Multiple unmet needs, families and consumers

A Literature Review for the In Community Project

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CONTENTS

RESEARCHERS' SUMMARY OF THE KEY ISSUES

This review of the literature on multiple unmet needs and the inclusion of families and consumers reveals gaps and critical issues. These gaps and issues are detailed throughout the remainder of this report and this executive summary alerts the reader to the key issues that are evident from our reading and critical analysis of the literature. We offer our analysis and summary of these gaps and critical issues.

1. People considered to have multiple unmet needs and their families continue to 'fall through' service gaps despite a plethora of policies, standards and good practice frameworks.

2. The ability to effectively meet the needs of consumers and families while balancing both the consumers' rights to confidentiality and the family's rights to information is consistently referred to as a 'tension'. Yet, some studies report no significant difference between the views of consumers and families when it comes to family involvement. This leads us to question where the idea of this tension originates, what sustains it, and how it can be addressed.

3. There is a significant gap in culturally competent understandings of multiple unmet needs and family inclusive practices. This is pertinent and of concern given the already high and growing population of ATSI people in prison, with a large majority reported to experience mental distress, long term trauma and substance use. For people living in rural and remote areas, there is a lack of appropriateness and continuity in service provision which is compounded by a multitude of other factors such as poverty, racism and intergenerational trauma; particularly for Indigenous Australians.

4. Policies, standards and good practice frameworks have not been systematically implemented or evaluated. We have been unable to locate any critically-informed research which explicitly details why mental health services have not embraced family inclusion. Ideas put forward relate to staff skills, training and attitudes; inadequate policy directions; and the impact of crisis situations. From our perspective, these arguments are unconvincing and suggestive of degrees of collusion between some researchers and mental health staff (practitioners, managers and policy-makers).

5. Given that family inclusive policies, standards and frameworks are rarely subject to evaluation or used as accountability mechanisms for the funding of government and non-

government services, the gap between policy and practice is inadvertently and implicitly sanctioned. Without mechanisms to ensure that family and consumer inclusion is implemented according to the policy direction, they remain aspirational, and families and consumers will continue to experience barriers to service delivery and exclusion. We believe this literature review highlights the need to move away from the development of more policies, practice guidelines and standards and instead work towards practical and widespread culture change.

6. While few examples of successful, meaningful and sustained family and consumer inclusion practices exist, those found to reflect person first and recovery principles (partially or fully), such as Open Dialogue, the Multiple and Complex Needs Initiative (MACNI) and Implementing Recovery through Organisational Change (ImROC) are characterised by:

   a. Deep listening to the lived experience of families and consumers.

   b. Vertical and horizontal cultural change (top-down, bottom-up and across all levels of the organisation).

   c. A willingness to critically reflect upon and name what is not working.

   d. A commitment by service providers to work in partnership and coproduction with consumers and family members.

   e. An openness to acknowledge, articulate and address power relations.

INTRODUCTION

This literature review for the In Community Project explores the experiences of, and responses to, people considered to have multiple unmet needs and their families. In this project, multiple unmet needs is defined to include a combination of mental distress, substance use and involvement in the criminal justice system. In Community is a partnership between Mental Health Matters 2 (MHM2) and Richmond Fellowship of Western Australia (RFWA) and aims to promote culture change in mental health service delivery practices. It particularly seeks to change current culture and create the conditions for meaningful, non-tokenistic involvement of consumers and families.

The scope of this literature review was established through consultations between the In Community partnership group and the Curtin research team. We acknowledge that families and consumers share commonalities and differences and we have endeavoured to locate literature specific to family inclusion. However as the literature often discusses 'family and consumer involvement' as a collapsed phenomenon; this review will reflect this concept while also paying attention to the unique experiences of families where such literature has been located. This review has focussed on material which adopts a person-first and personal recovery orientation; rather than a bio-medical, disease oriented stance.

As a starting point, cultural differences and diversity within, across, and between, families and individuals affected by mental distress is acknowledged and validated. It is also acknowledged that the experience of Aboriginal and Torres Strait Islander (ATSI) and Culturally and Linguistically Diverse (CaLD) consumers and their families is usually problematic and unsatisfactory due to a lack of cultural security within mental health services (Szmukler & Bloch, 1997). However, very little of the literature refers to cultural diversity; which means the findings presented in this review may not be reflective of, or relevant to, ATSI and CaLD peoples' lived experiences.

It is also important to clarify the use of specific terminology within this document. The term mental distress is used to reflect 'mental illness' and 'mental health' experiences. While a range of terms such as 'service user', 'survivor' and 'client' are found in the literature, the term 'consumer' is common in Australian policy, standards and service delivery and indicates a relationship between a consumer and provider and based on the delivery of a service

(Lammers & Happell, 2004b). It is acknowledged that there are limitations with this term, particularly for individuals who experience mental distress and who do not consume services. However, given the frequency of use, the term consumer is adopted in this review. The terms 'carer' and 'family' are used interchangeably in the literature to suggest the provision of different types of support, roles and identities. Although the term 'carer' is helpful in recognising a specific group of people and their role, it is contested for reasons such as implying a relationship of dependency and being unreflective of people's chosen identities (Stanbridge & Burbach, 2007; Van Schoubroeck, 2012). Despite this, the term is commonly used in Australia.

It is also important to note that 'family' encapsulates whomever a consumer may claim as family. This can include biological relatives, friends and other supporters. Aligned with this, the Open Dialogue approach uses the phrase "social network" which relates to "all important people, regardless of whether they are family or not." (Seikkula & Arnkil, 2014, p. 54). The term family is used here to encompass a broad range of relationships between consumers and those they are in relationship with. The research team acknowledges the limits and problems associated with the phrases 'family inclusion' or 'family inclusive practice', as their use does not necessarily guarantee meaningful involvement, authentic coproduction or partnership activities. However, in order to convey key concepts these phrases have been adopted in this review and depending on the literature source, may indicate meaningful, tokenistic or non-existent involvement. It is important to note that the majority of studies and reports which consider family involvement situate it in the context of promoting 'patient' adherence to 'treatment' (Velligan et al., 2009) with no significant consideration of the unique insights, experiences or needs of families.

