was an exploration of the participants perception of enablers and barriers to CC and collaboration, an opportunity to talk about what had changed in the past 12 months, and finally an invitation to imagine how things could be improved (refer to Appendix 3).

At the conclusion of the interview a brief verbal summary was provided, and participants were invited to provide further comments as desired. Additionally, participants were asked about their experience of being interviewed. This provided opportunity provided to check-in regarding the participant's emotional state prior to their departure (Serry & Liamputtong 2017, p.77).

### **3.4 Data analysis**

To unpack the lived experiences across the cohorts, this qualitative study and subsequent thematic data analysis followed the 6 steps as suggested by Braun and Clarke (2006, pp.86-93). Specifically, these refer to: 1. Engaging with the data; 2. Generating initial codes; 3. Searching for themes; 4. Reviewing themes; 5. Defining and naming themes; 6. Producing the report. Audio recordings were transcribed, and the researcher began the process of familiarisation with the data through reading, re-listening and re-reading. Initial codes were

generated with the aim of capturing as many clustered patterns as possible (Braun & Clarke 2006, p.89). To generate initial codes, a code map was developed for each cohort by identifying sub-themes (reviewed for frequency and coherence), ultimately grouping them as principal themes (Braun & Clarke 2006, pp. 89-92). Consistent with hermeneutical spiral methodology, analysis was applied within individual data, extended to being conducted within cohorts and then across cohorts to refine the findings (Robson 2002, pp.196-198; McCaffey et al 2012), resulting in a final set of overarching themes.

Further, a process of 'bracketing' was applied during the data analysis phase to include reflexivity, allowing recognition of any biases and to minimise such influence on the themes (Carpenter 2017, pp. 166-167). A journal was kept and referred to during routine supervision as part of this process. Rigour was further strengthened through inter-rater reliability, since another researcher validated the study themes and findings. The main findings are outlined in chapter 4.

## **Chapter 4: Results**

This chapter outlines the results of the thematic analysis for each of the 5 cohorts: consumers; carers; peer support workers; staff; and leaders. A series of sub-themes were clustered to form the principal themes for each distinct data group. These themes are explained in this chapter, and a cross-cohort analysis will be discussed in chapter 5.

### **4.1 Themes emerging from Consumer data**

The focus of this investigation was to understand the experience of service users, particularly in the context of collaboration with them, their carers and with other service providers. The importance of coordinated supports and ideas for service improvements were also explored. The following is a summary of the principle themes emerging from the analysis of ten interviews conducted with consumers between December 2018 and February 2019. The main themes extracted from consumer data were: The importance of feeling understood; The importance of an individualised approach; The need for staff to talk; Who are you? Instability of services; The hierarchy of knowledge and power.

#### **The importance of feeling understood**

Participants commented that when they feel understood by others, they are more likely to engage. Staff who take the time to listen and are non-judgmental are valued by the consumer cohort. Workers who have a lived experience of MIH were mentioned by many consumer participants as being good listeners who have a greater understanding of their needs.

Having workers with a lived experience is just gold mate. People with a lived experience know exactly what you are talking about when you are NQR [Not Quite Right]. (Participant 46)

### **The importance of an Individualised approach**

Consumers want services to be available when they need them, and staff to have the appropriate knowledge and skills to provide support. Extended hours of phone support for people on weekends and after hours would be beneficial for many and may avoid unnecessary hospitalisation. A consumer summed the issue up in saying 'Mental health is not 9-5 Monday to Friday...its 24/7 mate' (Participant 46). Participants found the NDIS booking system for supports an inflexible model leaving them without vital support when most needed.

When people are experiencing mental illness, consumers said they often feel vulnerable and fearful. Several subjects stated the importance of consistent and stabilising supports for them at these times. Most participants voiced the need for a gentle approach and a low stimulus environment to improve service accessibility. Some consumers lamented the loss of Community MH drop in centres, as these encouraged community connections and provided a MH focused, safe and welcoming environment, with quiet spaces for people who required them.

### **The need for staff to talk**

#### *What works*

With increased need for support when recovering from an acute episode of MIH, consumers said staff should be communicating about their needs and coordinating care. These participants also said that family are an important part of their care team. One participant described the importance of staff communication with the following quote.

It is definitely important because you have blind spots if you don't collaborate. Sometimes you are only comfortable - when you are unwell - speaking to a certain person. They need to talk to each other to find out what people require or need or want. (Participant 33)

### *Where things are stuck*

Consumers expressed concern that, when people are in hospital inpatient settings receiving treatment, staff don't talk to each other. This has resulted in people being treated without respect to their needs and wishes. One consumer said 'They never talk to each other. They just think they know what's best' (Participant 41).

Prior to NDIS, Community MH service providers would work to coordinate with clinical MH services. Consumer participants report that this is no longer the case. Referring to their new NDIS core support staff, one participant said the following.

Sometimes it is hard because they ask me how I've been, and I have to go through it all again. They should just go to the office and find out how I have been and then I can just fill in the blanks. I think they should communicate more. (Participant 41)

### **Who are you? Instability of services**

Consumers desire a more consistent service from providers, and a continuity of care. When workers change it means the consumer is required to tell their story over again. They say this can be re-traumatising. With NDIS, consumer participants have noticed that they are getting different staff attending to support them all the time and they don't feel they can talk openly with them about what is on their mind.

Yeah it was nice to have someone come over and clean up my house, but when I started talking to them about stuff, they didn't want to know. And it's a different person every week so when they turn up its like- Whoa! who are you? (Participant 18)

Additionally, consumers expressed concern that NDIS support workers will no longer be able to visit them at home due to core support pricing issues under the scheme.

### **The hierarchy of knowledge and power**

Consumers perceive that their privacy is often violated when they become mentally unwell. Staff at clinical MH services frequently ask them to tell their story and seek safety information. This sense of power appears to cause resentment between provider and consumer, disrupting the establishment of a working relationship. One participant said 'They just want to know everything about you. I like my case manager a lot, but I need my privacy' (Participant 21).

On the other hand, when the consumer wants something from the staff, they feel ignored and shunned, or a 'bother' to staff. When asked what they would like inpatient staff to change one respondent said: 'Not sit in the fishbowl all day. You know, you knock on the door and no one comes. You only see them when they are handing out medication' (Participant 41).

Several participants felt further alienated from staff by medical and service acronyms and appeared to lack the health literacy to understand and communicate effectively. This is further compounded by their lack of trust in staff and services based on past negative experiences.

Trust has been abused so many times by people who call themselves the professionals and that are there to help I really feel that it's just going to be held against me and instead of getting the help I'm just going to be punished for it. (Participant 23)

### **4.2 Themes emerging from Carer data**

Three focus groups were conducted involving ten carers in total. The first was a group of five carers, 3 of which were carer consultants from the local area MH service. The second was a couple, both carers, who had various caring responsibilities for loved ones with MIH, intellectual and physical disabilities. The third was a group of three carers, all from the same family, who had responsibilities as carers for various other members of the extended family who experienced MIH and co-occurring issues such as substance use. Principal themes were: Carers feel left out of the care; Getting lost in the maze; Supporting others in the

absence of being supported yourself. Within themes are sub-themes of enablers and barriers to coordinated care.

### **Carers feel left out of the care**

#### *What works*

Where the consumer consents to the involvement of their carer, collaboration and coordination is more likely. Carers said they would be more effective in their work with service providers and gaining access to services for their loved ones if they had knowledge of the language and information required by workers in 'the system'. Knowing who to contact and when to contact them is an important aspect of collaboration from the carers' perspective.