Within this review, the concept of family and consumer inclusion is based on meaningful involvement and participation in planning, service delivery, evaluation, research, workforce reform and policy activities in mental health (National Mental Health Consumer and Carer Forum, 2010). Such involvement can change organisational and service delivery cultures and contribute to workforce development and reform; however it can also be enacted in a tokenistic manner. Therefore the principles of coproduction which privilege the existing capabilities and resources of consumers and families, within a de-centred professional relationship are essential (New Economics Foundation, 2013). While it is

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common for consumers and families to be presented as a collapsed or singular identity in the literature, most studies suggest that the level of family involvement is much less than that of consumers (albeit that is also well below par). Family involvement is often positioned as a 'challenge' or 'difficult'. It is argued that family members become reluctant to repeatedly share their views and experiences when involvement is invited haphazardly and no long term tangible outcomes or changes occur for the consumer or family (Lammers & Happell, 2004b; Simpson, Jones, Barlow, & Cox, 2014).

Despite a robust evidence base for the positive impact family involvement (Leggatt, 2011), and calls for partnership between families and mental health professionals since the early 1960s (Evans, Bullard, & Solomon, 1961), history shows that families are often blamed for their loved one's mental distress. The deeply ingrained culturally, historically and socially informed belief that 'family dysfunction' causes mental distress is transmitted by mental health practitioners, the media (Furlong, 2001), researchers and academics. The theory of 'expressed emotion' is commonly drawn upon in mental health and like 'family dysfunction' arguments asserts that there is an indisputable correlation between relatives' emotional involvement, the consumer's mental distress, and the probability of 'relapse' (Brown, Birley, & Wing, 1972; Furlong, 2001).

This review begins by providing an overview of international and Australian policy, carer recognition acts and other legislation on family involvement. It then explores barriers to family inclusion, including the little that is documented about rural and remote experiences, Indigenous communities and CALD groups. Family inclusion barriers and a description of approaches and programs which specifically aim to include families are considered. Finally, critical issues and questions raised by this review are outlined and the researchers present their reflections and questions. The methodology used to scope, search and select relevant literature can be found in Appendix 1.

THE POLICY FRAMEWORK FOR FAMILY INVOLVEMENT

The World Health Organization (WHO) recommends the formation of partnerships between service providers, consumers and families in order to improve the quality of mental health services; facilitate empowerment; expand involvement in policy and programs; promote relationships between consumers and their families; support family advocates; and ensure

appropriate allocations of funding to consumers and families (World Health Organisation, 2004). Similarly, the Canadian Mental Health Association outlines the positive impact and types of roles adopted by families, which include informal case management, advocacy, and provision of crucial information on the consumers' lived experiences (Canadian Mental Health Association, 2006). As in other countries, the United Kingdom's Carers' Recognition Act (1995) sets out the conditions for family involvement; however it is argued that it has had minimal impact on the extent to which families are systematically included (Hervey & Ramsay, 2004). The importance of social networks and family supports in a consumer's life is noted in the US Department of Health and Human Services' National Consensus Statement on Mental Health Recovery (Substance Abuse and Mental Health Service Administation, 2004). The American Psychiatric Association encourages family involvement "to the greatest extent possible" in treatment planning, goal setting and service delivery (American Psychiatric Association, 1997, p. 165).

Consumer and family participation was first identified in Australian policy in 1992 with the publication of the National Mental Health Plan (Commonwealth of Australia, 1992). The plan promoted extensive changes to the structure and delivery of services and the expectation of consumer and family participation in the planning, designing and delivery of services (Commonwealth of Australia, 1992, 1996; Lakeman, 2008a). The plan argued that participation in service delivery development and delivery of programs would build environments which created the conditions for consumer and family empowerment (Lakeman, 2008a). Similarly, the plan asserted that families should be seen as allies, partners and collaborators in 'treatment' (Commonwealth of Australia, 1996). As with policy documents and frameworks, Carers' Recognition Acts can be found in all states and territories of Australia.

The WA Mental Health Commission's "Mental Health 2020: Making it Personal and Everybody's Business" positions consumers and families as partners and asserts that they should be meaningfully involved in leading mental health reform across Western Australia (Government of Western Australia, 2013). The Western Australian document "Supporting Consumer, Family and Carer Engagement Policy and Guidelines" stipulates five practices (informing, consulting, involving, collaboration and empowering) which underpin consumer and family involvement (Government of Western Australia, 2013). The recently released West Australian "Mental Health, Alcohol and Other Drug Service Plan 2015-2025" promises an agenda for improved, inclusive experiences for consumers and their families through the development of redesigned service models, sector-wide strengthening of service delivery partnerships and improved service coordination and integration (Government of Western Australia, 2015).

Despite the promising picture presented by policy and legislation over the last two decades and more, the exclusion of family and consumers continues (Groom, Hickie, & Davenport, 2003; Mental Health Council of Australia, 2009; The Human Rights and Equal Oppurtunity Commission, 1993), and there is no evidence of any sustained implementation of systemic developments that firmly embed consumers and families at the heart of recovery-focussed service delivery and design (Rosen, Goldbloom, & McGeorge, 2010).

> **KEY MESSAGES: POLICY AND FAMILY INCLUSION**
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> - The recognition of the positive impacts of family inclusion are highlighted in mental health policies worldwide.
> - Despite the World Health Organization arguing for family involvement in mental health services since 2004, and some countries having policies which refer to family inclusion since the late 1990s, there is a major gap between policy and sustained family inclusion in services.
> - In summary, the involvement of families in most developed countries is a policy and legislative aspiration and not a practice reality.