#### *Where things are stuck*

When the consumer does not consent, or where staff don't value collaborating with carers and their expert knowledge of the consumer, carers may be left out of the care team. Carers are the main person in the consumers life in many cases and said they need communication even without consent at times. 'He wanted the separation from us as carers but then how could we support him if he didn't involve us' (Participant 48a).

Several carers in this study said that they were not contacted by staff until there was a situation with an element of risk to the consumer or to those around them, or when the consumer was to be discharged from care. 'Ideally staff should call carers periodically to keep them in the loop' (Participant 40a).

### **Getting lost in the maze**

#### *Where things are stuck*

Carers are tasked with navigating the services and are often the conduit for engagement with providers. All carers reported the significant changes to MH services have left them struggling to navigate supports for their loved ones. Specific examples provided by carers were the NDIS for psychosocial disability support, and the introduction of 'Stepped care' for primary MH issues. Most expressed concern about the inconsistency of supports and one carer said 'It is just a complete roll of the dice as to whether you are supported well or not' (Participant 48c).



Carers identified the issues that their loved one's experience in engaging with supports in the first instance, and how this is compounded by the complicated, non-systematic service provision for people with MIH. In supporting a love one to make contact with a provider one carer said 'It's a massive build up just to make a phone call and then you find that there isn't a positive outcome from it'(Participant 48b).

#### *What works*

Carers invest a lot of time and energy in supporting their loved ones to engage with services and when the services don't respond this causes frustration. Carers made the following suggestions for improvements to service navigation: a navigator role to be introduced to assist carers and consumers to locate appropriate supports; a concierge role at inpatient facilities; a central point of information about various supports online; a reassuring first person to take the consumer to the service for the first visit.

#### **Supporting others in the absence of being supported yourself**

##### *Where things are stuck*

When consumers are not doing well carers say they are left wondering who to turn to for support. One carer said 'It is hard to get support for people who are not a direct risk to themselves or others' (Participant 40b). Carers expressed concern that the threshold for crisis service involvement is too high and that they are expected to manage risky situations for which they feel ill-prepared. Additionally, carers said they are reluctant to have police involved as this adds to the trauma for everyone. A preventative approach was recommended by carers to avoid traumatic acute interventions.

Even when a consumer has been hospitalised, there may not be sufficient community supports upon discharge home, and carers say they are left holding the greater responsibility again. The only point of contact for carers in many situations is the G.P. One carer said 'Everything stopped at the GP...and that was it...you're on your own' (Participant 40e).

Providing care for loved ones is expensive and often involves time out of the workforce. Carers highlighted the costly nature of getting appropriate tests to prove a person's incapacity and eligibility for supports such as NDIS and the Disability Support Pension (DSP).

Ideally, these tests need to be subsidised along with Clinical Psychological services. ‘Most of the cost of the care is done by the carers. It is a monstrous cost that is not seen’ (Participant 48a). Since the introduction of NDIS, carers say it is no longer possible to access appropriate respite, education and support. These supports are required to ensure carers can continue in their caring role.

### 4.3 Themes emerging from Peer Support Worker data

#### **Holding the hope**

PSWs are motivated by the belief that they can make a difference in the lives of consumers and carers. ‘You know you can actually step into someone’s space and make a difference at that time’ (Participant 44). These staff have a unique ability to hold the hope for consumers with their personal knowledge of what can help people along their recovery journey. PSWs believe having empathy and understanding ‘where people are at’ are key enablers of collaboration with consumers. PSWs believe in treating people as individuals, listening to their story and providing thoughtful reflections. It is this human element that enhances a sense of hope for recovery. ‘I think you just have to be human and just connect with people. It’s showing an interest in something greater than yourself’ (Participant 44).

#### **Feeling isolated amid the push and pull**

The NDIS has not been good for PSWs, with billable hours and increased paperwork requirements. NDIS PSWs reported that they do not have access to phones or vehicles and are only paid for the time they spend with the individual. There is no time to communicate with other staff or attend network meetings. Participants said when they are isolated it is harder to connect and to be heard.

In general, PSWs are often employed in part-time roles and lack capacity to attend network or care team meetings. This has left many not knowing where their role fits into the broader scheme of service provision. ‘I feel isolated in my role. No one has made any mention of networking opportunities’ (Participant 14).

#### **Disempowerment**

Some PSWs feel that their advisory work often does not achieve any real outcomes. It would appear to them that the solutions they suggest are too hard to be implemented. With their

main qualification being their lived experience, PSWs perceive a hierarchy between other service staff and themselves. Stigma is still very much attached to MIH and PSWs think other staff see them as an unstable aspect of the workforce. For this reason, coordinated care may be more difficult to achieve between the PSW and other providers.

#### 4.4 Themes emerging from Staff data

Staff participants were more certain than leader participants in the belief that “it is not what you know it is who you know” and that individuals facilitate the coordination of care. Main themes extracted from staff data were: desire for clarity through contact; desire for knowledge; desire for communication; desire for someone to share the load. Staff focussed on barriers but were clear and detailed in their description of the personal and service attributes that enabled the work with other providers.

##### **The desire for clarity through contact**

###### *What works*

The personal relationship with other providers as a key facilitator for coordination of supports was cited by numerous interviewees. Important aspects of a working relationship were seen by staff to be: good clear communication; face to face meetings; mutual respect; clarity of roles; shared goals and understanding; being responsive, trustworthy and reliable; and a proactive approach. One participant asked others to ‘Recognise the value of each person’s piece of the puzzle. In a lot of ways that is missed. Those insights provide clarity to the picture’ (Participant 18).

Staff say they need to navigate the service sectors for consumers in many cases. Network meetings, including the Eastern Dual Diagnosis linkages, were mentioned by many staff respondents as a good way to get to know other providers and ‘put a name to a face’. Informal referral pathways are formed when staff get to know each-other and this enables improved service navigation. ‘Like any relationship we need to spend more time with each other and connect’ (Participant 13).

###### *Where things feel stuck*

With the various sector reforms, and in particular with NDIS, staff report that there have been numerous workforce changes. Stability of the workforce is seen as an important

enabler for quality CC. 'Collaboration depends on established relationships' (Participant 13). 'When someone leaves you have to build those relationships again' (Participant 19).

### **The desire for knowledge**

The importance of staff knowledge as a key enabler of collaborative and coordinated care was frequently mentioned by staff respondents. At the commencement of interviews, it became apparent that staff were not receiving any real CC training as part of their basic professional qualifications. Moreover, all staff reported that they learnt how to coordinate supports and collaborate across services once they were in the work environment.

#### *What works*

Staff indicate that network meetings promote cross-sector learning. They help staff know: the various service access criteria, the language and culture of other sectors, and the common issues faced across the system. Staff view these meetings as a good investment in time, as resources are often shared to enhance consistency of practices and reduce duplication. EMHSCA workforce development events, where service coordination focused training is provided across sectors, were frequently cited as good opportunities for gaining knowledge and skills to work collaboratively.

#### *Where things feel stuck*

Staff report that with the current system changes, there has been a loss of workers with knowledge in the MH sector. New staff lack experience, and pricing under the FFS model leaves no room for building their knowledge, skills, and capacity to work across sectors. NDIS pricing is so low that less experienced workers are being employed without adequate skills to manage the complexities of the MH consumer cohort. Participants say newer staff fear risk issues and the potential for making mistakes. Staff capacity building is now limited due to the exclusive direct care focus under the FFS model.