FAMILY INCLUSION AND EXCLUSION IN SERVICE DELIVERY

The exclusion of families across all levels of the mental health system including individual recovery planning, service delivery, policy and research is well established (Bogart & Solomon, 1999; Burns-Lynch, Murphy, Gill, & Brice, 2014; Goodwin & Happell, 2007a; Hitchen, Watkins, Williamson, Ambury, & et al., 2011; Kavanagh, Young, Boyce, Clair, & et al., 1998; Lakeman, 2008a, 2008b; Lammers & Happell, 2004a, 2004b; Tambuyzer & Audenhove, 2013). Family and consumer exclusion in mental health can occur in multiple ways, modes and forums (Mental Health Council of Australia, 2009, 2012). This exclusion is compounded when there is involvement in the criminal justice system, drug and alcohol issues, people live in rural or remote locations (Goodwin & Happell, 2007a, 2007b), or identification as ATSI or CALD (Mental Health Council of Australia, 2012). These experiences are compounded when families may constitute "hidden carers" (Mental Health Council of Australia, 2009, p. 88; 2012) which involves people who:

- Are not recognised or acknowledged by support services as supporters and 'carers'.
- Do not describe or frame their experience as 'caring'.
- Support individuals involved in the forensic system, who experience mental distress and/or use substances and, due to the fear of stigma and discrimination from their community or other family members, do not access support.
- May not wish to reveal themselves or their loved ones, for example, people in same sex relationships.
- Young people in the 'carer' role.

The type of language used in policy documents and by services and service providers can exclude and alienate families and consumers (Lammers & Happell, 2004a). Practitioner skill sets; the amount of training and knowledge staff have received; confidentiality; and information-sharing practices have been found to create the conditions for the exclusion of families (Cooper, Fairhurst, Hill, Ollerton, & Roscoe, 2006; Lammers & Happell, 2004a). This is accompanied by the assertion that meeting the needs of both consumers and families is difficult and creates 'tension' within the professional role. This belief can underpin the practice of not involving families (Goodwin & Happell, 2007b; Lammers & Happell, 2004a) and is based on the argument that service providers struggle in their endeavours to balance the supposedly competing needs of consumers and families (Cleary, Freeman, & Walter, 2006).

The notion of personal recovery can appear to be at odds with family involvement, with its emphasis on autonomy, self-determination, and consumer ownership and responsibility for the recovery journey (Wyder & Bland, 2014). However, it is well established the personal recovery occurs in the context of relationships and community and the consumer and family recovery journey is usually intricately connected (Coleman, 2011; Wyder & Bland, 2014). We now turn to consider the policy context in relation to multiple unmet needs.

> **KEY MESSAGES: FAMILY INCLUSION IN SERVICE DELIVERY**
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> ❖ Family exclusion is widespread despite policies, standards and legislation requiring family involvement.
> ❖ The needs and experiences of 'hidden carers' and those with diverse needs are often overlooked.
> ❖ A broad range of reasons are commonly put forward as to why practitioners do not involve families.
> ❖ Personal recovery is framed as an individual journey; however families play a central role through connection, support and in depth knowledge of the person.

MULTIPLE UNMET NEEDS, POLICY AND SERVICE DELIVERY BARRIERS

Policy relating to people with multiple unmet needs is scarce, however a range of guidelines and frameworks have been found which refer to consumers experiencing co-occurring mental distress and substance use. These guidelines rarely extend to include involvement in the criminal justice system (Rolfe & Cutcliffe, 2006). The Western Australian Mental Health Commission has acknowledged that it does not respond effectively to people considered to have multiple unmet needs, particularly in relation to criminal justice involvement (Van Schoubroeck, 2012). This group is argued to be the "most vulnerable in our community" (Hamilton, 2011, p. 320) and their comprehensive exclusion from services on the basis of being 'too difficult' or 'too high risk' commonly leads to an exacerbation of complexity and exclusion. Despite the prevalence of consumers with multiple unmet needs presenting in the mental health, alcohol and other drug and criminal justice systems, they continue to be seen as the exception; rather than the norm (Minkoff & Cline, 2006).

The 2002 Substance Abuse and Mental Health Services Administration (SAMSAH) Report to Congress gave attention to the significantly poorer outcomes and higher costs associated with individuals with multiple unmet needs in health and human services (Substance Abuse and Mental Health Services Administation, 2002). The report acknowledged that multiple unmet needs should be a service expectation rather than an exception, and systems should follow the concept of "any door is the right door" (Minkoff & Cline, 2004a, 2006; Substance Abuse and Mental Health Services Administation, 2002, p. 2). While the report does not reflect a contemporary understanding of recovery principles, it is inclusive of families, arguing that "treatment of an individual in the context of his or her family helps the household as a whole realize improvement and decreases the likelihood that mental illness and substance abuse will become an ongoing pattern" (Substance Abuse and Mental Health Services Administation, 2002, p. 17).

The Multiple and Complex Needs Initiative (MACNI) implemented in Victoria, Australia between 2004 and 2009 aimed to address multiple unmet needs of "mental illness, intellectual disability, acquired brain injury, physical disability, behavioural difficulties, homelessness, social isolation, family dysfunction and substance use" (Hamilton, 2011, p. 307). The project was based on an assumption that people experiencing some or all of these issues would have involvement in the criminal justice system. The project targeted diagnoses

such as schizophrenia or bipolar affective disorder because of the perceived 'higher risk' associated with these diagnoses. As a result, diagnoses such as personality disorder, anxiety and depression were less likely to be accepted into the program (Hamilton, 2011). It is reported that an increased focus on efficiency, specialisation and the siloed nature of government and non-government agencies excludes those considered to have multiple unmet needs (Hamilton, 2011).

An American study exploring the correlation between 'co-occurring disorders' and incarceration found that the majority of people considered to have multiple unmet needs do not receive 'treatment', and if received, it is rarely effective or coordinated (Eberwein, 2011). It is argued that service systems have a unique set of philosophical beliefs, administrative frameworks and funding processes which inadvertently mitigate against coordinated and seamless 'care' for consumers (Eberwein, 2011). One qualitative study exploring the effectiveness of treatment for women described as having co-occurring mental distress and substance use found that major barriers to receiving a service included negative staff attitudes and behaviours which blamed and judged the women; a lack of services coordination; and singular approaches to treatment where one issue was neglected while another was 'treated' (Penn, Brooks, & Brenda DeWitt, 2002).

Women and Indigenous Australians have distinct, layered and intersecting experiences of multiple unmet needs (Hamilton, 2011). The overrepresentation of Indigenous Australians in prison (Australian Bureau of Statistics, 2014) is also noted here, along with the increasing numbers of Aboriginal women in prison who are reported to have higher rates of mental distress and histories of sexual and physical traumas (Hamilton, 2011). While women are considered to have different and more problematic experiences than their male counterparts in relation to multiple unmet needs, limited research has been conducted in this area (Bramley et al., 2015).

Reluctance to work with consumers with a criminal record has been identified by Couturier, Maue, and McVey (2005). When returning to the community, the issue of multiple forms of stigma, and service exclusions are significant for people with 'forensic' histories, particularly if substance use is present (Rolfe & Cutcliffe, 2006). The media's contribution to perpetuating stigma and prejudice is said to increase public fear and distorts the perceived connection between 'mental illness' and crime (Rolfe & Cutcliffe, 2006). Additionally, the

limited number of appropriate service responses (especially in rural and regional areas) exacerbates the problems individuals with multiple unmet needs and their families face in relation to exclusion from services (Couturier et al., 2005).

A recent UK report "Hard Edges: Severe and Multiple Disadvantage" (Bramley et al., 2015) highlighted how people considered to have multiple unmet needs including mental distress, homelessness, substance use and criminal justice involvement fall through the gap between policy rhetoric and service delivery realities. It is argued that this occurs because service providers categorise people's needs and experiences as separate entities; rather than conceptualising the person in relation to the complete and multiple unmet needs. Additionally, the knowledge base of each profession informs the response to the person; with many professionals prioritising one unmet need over another; based on their professional disciplinary knowledge and biases (Bramley et al., 2015). It is argued that this group are frequently viewed through detached and uncoordinated 'professional lenses'. Both policy and service delivery can be disjointed; rarely based on evidence; and unreflective of structural, systemic, family and personal factors (Bramley et al., 2015).

An Australian study (David, 2011) on the experience of family members of individuals with co-occurring mental distress and substance misuse issues reports that a wide range of roles are adopted by family members and can include advocacy to find and access services; ensuring safety; minimising the impacts of risky behaviour and choices; providing emotional, physical and practical support; friend; and ally. In relation to service access, families in this study argued that without an assertive advocacy stance on

> **KEY MESSAGES: MULTIPLE UNMET NEEDS, POLICY AND SERVICE DELIVERY**
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> ❖ People considered to have multiple unmet needs are continually excluded from services on the basis of being perceived as 'too difficult' or 'too high risk' and are framed as the exception.
> ❖ Indigenous people and women are considered to have particularly complex intersections of multiple unmet needs
> ❖ Practitioners and service delivery responses are often detached and fragmented.

their behalf, consumers would be unlikely to receive the support and help from a range of mental health, drug and alcohol and related services (David, 2011). Family members in this study also spoke of the singular focus of services, which often provided contradictory and fragmented advice and information. Meaningful involvement of these families was reported to be rare.

ATSI, CALD, RURAL AND REMOTE EXPERIENCES

Exclusion is compounded for those who live in rural and remote areas, Indigenous Australians, and CaLD communities (Mental Health Council of Australia, 2009). Limited, immediate access to local mental health services creates a particular set of barriers and problems, and it is not uncommon for consumers to be transported away from home towns and families not informed or involved. Responses by regions such as employing fly in, fly out psychiatrists and mental health practitioners undermines continuity of service delivery and trust between the practitioner, consumer and family. These types of staffing arrangements also mean that practitioners lack local knowledge and cultural sensitivity. The situation is further compounded by poor information sharing practices which result in consumers and families having to tell their story numerous times (Mental Health Council of Australia, 2009). Goodwin and Happell (2007b) report that geographical distance is a significant contributor to the breakdown of communication between service providers and families in rural areas.

Indigenous family members are less likely to identify as 'carers' (Mental Health Council of Australia, 2009); which suggests it may not be a culturally-transferable concept (Wright, 2008). The specific needs of Indigenous families supporting people experiencing mental distress are often understated (House of Representatives Standing Committee on Family, 2009). Wright (2008) argues that Indigenous 'carers' experience the greatest level of marginalisation with many living in poverty and experiencing ongoing scrutiny by government bodies in areas such as corrections, welfare, housing, health and income support. The issue of trauma within Indigenous communities is a reoccurring theme including daily socio-political traumas (such as poverty, racism and economic exclusion) and historical and current trauma (Mental Health Council of Australia, 2009). Key issues such as unresolved intergenerational trauma, supports needed during 'sorry time', community shame associated with having a family member with mental distress, and discomfort in asking for help are central to the

experience for many Indigenous Australians (Mental Health Council of Australia, 2009). It is reported that the place and influence of culture is disregarded by most service providers who lack understanding of the intersections of culture, trauma, poverty, mental distress, substance use and criminal justice involvement (Mental Health Council of Australia, 2009).

Similar issues of cultural insensitivity and disregard are reported by CaLD families who commonly experience culturally incompetent mental health services (Mental Health Council of Australia, 2009). Stigma and discrimination are significant issues noted by CALD families and supporters as mental distress is often viewed differently to mainstream populations. Some cultural groups view mental distress as a "weakness and that it should not be discussed outside the family" (Mental Health Council of Australia, 2012, p. 37). Stigma and cultural

norms of caring for one's family without external assistance can lead to unmanageable crisis situations for many CaLD families (Mental Health Council of Australia, 2012).

Farooq and Fear (2003) argue that the use of interpreters can be problematic and requires cultural competence as well as the ability translate. Furthermore, Cross and Bloomer (2010) report that respect and cultural understanding are key to working well with CaLD consumers. Overall, the lack of credible research relating to the impact of race and

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KEY MESSAGES: ATSI, CaLD, RURAL AND REMOTE EXPERIENCES

❖ Exclusion is compounded for specific population groups such as those who live in rural and remote areas (of which a large majority are Indigenous), urban Indigenous Australians and CaLD communities.