### **The desire for communication**

#### *What works*

Commonly staff spoke about a working relationship beginning with a willingness to communicate and demonstration of respect for others by listening to their perspectives. Knowing how and when to share essential information supports coordinated care, as does

communication that is regular, timely and responsive. One AOD staff group found that knowing the language of other sectors helped to diminish potential power dynamics and enabled effective communication of consumer needs.

Staff advised that Identification of a suitable method of communication between care team members should occur at the first team meeting. Minutes taken at care team meetings help to keep all members informed about the consumers' needs and desires. Emailing information is the most convenient and expedient method although care must be taken to ensure the security of personal details.

#### *Where things feel stuck*

'It is not the clients that are the problem. It is getting the professionals together that is the challenge' (Participant 19). Power dynamics between providers occur when there is lack of respect for the skills and knowledge of other sectors and supports. 'So why are you ringing me? You are just the podiatrist' S15. The perceived service hierarchy may be one reason for the lack of communication between non-clinical support services, such as AOD and homelessness services, and clinical MH services. Other perceived reasons included a lack of time and value placed on working in a coordinated way across sectors. Staff also say some providers believe that they can 'go it alone' and provide the best all round support for the individual consumer.

### **The desire for someone to share the load**

#### *What works*

Staff report that most services are siloed and operate with an internal focus. Almost half the staff participants mentioned the value of co-locating services. 'You don't have to make a dozen phone calls to get to the right person. You've got the information right there' (Participant 5). Some benefits included: ready access to secondary consultation, sharing resources, a culture of collaboration on site, warm referrals, and consumers need only attend one location to have their needs addressed.

#### *Where things feel stuck*

Staff said that access and exclusion criteria make it very challenging to get support for people in need. Crisis supports are only available when something life threatening, or worse, has happened and support to prevent escalation is almost non-existent.

If people are saying the right things, then it is really hard to get services to take action. One woman had 5 or 6 referrals to CATT [Crisis Assessment and Treatment Team] and she was not hospitalized until she broke her legs jumping out of a window. (Participant 6)

Non-clinical staff say that is not appropriate to manage the risk issues, and they need support from clinical services. Unfortunately, without a coordinated and collaborative framework for service provision, high risk situations are frequently managed by staff who, with the best intentions, lack the power and resources to enable safe care for consumers and their families.

## 4.5 Themes emerging from Leader data

Leaders echoed many of the issues and ideas from staff interviews but were more focused on enablers to collaboration than barriers to CC. All were current or past members of EMHSCA and expressed optimism about the capacity for 'the Alliance' to maintain collaboration during times of system change.

### 4.5.1 Enablers

#### **We need a voice to unite the services**

EMHSCA was described by this cohort as a strong leadership group that provides 'a voice to unite the services' and keep providers working together 'no matter what'. It was believed that having a funded project officer allows the work to be possible. Leaders said that mutual understandings, clear expectations and aims, and shared values across services were essential to support collaboration.

More recently, the presence of a common enemy such as the NDIS was cited as a driver for collaboration. Notably, leaders reported that competition can be an enabler when services are drawn together to meet the needs of a competitive tender application, however this collaboration may dissolve when the partners no longer require each other's help to facilitate funding.

### **The ‘spirit of collaboration’ inhabits the individual**

Leaders raised the question of whether it is the personal relationship developed with other providers that enables the collaborative work. Where some leaders saw as essential the need to have a face to face relationship and that trust develops quickly with a more personal approach, others were certain that it was the job description that enabled the collaboration. Either way, it was clear that leaders valued face to face relationships with other providers, enabling more accurate referrals, coordinated practices and secondary consultations.

Having a dedicated role that supports CC, such as Partners In Recovery (PIR) or similar, was seen to provide an unbiased and skilled enabler as ‘the glue’ to align services for improved consumer support. This was considered most appropriate when a person had a complex array of support needs. Such models were reportedly about to disappear with the NDIS taking funding from community MH supports at the time of the study.

#### **4.5.2 Barriers**

##### **The impacts of disruption**

Leaders report change fatigue, with too many simultaneous reforms, most recently in relation to MH supports. Leaders are concerned that difficulties navigating services, and a lack of knowledge of new providers, mean it is increasingly unlikely that staff will make suitable connections to enable CC. ‘Capacity for really positive collaboration and coordination has been seriously hindered by changes to the sector. It’s a big step backwards’ (Participant 2). Current through-put models of service provision leave little room for networking and care team communication, however the greatest threat to CC was reported by leaders to be the tight costing FFS models as funding is restricted to direct care activities. NDIS is one such model but similar issues exist for G. P’s and other private providers who are unable to connect with care teams to provide continuity of care.

FFS affects collaboration because everything is about the invoice. It is a transactional approach. You’re purchasing this from me. It’s gone from relational to transactional. (Participant 16)

##### **The challenges of reinventing ways forward**

Leaders noted the various disruptions caused by service reforms and were keen to support the continuation of collaborative practices, outlining a range of measures to support improvements to health and community services' connectivity. They say CC needs *not* to be a 'nice to do' but rather a 'need to do' aspect of service provision and that a 'culture of collaboration' is needed. Development of this culture will require a systemic and multi-level investment that has suitable outcome measures attached, as opposed to the current reactive and short-sighted policy and short-term service funding that is output focussed. FFS models such as the NDIS do not encourage such an approach. Leaders expressed a desire for a co-design of the sectors and system with all stakeholders having equal opportunity to provide input into redevelopment.

Leaders believe CC and collaboration should be written into all funding and tender applications, with clear accountability mechanisms. The NDIS should have billable hours for CC and networking. G. P's and Psychiatrists also need to be funded to work across sectors when necessary if true 'wrap around care' is to be achieved. The change may be best driven through accreditation processes whereby services have a set of Key Performance Indicators to measure the shared care practices.

Participants suggest information sharing could be improved by aligning data systems, consent processes and paperwork. Ideally, shared care plans should be visible across services. Consent is required for this to take place. Technology is required to enhance accessibility to care team meetings and networks. Online communication platforms allow busy workers to engage when time and resources do not permit movement between services.