❖ There is limited access to immediate local acute mental health services in rural and remote areas which creates a particular set of issues for individuals and their families.

❖ Little is known about what constitutes caregiving for Indigenous people.

❖ Both ATSI and CaLD consumers and families experience cultural insensitivity.

❖ Overall, there is a lack of credible research relating to the intersections of race and ethnicity on care-giving roles.

ethnicity on the care-giving role is concerning (Wright, 2008). The review now considers issues associated with family inclusion in service provision practices.

FAMILY INCLUSION AND SERVICE PROVISION PRACTICES

A range of barriers to inclusion of families in service provision are reported in the literature. It is the research team's opinion that there is limited in depth and critical research on why practitioners do not include families, and we would argue this is a gap in existing evidence and knowledge. It seems to us that there are few researchers willing to critically examine their own or other professions' practices in family inclusion and exclusion. Given this, we have considered the available literature and present the findings here.

'Family estrangement' resulting from familial exhaustion, fatigue and 'carer burden' is cited by practitioners as a reason why they do not involve families (Lakeman, 2008a; Mannion et al., 2012). Other barriers reported include the geographic distance between the family and the consumer, communication barriers for those who speak English as a second language, family conflict, and the difficulty for employed family members to attend service provider appointments during working hours (Reed & Harding, 2015; Tambuyzer & Audenhove, 2013).

Mannion et al. (2012) studied community psychiatrists who reported five barriers to family inclusion:

- Not having the confidence and expertise to work collaboratively with families.
- Limited knowledge on family experiences and needs.
- Formal or informal policies that discourage the inclusion of families.
- A lack of family-inclusive policies.
- Financial and regulatory considerations (This reflects the North American health insurance context where psychiatrists resist longer appointments as the costs of these appointments are not covered by health insurance funds and reportedly leave the psychiatrists 'out of pocket'.)

In relation to family members where the loved one experiences mental distress and problematic substance use, service providers argue that administrative demands, workload pressures and insufficient time precludes them from involving families (David, 2011). Service providers often claim that they do not involve families at the consumer's request; however some authors suggest that it is still possible to engage with families when a consumer refuses family involvement (David, 2011). A Queensland study by Lakeman (2008a) reports that consumers chose to not have their family involved because they did not want to burden their families, they felt able to cope independently, they did not want family to know they were using substances, or due to family conflict and fear of violence (Lakeman, 2008a). In contrast, Tambuyzer and Audenhove (2013) argue that there are no significant differences between consumer and family views on family involvement in areas such as information provision and collaboration in treatment decisions.

> **KEY MESSAGES: BARRIERS TO FAMILY INCLUSION**
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> ❖ Mental health practitioners cite a number of barriers to family-inclusive practice, yet there is a lack of critical research evidence which provides a solid and useful body of knowledge on why these practices occur.
> ❖ While some consumers may choose not to have family involved, many desire this. It would seem that the important issue is that consumers are able to choose who is involved and how they are involved.

Exclusionary language

The dominance of bio-medical language and medical discourse within mental health services excludes, depersonalises and alienates consumers and families (Hitchen et al., 2011). This particularly extends to insensitive language used to describe consumers and family members such as the 'burden of care' for families and consumers 'being managed'. In one study, a consumer responded in the following way:

We are not a burden …
we can shift from their …
perception of being a
burden of care to
actually leading the way
in reforming the
proactive health
prevention's (sic) that
can prevent people from
experiencing serious
episodes of mental
health problems
(participant cited in
Lammers & Happell,
2004c, p. 265).

> **KEY MESSAGES: EXCLUSIONARY LANGUAGE**
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> ❖ Bio-medical language and medical discourses exclude, depersonalise and alienate consumers and family members.
> ❖ Many taken for granted terms (for example 'burden of care') are experienced as offensive and disrespectful by families and consumers.

In another study, a study participant described the experience as "jumping into a pool of language, it is English but not plain, everyday English" (participant cited in Hitchen et al., 2011, p. 169).

Practitioner knowledge, skills and attitudes

It is commonly reported that staff skills and knowledge are major barriers to family inclusion in the substance use and mental health fields (Cleary et al., 2006; Cooper et al., 2006; Mannion et al., 2012). Negative and stigmatising attitudes held by practitioners have been identified as widespread (Cooper et al., 2006; Rolfe & Cutcliffe, 2006). It is argued that practitioners do not have broad and inclusive definitions of families and carers; thereby inadvertently excluding key supporters and allies (National Mental Health Consumer and Carer Forum, 2009). Despite people considered to have multiple unmet needs being commonly described as 'difficult to engage', Cooper et al. (2006) suggest that it is services which are actually difficult to engage, not consumers. A UK study by Davies, Heslop, Onyett, and Seteriou (2014, p. 62) found that 51 of 55 individuals who were considered "hard to engage" wanted help. The four consumers who rejected services explained that their reluctance to engage resulted from previous negative experiences with services. This

highlights the responsibility of services to persistently, respectfully and proactively engage. It also suggests that if services were focussed on, and responsive to, consumers' priorities, building professional relationships, and demonstrating their trustworthiness, consumers "may not be so 'hard to engage' after all" (Davies et al., 2014, p. 66).

A UK study described how many staff continue to view families as the cause of a consumers' "difficulties" or as an obstacle to treatment (Stanbridge & Burbach, 2007, p. 30); which results in practitioners avoiding contact with families or thinking their involvement is unnecessary. An Australian study found that nurses and psychiatrists hold the most negative attitudes toward consumer participation (Bennetts, Cross, & Bloomer, 2011).