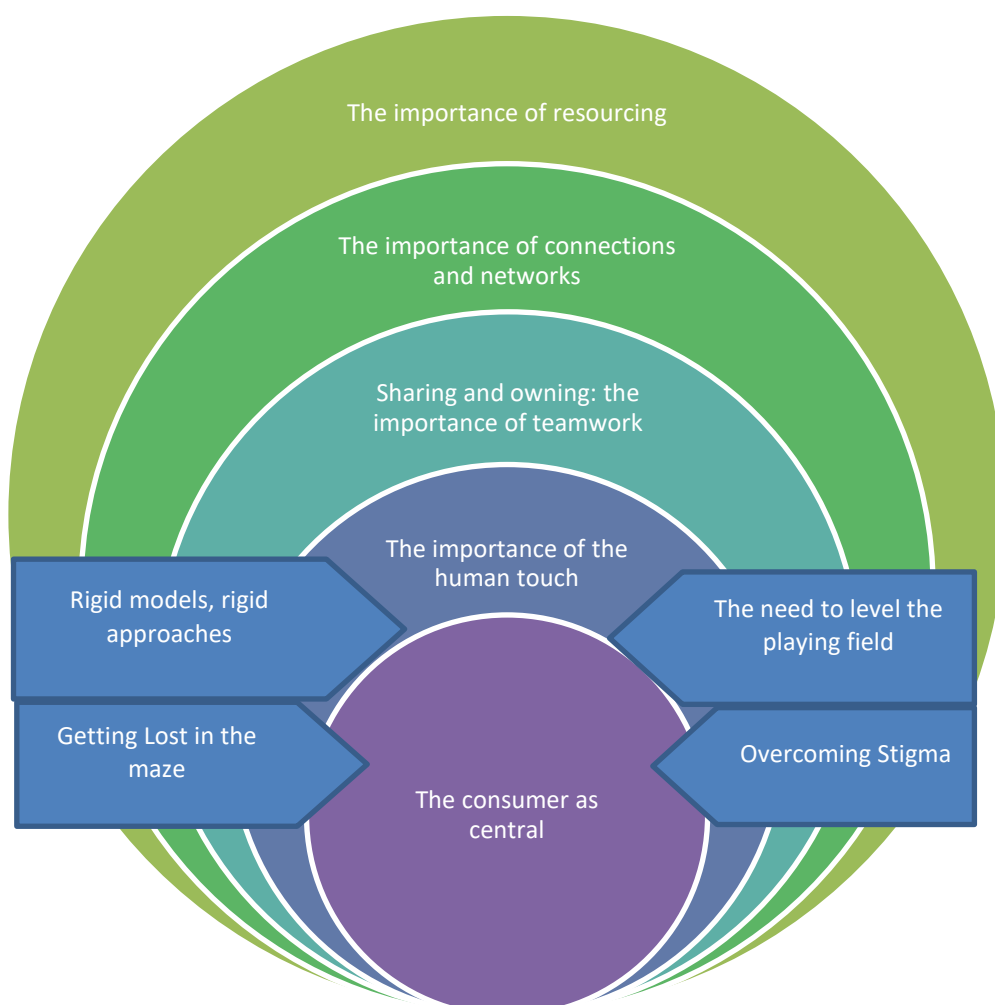
Sharing resources across services and sectors can enhance consistency of practice and avoids "reinventing the wheel". To sustain this practice in a competitive environment, the use of creative commons enables sharing whilst acknowledging the original developer.



## Chapter 5: Discussion

There were several consistent themes across all cohort data sets (refer to Appendix I) that inform what enables CC and collaboration: 1. the consumer as central; 2. importance of the human touch; 3. sharing and owning: the importance of teamwork; 4. the importance of connections and networks; 5. the importance of resourcing. There were four key barriers identified that are eroding the quality of CC and collaboration: 1. Rigid models, rigid approaches; 2. Getting lost in the maze; 3. The need to level the playing field; and 4. Overcoming stigma. These themes and their relationship to each other are depicted in Figure 6 below.

Figure 6: Depiction of the key enablers and barriers to collaborative and coordinated care for people who experience MIH and co-occurring issues in the Eastern Metropolitan Region of Melbourne.



## **Enablers to collaborative and coordinated care**

In a synthesis of CC literature, Ehrlich et al (2009) summarise their findings with the following 3 functions of coordinated services: 1. continuity of care for consumers; 2. Care teams and knowledge sharing; 3. Integrated networks. The findings of the current study align with Ehrlich et al's (2009, pp. 622-626), and expand them to include description of the mechanisms by which consumers may be engaged as well as contemporary and contextual recommendations regarding resourcing and structural supports.

### **1. The consumer as central**

The consumer as the centre of their care (as described in this paper's introduction) is a concept that is commonly understood within service coordination models and MH recovery frameworks (Commonwealth government 2013; PCP Victoria 2012, pp. 23-24). An understanding of this concept was conveyed by many of the staff and leader participants in this study. When the consumer is central to the work and they are well engaged it is their goals that guide the composition of the care team. From this study it was clear that a tailored approach for each individual is required if staff are going to engage consumers effectively.

### **2. The importance of the human touch**

Many people accessing services have been traumatised at some time and the effects can be enduring (Marel et al 2016, p.113). Consumers said they need a gentler approach to care and less stimulating environments which will enable them to work with service providers. Being visited at home can reduce the barriers for people in accessing supports and enable relationships to develop that enable a team approach to care planning.

The value of having workers with a lived experience of MIH was mentioned multiple times by every cohort. This raised the question of what attributes make PSWs effective in the workforce. Consumer participants outlined the value of PSWs as having the ability to understand and empathise with people who are experiencing symptoms of mental illness. It appeared from the data that consumers found it easier to trust PSWs, possibly because they felt they were understood. "I know one (staff member) cares coz we talk. And she's been where I've been" (Participant 22).

PSW study participants described a kind of humanity in their work that they saw as essential elements of collaboration with consumers. Being human was described as having compassion, empathy, warmth, friendliness and showing interest in others as individuals. The ability to hold the hope for people when they cannot hold it for themselves and a belief that people can change, were seen as key aspects of a human approach.

### 3. Sharing and owning: the importance of teamwork

Flatua et al (2013, p.97) found that there was 'significant overlap' of consumer characteristics across service sectors and recommended a need for improving intra-service communications. For the current study, staff and leader participants valued cross-sector work and described the utility of connecting consumer's supports as: the clarification of various roles and expectations; mutual respect; more creative problem solving; clear communication mechanisms; a sharing of any safety issues; and improved continuity of care for people. Care team meetings were seen to encourage a more holistic view of the consumer's situation and support person-centred care. Staff and leaders spoke about the importance of having just one care plan for the consumer to clarify responsibilities and show how all supports fit together to enable the person's goals. This is a key aim of the Service Coordination Framework outlined by PCP Victoria (2012, pp.22-23).

Consumers voiced that the coordination of supports is important to them, especially when they are experiencing exacerbations in MIH, as it lifts some of the burden of engagement at more challenging times. Rollins et al (2018, pp.8-9) asked consumers about how they manage co-occurring severe MIH and physical health issues and their views on CC and found that they viewed CC as convenient. Consumers appreciated friendly and knowledgeable staff and efficient communication between providers but said they would like more responsive communication from services at times (Rollins et al 2018, pp. 8-9). Flatau et al (2013, p.94) found similarly that consumers appreciated CC as it reduced confusion and the uncomfortable re-telling of their stories.

Carers described their desire to have their role acknowledged by staff and to have more open communication with the care team, which aligns with findings by Olasoji, Maude and McCauley (2017). In many cases the carer is the main person involved in the consumer's life

and they carry the greatest burden of responsibility and knowledge in the care team, apart from the consumer themselves.

#### 4. The importance of connections and networks

A strong theme emerging from the data across cohorts was of the need to build the knowledge and capacity of staff to work more collaboratively and to provide a high-quality service to consumers. Broadbent and Moxham (2014, p.232) demonstrated that it is easier for staff to interact across services and sectors when they are aware of the cultural differences and have some knowledge of the language required to reach a shared understanding of the consumer's needs. Network meetings and shared training provide useful opportunities to connect and educate staff for this purpose (Broadbent & Moxham 2014; Crotty Henderson & Fuller 2012).

The importance of the regional alliance in uniting services, sharing information and problem solving was outlined by many participants across staff and leader cohorts. Additionally, the importance of a personal relationship with other providers was highlighted and the view commonly held that effective coordination of supports is person dependent. This idea is supported by studies by Green et al (2018), Banfield and Forbes (2018), Groenkjaer et al (2017), Crotty, Henderson & Fuller (2012), and Overbeck, Davidsen and Kousgaard (2016) who all found there was a need for personal relationships to enable CC, with most identifying specific traits of staff that enhance relationship development.