In researching service provider attitudes towards family inclusive strategies, Stanbridge and Burbach (2007) found that some service providers rejected the need for a strategy because they perceived themselves to be practising in a family inclusive manner. Others resisted a family inclusion strategy on the basis that it would increase workloads and expose practitioners to situations they had insufficient skills or organisational guidelines to manage (similar findings reported by Goodwin and Happell (2007b). In a sample of 61 family members, four reported reduced familial stress because they had been valued and included by the mental health team (Lakeman, 2008a). Families report the importance of

> **Key messages – staff experiences and attitudes**
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> ❖ Practitioners working in the substance use and mental health fields often lack the requisite skills and knowledge to work effectively with people experiencing mental distress and substance misuse.
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> ❖ It is suggested that services, and not consumers, are difficult to engage.
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> ❖ There is a continued belief that families are the cause of their relatives' 'difficulties' and constitute a barrier to 'treatment'.
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> ❖ Practitioners who do not believe family inclusion is important avoid contact with families.
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> ❖ Nurses and psychiatrists were identified as holding the most negative attitudes toward consumer participation.

encouragement and respect by mental health staff, yet noted this was less likely to occur once their loved one was discharged to the community (Goodwin & Happell, 2007a).

Confidentiality and information sharing

Issues associated with confidentiality and information sharing between service providers and families are consistently mentioned as barriers to family inclusion (Cleary et al., 2006). However, as already noted, family involvement improves relationships (Stanbridge & Burbach, 2007) and many consumers want their families to be provided with information on their 'illness' (Goodwin & Happell, 2007b; Lakeman, 2008a). Good practice is based on balancing the consumer's human right to privacy and the family need for information (Szmukler & Bloch, 1997) and it is acknowledged that there are times when it is inappropriate to share information with families; such as when consumers report experiences of abuse or fear within the family network (National Mental Health Consumer and Carer Forum, 2009).

Practitioner arguments about confidentiality are often experienced by families as a "smokescreen" (Chan & O'Brien, 2011, p. 387), and a source of significant frustration (Goodwin & Happell, 2007b; Lammers & Happell, 2004a). Disempowerment, stigma and discrimination can result when service providers share information without consent (National Mental Health Consumer and Carer Forum, 2009). Similarly, some family members report sharing confidential information with practitioners which is in turn relayed to the consumer; jeopardising consumer and family relationships and breaching the family's confidentiality (Lammers & Happell, 2004a).

Practitioners argue that legal, ethical and policy complexity and requirements prevent them from sharing information with families (Chan & O'Brien, 2011; Lammers & Happell, 2004a). These complexities often "contribute to a (largely unfounded) fear of litigation, which forces professionals to, in many cases, simply say nothing", (National Mental Health Consumer & Carer Forum, 2009, p. 15). This stance then leads practitioners to avoid exploring, testing and progressing issues associated with confidentiality. Reasons put forward by practitioners for not sharing information with families include the dominant bio-medical culture of solely focussing on the consumer; workload demands and pressures; poor knowledge of, and confidence in privacy legislation; consumers refusing practitioner requests to share information; and organisational cultures which inhibit information sharing practices (National Mental Health Consumer & Carer Forum, 2009). However, families argue that service providers can at the minimum, listen to them as this does not require the practitioner to share or disclose confidential information (Lavoie-Tremblay et al., 2012). Ideas for addressing this barrier to family inclusion are discussed in the next section.

> **KEY MESSAGES:**
> **CONFIDENTIALITY**
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> ❖ Confidentiality and information sharing practices are cited as common barriers to family inclusion.
> ❖ Confidentiality is an area of significant frustration for families.
> ❖ Practitioners find confidentiality and privacy complex areas to navigate.

CHANGING CULTURE

The majority of studies suggest that a comprehensive shift in attitudes and values is needed to authentically involve consumers and families. While consumers and families acknowledge the contributions of recovery oriented practitioners and allies, the lack of widespread and in depth adoption of person-first, inclusive and recovery approaches means their inclusion is limited (Hitchen et al., 2011). If the mental health service delivery system were to change culture, the following would be evident:

- Implementation and monitoring of existing practice standards and frameworks (Lakeman, 2008b);

- Transformation of staff attitudes which promote understanding of, and possibilities for, people with multiple unmet needs (Rolfe & Cutcliffe, 2006);

- Meaningful embedding and valuing of the lived experience of consumers and families into routine practice (Tambuyzer & Audenhove, 2013)

- Critically examining, articulating and addressing power relations in the mental health system which create and reinforce the exclusion of lived experience voices (Bennetts et al., 2011; Hitchen et al., 2011).

As confidentiality is cited as a key barrier to the involvement of families, ways to address the issue are now addressed.

Frameworks for addressing confidentiality issues

Australian and international work has been undertaken on ways to

> ### KEY MESSAGES: CULTURE CHANGE
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> ❖ Culture change in mental health is consistently called for.
> ❖ A shift in attitudes and values relating to family inclusion is necessary at all levels of the mental health system and across all parts of mental health organisations.

address the issues associated with confidentiality and privacy. In particular, the Australian National Mental Health Consumer & Carer Forum (2009) work provides helpful direction. Overall, the recommendations are made within a context of changing culture within service delivery and cover areas such as factual and relevant training on confidentiality legislation and improved organisational processes which carefully monitor practice. Other cultural change ideas include "normalising the concept of information-sharing" (National Mental Health Consumer & Carer Forum, 2009, p. 36) and providing supports for practitioners (such as a privacy helpline).

As well as these culture change ideas, some practical steps are proposed, starting with open conversations with consumers about confidentiality and information sharing. These conversations should be ongoing and form part of the review of work with the person. Similar conversations should also take place with family members; which all lead to common understandings of possibilities and limitations. Such approaches are framed as "tripartite relationships" (National Mental Health Consumer & Carer Forum, 2009, p. 38), and are

suggestive of good or best practice. Mike Slade and his colleagues (Slade et al., 2007) have mapped the course of action to be taken when a consumer refuses consent and, these strategies could form part of the tripartite relationship and conversations about information sharing. Such approaches include unpacking the consumer's decision with them; assessing the consumer's ability to make informed decisions; communicating the decision and exploring the implications of the consumer's decision with the family; and assessing and deciding if information needs to be shared, and with whom (Slade et al., 2007). We now consider the culture change impact of reform and practice standards.