According to Flatau et al (2013, p.96), modes of integrated care include internal provision of multiple services, and external collaborative partnerships. Recommendations regarding service integration included the need for 1. effective models of integration for people who have complex needs; 2. development of structural mechanisms within service networks to assist with sharing policy, protocols and care plan documents; 3. improved cross-sector communications and connectivity; and 4. governments should better meet the associated costs of these measures (Flatau et al 2013, p.97).

#### 5. The importance of resourcing

The findings of this study support the need for a systematised suite of supports to simplify the journey for consumers and to enable staff to provide appropriate long-term planning

and referrals. The current system is fragmented with no central point of navigation for people.

A well-resourced service system enables CC. Consumers report that when staff are busy and task focussed, they are not getting the person-centred support they need, and the human touch is lost. Services need to be tailored to the individual's needs. This flexible approach to support is important to enable consumers to engage. Carers shared these perspectives and added that staff only seek to collaborate with carers when consumers are in crisis.

Staff and leaders reiterated the importance of being well resourced to provide responsive and coordinated services and said that when there are insufficient staff hours it is not possible to work as a care team across services. An important development to support CC would be the introduction of key performance indicators linked to collaboration. Outcome measures are required to demonstrate the effectiveness of a coordinated approach.

When staffing is stable the relationships built between services are preserved and can develop. Multiple sector reforms have seen significant staff attrition causing disruption to relationships that support CC (Frost et al 2019) .

### **Barriers to Collaborative and Coordinated care**

#### **1. Rigid models, rigid approaches**

A lack of staff time and resources was mentioned by the majority of participants. Competing demands on staff time, and a focus on risk management can mean staff do not prioritise connections with other providers. Additionally, staff changes, and attrition were identified as barriers to collaborative and coordinated care. Staff talk about playing 'phone tag' due to limited hours of employment, or limited time working during weekdays. Many projects and programs are only funded for very short terms, leading to a substantially reduced capacity for service coordination.

Tight costing models and efficiencies under the NDIS mean reduced service quality and capacity to participate in coordinated care. Monitoring of MH and safety issues and communicating these issues to Clinical MH supports is rarely occurring under the NDIS. Similar issues occur for G. P's and private psychiatrists who are unable to participate in shared care due to a lack of funded time to connect with the care team.

Coordination is difficult to measure. We have output driven performance measures rather than outcome driven ones. A throughput model does not support networking, capacity building or care coordination across services.

## 2. Getting lost in the maze

Consumers who have complex support needs often rely on carers to navigate services (Olasoji, Maude & McCauley 2017, p.407). Locating services is challenging for the following reasons: 1. There is no one central point of information about all services available; 2. Access criteria for services can be confusing and leave gaps in the service system; 3. Multiple system reforms mean that information is quickly out of date. Carers need to rely on staff knowledge in many cases.

Staff complain of change fatigue with too many changes occurring simultaneously leading to increasing problems with service navigation. Difficulties with navigating services and a lack of knowledge about other providers can make it unlikely that service providers will make suitable connections to enable care coordination.

## 3. The need to level the playing field

Jones and Delaney (2014, p.12) searched for the meaning of CC with a qualitative study involving 4 MH professionals and discovered that strategic healthcare leads to intrusive medically driven systems that support power imbalance and erode collaborative practice between service providers and consumers. In relation to MH, much of this hierarchy pertains to the MH clinicians' ability and requirement to manage crisis and ameliorate risk for consumers and the community at large.

With the introduction of Recovery Oriented Practice (ROP) across MH services, both clinical and non-clinical, there exists an understanding that the consumer is the expert in their own care, and that services are to support them to progress along their journey of recovery from the consequences of mental ill-health. It appears that this remains aspirational despite efforts to introduce the ROP to clinical MH services (Davies and Gray 2015).

#### 4. Overcoming stigma

Mental illness continues to attract stigma in spite of targeted community efforts to alleviate it (Victorian Government 2015, p.14). Consumers report that the stigma of mental illness can prevent them from seeking support, and when they do, they can find some staff perpetuate the stigma and confirm their fears. Carers may be stigmatised for their perceived role in the consumers illness. Some staff also experience stigma. In the past, AOD practitioners were stigmatised as “ex-users” just wanting to give back to the community. This can inhibit the development of a working relationship with clinical services.

#### **Study strengths & limitations**

Whilst this study aimed to investigate a particular region, generalisability of this study may be limited, and it would be ideal to compare results with similar studies from other areas of Victoria. The fact that all staff and service leaders had some relationship to the work of EMHSCA in supporting CC across the region may have been both a limitation in that their knowledge may have biased responses, and a strength in that all participants would have good knowledge of the concept, and their responses would be well informed.

Consumer sampling was restricted by availability of willing participants, resulting in consumers being almost exclusively sourced from tertiary MH services and at a more acute point on the continuum of recovery. It is not known whether this impacted on the findings.

The topic of this study elicited passionate responses from many of the subjects. The nature of self-report means that participants may be prone to exaggerate their views in hope that the research may highlight the issues they are experiencing. Selective memory and attribution may also be factors for participants in providing a self-report. Data saturation for staff cohorts was not optimal due to the diversity of MH experience of the participants from various service-delivery backgrounds, and data content reflected this.

This research involved a broad range of service providers with a varied mix of disciplines and experiences. The large sample sizes enabled a thorough analysis of the enablers and barriers and the ability to provide significant recommendations for systemic change.

## Chapter 6: Conclusions

### 6.1 Summary of Findings and Implications for practice

Building on the work of a local MH Service coordination alliance, this study set out to identify potential ways in which CC and collaboration could be preserved and improved by investigating this complex phenomenon from the viewpoint of service users and service providers. This multi-level study included a variety of service sectors and provided an opportunity to engage in a rich understanding of the enablers and barriers from a range of perspectives. Much of this discourse has confirmed results of previous studies on the topic while addressing key gaps in the literature. Knowledge of how the various and rapid sector reforms are affecting service providers and users, and exploration of what people think needs to change, has led to a series of recommendations for future research and potential system change.

The overarching theme across all sets of data is captured in the phrase “it is who you know *and* what you know that makes collaborative practice work”. As enablers, relationships and service knowledge are critical factors in CC. These are supported by a gentle and flexible service environment, service navigation tools and roles, clear communication mechanisms, cross-sector training, staff networks and alliances. Appropriate resourcing of health and human services is needed to support the human connections that enable coordinated supports and consumer engagement. Significant barriers to CC and collaboration included: stigmatisation of MIH; the complex and unnavigable service system; a hierarchical system; and most significantly, the rapid and frequent system reforms including the introduction of FFS models to deliver psychosocial disability supports.

All 59 research participants were asked to consider ways of improving and supporting CC and collaboration. A series of clear recommendations have emerged from the study data in relation to service navigation, consumer friendly environments for support, stability of the workforce and developing a standard knowledge base across service sectors. These address the research question of what can be done to improve CC and collaboration.



### 1. The importance of service navigation

There is a clear and demonstrated need for a simple and comprehensive tool to enable navigation of supports, both for the community and for service providers themselves. With easy access to up-to-date information about which services are available and appropriate for people, consumers are more likely to locate the right supports to enable their journey of recovery and are less likely to fall through the gaps in service provision. This in turn will reduce future costs.

### 2. The importance of a gentle environment

Consumers have requested consideration of the development of service environments that reduce anxiety and enable connection. The worker is an intrinsic aspect of the service environment and capacity building of staff needs to include trauma informed practice and customer service skills. When consumers are most disabled by their symptoms their home environment is likely to be the most useful place for services to engage in provision of supports.

### 3. The importance of a stable workforce

Policy and system reform should focus on stabilisation of the workforce across all health and community service sectors to enable relationships to be established and sustained for optimal CC. Consideration should be given to abandoning FFS models and identifying better methods, such as long term block funding, that support collaborative practices. Output driven models allow little time for workers to communicate and develop shared understandings. It seems likely that a change in focus, to measure the outcomes of collaborative practices, would enable services to provide more flexible and coordinated responses to the needs of consumers and carers.

### 4. The importance of standardising worker knowledge across sectors

When staff know how to identify the consumer's issues effectively, they are better equipped to communicate and advocate for them in accessing services and planning their care. This requires training and tools. Both tertiary and non-tertiary education providers should consider how they can effectively broaden the knowledge base of health and community

service workers as part of their initial training. Once in the workforce, support is required in the form of funding and policy to enable both a) the development and delivery of, and b) attendance at cross-sector training. Screening tools can support staff to better identify a broad range of consumer needs and encourage the use of appropriate language for cross-sector communication.

## 6.2 Recommendations for future research

Future research is required to identify the most efficient methods of providing a more stable workforce and reducing staff attrition. An economic evaluation and cost comparison of existing health and community service funding models would be useful to guide future policy decisions. A contemporary Health Impact Assessment (HIA) of FFS models can support any proposal to avoid future use (and abandon current use) of these in relation to health and human services.

Further studies are required to, investigate useful and cost-effective ways to optimise the environment for service provision, and direct funding to support developments to service structure and practice. A co-design approach is recommended to ensure the service users' needs are incorporated into future service design.

## Declaration of interest

The researcher was employed as the project officer for the Eastern Mental Health Service Coordination Alliance and as the Mental Health NDIS Program lead at Eastern Health whilst also undertaking research there with Deakin University.

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# Appendices

## Appendix 1: Glossary

### List of Abbreviations

AOD - Alcohol and other drugs

CATT – Crisis Assessment & Treatment Team

CC – Care Coordination

CM – Case Management

DHS – Department of Human Services

DHHS – Department of Health and Human Services

DSP – Disability Support Pension

EMHSCA – Eastern Mental Health Service Coordination Alliance

EMR – Eastern Metropolitan Region

FFS – Fee-for-service

GP – General Practitioner (medical)

MH - Mental Health

MHCSS – Mental Health Community Support Services

MIH – Mental ill-health

MOU – Memorandum of Understanding

NDIS – National Disability Insurance Scheme

PARC – Prevention and Recovery Care

PCP -Primary Care Partnership

PH – Primary Health

PHaMS – Personal Helpers and Mentors Service

PIR – Partners In Recovery

PSW – Peer Support Worker

ROP -Recovery Oriented Practice

SCF- Service Coordination Framework

## Terminology

Carer – Family members or friends of a consumer who provide care to the consumer within their relationship as defined by the Carers’ Recognition Act 2012 (Victorian Government 2012, p.2). Carers may not necessarily live with the consumer for whom they care. Children can be carers too.

Collaborative – 1. Two or more people or organisations working together for a particular purpose; 2. All parties to the recovery plan participate as equals in all processes of coordinated shared care required.

Consumer – Someone who has been diagnosed with a mental illness, has direct experience of MH services or identifies as a consumer (VMIAC). The term “consumer” refers to people who directly or indirectly make use of MH services.

Dual Diagnosis – the term use to describe the co-occurrence of MH and Substance Use diagnoses.

Recovery Oriented Practice - A core component of ongoing health care reforms that emphasises the personal journey of people with mental illness (Australian Government, 2019)

Recovery Plan – A consumer’s plan that articulates what is important in their life including goals, hopes, dreams and identified supports (Glover 2013).

## Appendix 2: Ethics approval



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ABN 68 223 819 017

### Human Research Ethics Committee - Scientific and Ethical Review Ethical Approval – Granted

12 October 2018

Dear Bronwyn Williams,

LR72-2018 – Investigating the enablers and barriers to collaborative and coordinated care for people who experience mental ill-health in Melbourne's east.

---

Principal Investigator: Bronwyn Williams

Associate Investigator: Dr Shane McIver

Eastern Health Sites: Eastern Mental Health Service Coordination Alliance

Approval Period: On-going - subject to a satisfactory progress report being submitted annually

Thank you for the submission of the above project for review. The project has been reviewed by the Eastern Health Human Research Ethics Committee. The project considered low risk in accordance with definitions given in the National Statement (2007). All queries have now been addressed and the project is **APPROVED**.

Documents submitted for review:

- Low Risk & Negligible Risk Research Application Form v1.3 dated 12 October 2018
- Staff Participant Information Sheet and Consent Form v1.2 dated 12 October 2018
- Carer Participant Information Sheet and Consent Form v1.2 dated 12 October 2018
- Information sheet for staff to introduce project v1.2 dated 12 October 2018
- Project Proposal v1.4 dated 27 August 2018
- Project Plan v1.3
- Research Questions – Script v1 dated 19 September 2018
- Consumer and Carer Participant Poster v1.2 dated 12 October 2018

#### Conditions of Eastern Health Approval

- Any changes to the approved Protocol or other documents used in the conduct of the study must be submitted for ethical review and approval prior to use.
- Significant Safety Issues or unforeseen events should be notified to the Eastern Health Human Research Ethics Committee promptly for noting and reporting to hospital insurers.
- Continuing approval is subject to the timely submission of a satisfactory progress report. The progress report must be submitted every February for the preceding calendar year until project completion. The template (Progress Report – Project Form (HREC)) can be downloaded from our web-page: <https://www.easternhealth.org.au/research-ethics/guidance/quick-links-to-forms-and-templates>
- Report any change in personnel involved in the research project

- Research data stored on personal computers, USBs and other portable electronic devices must not be identifiable. No patients' identifiable information or UR numbers must be stored on these devices.
- Electronic storage devices must be password protected or encrypted.
- The conduct of research must be compliant with the conditions of ethics approval and Eastern Health policies
- It is very important that the role of Eastern Health is acknowledged in publications. Publications provide evidence of the contribution that participants, researchers and funding sources make.

Yours sincerely



Robert Reid  
Ethics Governance and Project Officer  
Office of Research and Ethics

On behalf of:

1. Eastern Health Human Research Ethics Committee (Ethics Approval)
2. Executive Director Medical Services and Research (Site Authorisation)



Human Research Ethics

Deakin Research Integrity  
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Telephone 03 9251 7123  
research-ethics@deakin.edu.au

**Memorandum**

**To:** Dr Shane McIver  
School of Health & Social Development

B

**cc:**

**From:** Deakin University Human Research Ethics Committee (DUHREC)

**Date:** 30 October, 2018

**Subject:**

Investigating the enablers and barriers to collaborative and coordinated care for people who experience mental ill-health in Melbourne's east

Please quote this project number in all future communications

Approval granted by Eastern Health HREC for this project will be noted at the DUHREC meeting to be held on 12/11/2018.

It will be noted that approval has been granted for Dr Shane McIver, School of Health & Social Development, to undertake this project as stipulated in Eastern Health HREC approval documentation.