Practice standards and reform activities

While practice standards offer a potential mechanism for changing culture to meaningfully include consumers and families, they are rarely evaluated. One exception was found on family involvement in the Townsville District Mental Health Service, Queensland. The methodology involved file audits

> **KEY MESSAGES: ADDRESSING CONFIDENTIALITY BARRIERS**
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> ❖ Addressing the perceived barrier to confidentiality forms a key part of culture change and involves both values and practical actions.
> ❖ A tripartite relationship has the potential to expand understanding, improve relationships and embed the lived experience of families and consumers as the central reference point.
> ❖ Frameworks exist for responding to consumers who do not consent to share information with family members.

and surveys with families supporting consumers in both acute and community settings. While some variation can be found in the inclusion of families within acute and community settings, the overall message is that practitioners were inconsistent in their application of the standards.

Lakeman (2008b) reports that individual practitioners' engagement with, and commitment to, family inclusion determined how much families were involved. File audits revealed inadequate reporting practices which focussed on symptoms or crisis events with little attention to context. While not evaluated, a similar project in the UK concluded that

family inclusion is successful if service providers embrace and endorse family involvement (Worthington, Rooney, & Hannan, 2013).

Despite consumer and family inclusion being a central feature of mental health reform since 1992, there is room for significant improvement and action. Consumer participation is often tokenistic; merely a matter of ticking a compliance box (Lammers & Happell, 2004a). In contrast, family involvement is often the result of their own lobbying and advocacy; rather than being invited to participate by services and practitioners (Lammers & Happell, 2004a). We now consider specific approaches which involve families and seek to change culture.

Dialogic approaches

Open Dialogue started in Western Lapland, Finland in 1984 and challenges traditional psychiatric practices (Seikkula, Arnkil, & Eriksson, 2003). This approach invites families to join in the planning of 'treatment' when their relative is first hospitalised. This positions families and consumers as active participants in a shared process, which does not follow the usual approach of being led by the professional 'expert'. The approach continues to evolve and is now deeply

> **KEY MESSAGES: PRACTICE STANDARDS AND REFORM ACTIVITIES**
>
> ❖ Practice standards provide a tangible mechanism to promote and measure compliance with, and accountability to, policies relating to family and consumer inclusive practice.
> ❖ A Queensland study found that practitioner commitment to family inclusion practice lies at the heart of uniform application of practice standards.
> ❖ Families report no meaningful change in relation to their involvement despite reform and the introduction of practice standards.

embedded in the Western Lapland psychiatric system where dialogue is regarded as the basis for all psychiatric 'treatment'. Open Dialogue aims to mobilise family resources, strengths and solutions (Seikkula & Arnkil, 2014), and its basic principles are:

1) **Immediate help**: The professional team arrange an initial meeting with the consumer, their family, and other relevant people or services such as the referring agency within 24 hours of contact.

2) **Social network approach**: The consumer and key members of their social network (family, friends, and neighbours) and key workers from other agencies are invited to attend the first meeting with the aim of mobilising support for the consumer and family.

3) **Flexibility and mobility**: Treatment responses are adapted to the specific and changing needs of each consumer and their family.

4) **Responsibility and continuity**: The practitioner who has first contact with the consumer takes responsibility for 'treatment' for as long as is necessary in both hospital and community settings.

5) **Tolerance of uncertainty**: It is acknowledged that rapid solutions are unlikely. Therefore, the focus is on creating safe relationships for joint processes of recovery.

6) **Dialogism**: The primary focus is on creating dialogue through the relationship with the consumer and their broader social network. A shared understanding of the situation is developed with all voices heard, and issues discussed when everyone is present including decisions relating to hospitalisation and medication. A shared language for the experience or situation that may not yet have words is generated through this dialogue and rapport (Seikkula, 2008; Seikkula & Arnkil, 2014; Seikkula et al., 2003).

The co-creation of a new language that the consumer, family and social network bring to the meeting enables a healing process which differs from bio-medically informed concepts such as 'symptoms' and 'difficult behaviour' (Seikkula, 2008; Seikkula & Arnkil, 2014). The multidisciplinary team is responsible for creating a relaxed environment in which each voice is respected and heard (Seikkula, 2008). The organisation of meetings involves limited pre-planning and one member of the professional team hosting the conversation. While the meeting starts with practitioners sharing their existing knowledge of the 'problem', the consumer, family and social network guide the conversation in regards to what they wish to discuss. It is considered important to ensure a slow pace and sufficient time within meetings so that each person has the space and opportunity to contribute. The practitioners reflect on the meeting and invite the consumer, family and social network to reflect also on what they

heard. Finally, the discussion is summarised and relevant decisions are agreed and endorsed (Seikkula, 2008).

The results of a quasi-experimental evaluation of Open Dialogue involving two groups – one receiving traditional treatments comprising psychiatric medications and another group receiving Open Dialogue and no psychiatric medications deserve consideration. Within the group who engaged in Open Dialogue, 58% had a diagnosis of schizophrenia. Key findings include:

- Compared to the control group who all received neuroleptic drugs, only 5% (n=3) required medication.
- A follow up study conducted two years later found that 82% of people in the Open Dialogue group experienced no or limited 'psychotic symptoms' compared to 50% of those group who had received traditional psychiatric treatments.

The evaluation of Open Dialogue has not extended to the impact on, and experiences of, families; however Seikkula (2008, p. 489) argues that the approach facilitates the mobilisation of a family's psychological resources instead of professionals taking over the 'care' of the consumer and inadvertently disempowering both the consumer and the family.

A similar approach known as 'Trialogue' was established in 1994 in Vienna, and aims to "facilitate communication about the personal experience in dealing with psychosis and its consequences" through involving the consumer, their family and service providers

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KEY MESSAGES: OPEN DIALOGUE

- ❖ Open Dialogue aims to mobilise family and consumer resources, strengths and solutions following six principles.
- ❖ Evaluation results for the approach report quality outcomes for consumers
- ❖ While evaluation results regarding the impact of the approach on families are not available, the inclusive and honouring approach presents a distinct alternative to dominant approaches to families and consumers.