The approval noted by the Deakin University Human Research Ethics Committee is given only for the project and for the period as stated in the memo. It is your responsibility to contact the HREC should the project be discontinued before the expected date of completion. You are reminded that:

The Deakin logo should be on any participant documents, including the Plain Language Statement, or where that is not possible, ensure Deakin University's involvement in the project is clearly written in the documentation

The Deakin Human Research Ethics Office needs to be notified immediately if any complaints are received  
An annual/progress report must be submitted to the approving HREC and at the conclusion of the project, a final report must be submitted to the Deakin HREC.

DUHREC may need to audit this project as part of the requirements for monitoring set out in the National Statement on Ethical Conduct in Human Research (2007).

Human Research Ethics Unit  
research-ethics@deakin.edu.au  
Telephone: 03 9251 7123



### **Appendix 3: Interview and focus group questions**

#### **Questions for consumer interviews:**

1. Today we are talking about your experiences of working with health and community services. Which services have you worked with?
2. Please tell me, if you will, what it is like for you to work with your support services (examples of types of services provided).
3. Do the services that support you appear to be working together with each other?
4. Has anything seemed to change in your experience of working with support services in the past year?
5. Do you have any ideas about how services could make things better for you?

Focus group questions will be based entirely on the interview questions.

#### **Questions for carer interviews:**

1. Today we are talking about your experiences of working with health and community services. Which services have you worked with?
2. Please tell me, if you will, what it is like for you working with your family member/loved one's support services? (examples of types of services provided).
3. Do the services that support your family member/loved one seem to be working together with each other?
4. Has anything changed in your experience of working with support services in the past year?
5. Do you have any ideas about how services could make things better for you?

Focus group questions will be based entirely on the interview questions.

#### **Questions for staff and leader interviews:**

1. Today we are talking about your experiences of working with other health and community services. Which services have you worked with?
2. What are a couple of things that stand out for you about working collaboratively with other services? (examples of types of services provided).
3. In your view what enables you to work together with other support services when you have a shared client?
4. What are some of the challenges to the collaborative and coordinated work with other providers?
5. Has anything changed for the better or for the worse for you in relation to how you work collaboratively with other providers in the past 12 months or so?
6. What are some of the things that you think would make collaborative and coordinated practice easier to achieve i.e. What would you improve if you could?

## **Types of local services**

**Mental health treatment** – Eastern Health Case manager; Psychiatrist; Mental Health Nurse; Psychologist; Social Worker; Occupational Therapist; Headspace; CYMHS; PARC; CCU; MST; Mental Health Clinic; Murnong; Chandler; Koonung; Mental Health unit; ECASA; ARBIAS.

**Mental Health community support** – Phams; Day 2 Day Living; Partners in recovery (PIR); MIND; NEAMI; MeWell; Uniting Prahlan; EACH; Wellways.

**Aboriginal services** – HICSA; Mullum Mullum; VACCA; Ngwala Willumbon; VAHS; Boorndawan Willam.

**Alcohol & other Drug support** – Counselling; Rehab; Detox; Anglicare; SURE; EACH; Turning Point; Eastern Health; Access health and community; Link health and community; Inspiro.

**Centrelink** – Social worker; employment.

**Community Services** – Carrington Health; Link Health & Community; Access Health & Community; Inspiro; Manningham Health & Community; EACH.

**Employment support** – Campbell Page; JobCo.; EACH.

**Family support** – Anglicare family services; Department of Human Services; Uniting; EDVOS.

**Housing/Homelessness support**– Wesley; Uniting; Anchor; Community Housing Limited (CHL); Harrison; EACH.

**Local Council support** – Home care; meals on wheels; Community house; family counselling; crisis support.

**Other supports** – G.P; Legal support; court support; financial counselling; etc...

Definitions (provided in Prompt sheet for staff and leaders)

Easy English – services working with you and your family/carer, and also your services working together with each other to support you better.

Coordinated care

“In practice, coordinated care should involve the coordinated delivery of individual services across multiple sectors, which is perceived as a seamless service system by clients, and results in overall improved client outcomes.” (Marel et al 2016)

## Appendix 4: Comparing sub-themes across study cohorts to establish principal themes

Cohort/ Theme	The consumer as central	The importance of the human touch	Sharing and owning: the importance of team work	The importance of connections and networks	The importance of resourcing
<b>Consumers</b>	<ul style="list-style-type: none"> <li>*Focus on personal strengths</li> <li>*See the person as a whole</li> <li>*Labels make it hard to get the right supports</li> <li>*Consumers have the right to privacy</li> <li>*I don't need their help. I can do it alone</li> <li>*Mental Health is 24/7 not 9 to 5</li> </ul>	<ul style="list-style-type: none"> <li>*Gentle supports and environments are more welcoming</li> <li>*Lived experience is gold. Peers get where you are at</li> <li>*Treating everyone as an individual</li> <li>*Customer service goes a long way</li> <li>*MH drop-in services are needed</li> </ul>	<ul style="list-style-type: none"> <li>*When supports talk to each other it makes things easier for consumers</li> <li>*Telling your story over and over is re-traumatising</li> <li>*Responsiveness and availability of services is important</li> <li>*Different workers all the time is not useful</li> </ul>	<ul style="list-style-type: none"> <li>*A one stop shop means easy access to supports</li> </ul>	<ul style="list-style-type: none"> <li>*Staff are busy, task focused and managing safety issues</li> </ul>
<b>Carers</b>	<ul style="list-style-type: none"> <li>*Consumers need to want their loved ones involved (consent)</li> </ul>	<ul style="list-style-type: none"> <li>*Meet people where they are most comfortable- home visits make access to supports easier</li> <li>*Staff need to be trauma informed</li> <li>*Need customer service training for</li> </ul>	<ul style="list-style-type: none"> <li>*Acknowledging the carer as a resource and key support</li> <li>*Identify the young carer</li> <li>*Lots of staff changes since NDIS</li> </ul>	<ul style="list-style-type: none"> <li>*Knowing the service system means we get the right supports</li> <li>*Accessing services is too complex</li> <li>*Carers are left to navigate the system without support</li> </ul>	<ul style="list-style-type: none"> <li>*When staff know their stuff the work gets done</li> <li>*Staff only call carers when there is a crisis</li> <li>*Carers are doing a lot of work for NDIS</li> </ul>

staff					
<b>Peer workers</b>	<ul style="list-style-type: none"> <li>*Provide choice about how people access services</li> <li>*People are individuals</li> <li>*Identify personal barriers to engagement</li> <li>*People can't deal with MIH when they have nowhere to live</li> </ul>	<ul style="list-style-type: none"> <li>*Being human</li> <li>*Holding hope for people</li> <li>*Showing compassion</li> <li>*Empathy and understanding where people are at</li> <li>*Warm and friendly</li> <li>*Listen and reflect</li> </ul>	<ul style="list-style-type: none"> <li>*Having respect for other staff</li> <li>*Feel isolated in role</li> <li>*Not supported by management to collaborate</li> <li>*Hierarchy between peers and other staff</li> <li>*Stigma is still evident</li> <li>*Handballing between services means people don't get support</li> </ul>	<ul style="list-style-type: none"> <li>*Staff need a good knowledge of services to provide holistic support</li> <li>*The MH system is not united</li> <li>*Staff keep changing under NDIS</li> <li>*We need more opportunities to meet F2F with other staff</li> </ul>	<ul style="list-style-type: none"> <li>*The right services at the right time</li> <li>*Services are not meeting demand</li> <li>*Staff too busy</li> <li>*Focus on throughput is not useful</li> <li>*Part time workforce makes communication difficult</li> <li>*Need one central point of service navigation</li> </ul>
<b>Staff</b>	<ul style="list-style-type: none"> <li>*People need someone to help them navigate the services and get the right supports</li> <li>*Consumers need to support the collaboration</li> <li>*They may not know who is supporting them</li> <li>*They may not think they need</li> </ul>	<ul style="list-style-type: none"> <li>*Warm referrals make it easier for people to engage</li> <li>*A 'no wrong door' approach helps make people feel welcome wherever they go</li> <li>*Meet people where they are at</li> <li>*Expand the lived experience workforce</li> </ul>	<ul style="list-style-type: none"> <li>*Good relationships start with clear communication and mutual respect</li> <li>*Care teams need to meet – it helps maintain a holistic view of people</li> <li>*Clarifying roles is important to avoid duplication of effort</li> <li>*Sharing the risk reduces</li> </ul>	<ul style="list-style-type: none"> <li>*It's not what you know it's who you know - Collaboration is person dependent</li> <li>*Network meetings help you to put a name to a face and support sharing information and resources</li> <li>*Common issues identified</li> <li>*Facilitates problem solving and</li> </ul>	<ul style="list-style-type: none"> <li>*Stability of staffing means relationships are preserved</li> <li>*With recent changes staff are leaving in droves</li> <li>*Colocation of services makes it easier to work together</li> <li>*Sometimes it is really hard to get the supports for people in need</li> <li>*MH services</li> </ul>

	<p>services to talk to each other</p> <p>*They may not trust services or be too unwell to work collaboratively</p>	<p>*The NDIS booking system is inflexible</p>	<p>worker anxiety and keeps people safer</p> <p>*Being responsive and reliable makes care coordination easier</p> <p>*Leaders need to support care coordination and collaborative practices</p> <p>*There is no case management or care coordination with NDIS</p> <p>*Care coordination roles keep the care team on track</p>	<p>innovation</p> <p>*Shared training opportunities</p> <p>*Getting to know services, their culture and language assists with communication and service navigation</p> <p>*EMHSCA encourages work across sectors and knowledge to develop</p> <p>*Leaders need to support attendance at network meetings</p> <p>*Competition between providers means they don't share so much</p>	<p>are crisis focussed services</p> <p>*Fee-for-service models mean no money for staff development or basic resources</p> <p>*NDIS supports are less skilled and cannot handle risk</p> <p>*The system is fragmented – bring the various service models together</p> <p>*Stop rushing people through the system as a statistic</p> <p>*Need one central point of service navigation</p>
<b>Leaders</b>	<p>*Believing collaboration is in the best interests of the consumer</p> <p>*Tailor the service to the individual</p> <p>*Build in flexibility to</p>	<p>*Embed the lived experience voice in the organisation</p> <p>*Good will to go above and beyond</p> <p>*Make the work about the consumer by staff</p>	<p>*One united care plan simplifies things for people</p> <p>*Shared templates bring consistency to the work</p> <p>*A care coordination role brings</p>	<p>*We need a voice to unite the services</p> <p>*EMHSCA keeps everyone together no matter what</p> <p>*Joint training and forums – capacity building</p>	<p>*Funding not supportive of staff working together</p> <p>*Need to align state and federal initiatives and funds</p> <p>*Lack of outcome measures to support care</p>

<p>services to better meet the needs of consumers</p> <ul style="list-style-type: none"> <li>*Involve consumers in the whole process of planning</li> <li>*Consumer s may need support to have a choice</li> </ul>	<p>coordinating calendars and supports</p>	<p>the team together for continuity of care</p> <ul style="list-style-type: none"> <li>*Creative problem solving together</li> <li>*The spirit of collaboration exists in the worker</li> <li>*Getting lost in the consent and info sharing issues</li> <li>*Care team meetings can solve issues of role confusion</li> <li>*NDIS staff cannot communicate or participate in care coordination</li> <li>*NDIS Support Coordination is not Care coordination</li> <li>*Perceived power and assumed hierarchy put people off working together</li> </ul>	<p>across sectors</p> <ul style="list-style-type: none"> <li>*Mutual respect</li> <li>*The work is supported by shared goals, values, mutual expectations and a commitment to coordinate care</li> <li>*Neutral territory preserves service relationships</li> <li>*EMHSCA provides opportunity to build face to face relationships</li> <li>*Staff need to understand each other better</li> <li>*Leaders need to model and lead the collaboration</li> <li>*Knowing about other services assists with navigation</li> <li>*It is great to put a name to a face</li> <li>*Networking helps staff to identify commonalities and cultural</li> </ul>	<p>coordination and collaboration</p> <ul style="list-style-type: none"> <li>*Pricing for NDIS supports are too low</li> <li>*You cannot communicate if you haven't got a phone</li> <li>*Implement screening tools</li> <li>*Work is crisis driven leaving no time for coordination of supports</li> <li>*Fee for service is competitive model</li> <li>*Throughput mindset and cost efficiencies inhibit care coordination efforts</li> <li>*Fund positions to drive change</li> <li>*Build collaboration into the system</li> </ul>
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differences  
\*Informal  
relationships  
are breaking  
down with  
system  
reforms

## 2019 Submission - Royal Commission into Victoria's Mental Health System

### Organisation Name

Eastern Mental Health Service Coordination Alliance

### Name

Ms Bronwyn Williams

### What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?

I think current campaigns such as R U OK? and celebrity honesty is already pretty effective. Workplace policy would be the area in need of tuning to ensure workers experiencing MH issues are not discriminated against and can continue on their recovery journey.

### What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?

N/A

### What is already working well and what can be done better to prevent suicide?

N/A

### What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.

N/A

### What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

N/A

### What are the needs of family members and carers and what can be done better to support them?

"Carers lack necessary respite. They carry the greatest responsibility and cost for their loved ones. Greater subsidies for necessary diagnostic tests for their loved ones such as Neuropsychological assessments would improve access to the DSP, NDIS and necessary supports. "

### What can be done to attract, retain and better support the mental health workforce, including peer support workers?

Better staffing would reduce the burden on the current workforce and help with retention. A more skilled workforce can better manage aggression etc... and reduce stress on the broader workforce. Build Care coordination and Collaboration into funding structures and introduce outcome measures that align to collaborative practice - thus providing better all round support for individuals with complex needs.

### What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?



"The environment needs to be gentler for people with moderate to severe Mental ill-health. Sensory modulation is required in workplaces and social and community areas. Flexibility such as working from home and flexi hours. Better resourcing of employees (i.e. phones, cars if job requires these) "

**Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?**

Abandon Fee-for-service models such as NDIS for psychosocial disability. Perform a Health-Impact-Assessment on the Fee-for-service model in relation to Mental Health (and other health more generally e.g. G.Ps). Align the various sectors with common knowledge and skills to enable a no-wrong-door approach to services.

**What can be done now to prepare for changes to Victorias mental health system and support improvements to last?**

Improve outcome measures and move away from funding aligned to output measures.

**Is there anything else you would like to share with the Royal Commission?**

I would like to share my thesis. I will upload the file as I don't have the time to write everything out in the boxes above. MH is part of a complex system beginning with the G.P. Fee-for-service models do not support care coordination and as such need urgent review. The Royal Commission needs to look at MH in the context of the whole system including housing and think in terms of Maslow's hierarchy of needs. MH is not achievable when people do not have their most basic needs met!