(Amering, Hofer, & Rath, 2002, p. 1). It is argued that Trialogue provides each participant with the opportunity to understand the subjective experience of psychosis leading to a shared meaning and common language in which a culture of discussion is created. Trialogue meetings have also spread beyond Vienna to Germany (Amering et al., 2002). No published evaluation results of Trialogue have been located.

Strategies and programs

This discussion examines four pertinent examples of family and consumer inclusion projects working with individuals considered to have multiple unmet needs. While each example may not fully represent best practice in recovery oriented, person-first practices, potentially relevant and useful components are evident.

Multiple and Complex Needs Initiative (MACNI)

The Victorian Multiple and Complex Needs Initiative (MACNI) was mentioned earlier and more detail is provided here. The project involved the identification of 247 people considered "at the extreme end of the continuum of complexity" (Hamilton, 2011, p. 308). The initiative targeted individuals over the age of 16 considered to have multiple unmet needs and focussed on housing, health, social connection and safety. Seventy-nine individuals were eligible for the initiative with 87% having a mental health diagnosis and 76% identified as using substances. Although not quantified, many of the consumers had experiences of the criminal justice system and shared "many of the characteristics typical of those who are imprisoned" (Hamilton, 2011, p. 307).

A MACNI coordinator was placed in every region of Victoria and one 'care plan' coordinator was allocated to every MACNI consumer, who worked with a maximum of two service users. The 'care plan' was developed over four to six months and focussed on stabilising accommodation, health, well-being, safety and social connectedness (State Government Victoria, 2009). Plans included the following:

- Priorities identified by service providers or other professionals.
- Consumer-directed goals.
- 'Engagement' strategies.
- The identification of relevant services and supports involved with the consumer including their roles and responsibilities.

- Development of a crisis plan specific to the individual.

Review of the plan occurred every six months and provided a mechanism for monitoring and evaluating the effectiveness of the MACNI service as well as the progress of the consumer. The review incorporated the perspectives of the individual, family, supporters, service providers and the care plan coordinator (State Government Victoria, 2005, 2009).

The evaluation of the program considered service system responsiveness and collaboration, consumer outcomes in key psychosocial areas, recommendations for changes and service gaps (State Government Victoria, 2005, 2009). The evaluation revealed that service delivery responses prior to its commencement were fragmented, costly, and reactive (Hamilton, 2011). However, after five years of operation, the results indicated that MACNI had positively impacted on people categorised as 'high risk', with people 'managed' in the community through coordinated and integrated service delivery arrangements. Given this result, Hamilton (2011) asserts that that the apparent complexity surrounding consumers lies within the service system rather than the person (Hamilton, 2011).

Data from the criminal justice system revealed a 76% decrease in emergency department hospital presentations; a 34% decrease in admissions' and a 57% reduction in hospital bed days (Department of Human Services, 2007). Service providers involved in MACNI reported a new willingness to work with people considered to have multiple unmet needs (Hamilton, 2011) and services experienced increased confidence and capacity to work with this group (Western Region Health Centre, 2013).

Implementing Recovery through Organisational Change (ImROC) Implementing Recovery through Organisational Change (ImROC) sets out ten key indicators for

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KEY MESSAGES: MACNI

- ❖ Prior to the MACNI project, service provision to people with multiple unmet needs was costly, reactive and siloed.
- ❖ Families and consumers were included in MACNI review processes.
- ❖ The MACNI demonstrates that people with multiple unmet needs can be supported successfully in the community.

assessment of organisational orientation to recovery practices and principles (ImROC, 2015). In the first phase of the program ImROC delivered on-site consultancy visits to 29 mental health services and their partners to assist in refocussing service delivery to align with recovery principles. This provided an opportunity for discussion and knowledge sharing in relation to overcoming practical issues of implementation and achieving culture change. Following this, the following key learnings and recommendations were identified:

1) Due to the uniqueness of each service, locally relevant goals were needed.

2) Change is possible and must be driven by partnerships between families, consumers and service providers. A culture of coproduction is imperative at every stage.

3) Training is not sufficient in changing the attitudes and behaviours of service providers. Sustained change is dependent on organisational practices such as informing and educating team leaders and managers through a process of coproduction and co-delivery.

4) The whole of an organisation needs to change and 'top down' or 'bottom up' approaches are not effective on their own. Organisational change needs to occur simultaneously, vertically and horizontally.

5) Risk management is a significant area of practice to be reviewed in relation to recovery approaches. Safety planning where the person manages their own risk in relation to their own goals is preferred.

6) The most powerful enabler of change is the involvement of people with lived experience; therefore the number of paid peer workers needs to increase.

7) Recovery colleges and peer support workers are the most important service developments for encouraging and expanding roles for people with lived experience in the workforce.

8) Service development is supported by outcome measures through evaluations of individual outcomes. This is particularly important given the existing gap in evidence based approaches (ImROC, 2015; Repper & Perkins, 2013).

The Team Recovery Implementation Plan (TRIP) is an instrument designed to achieve ImROC's goals of organisational change (Repper & Perkins, 2013). Based on the ideas of coproduction, TRIP is a framework designed to assist mental health teams to coproduce services, improve consumer experiences and enable recovery. TRIP structures the approach

to implementing recovery processes and builds ongoing processes of coproduction, co-delivery and co-review of service goals and plans. The four key elements of TRIP are:

- The identification of resources and assets within a team.
- A benchmarking tool that monitors the progress towards recovery-oriented practice.
- Identifying three priorities which are agreed upon by all involved, including an action plan for future progress.
- Using a process for systematic review and refinement of goals (Repper & Perkins, 2013).

Following implementation of TRIP in 15 statutory and voluntary mental health services, the importance of the process, rather than the outcomes, has been identified as most crucial (Repper & Perkins, 2013). Examples of coproduced action plans resulting from TRIP include:

- Personal recovery goals being included in care plans.
- Reviewing risk assessment and related policies.
- The inclusion of consumers on staff interview panels (Repper & Perkins, 2013).

Repper and Perkins (2013) report that the benchmark rating of alignment to recovery principles in one acute ward increased from 1.7 to 3.8 over a period of four years after the following changes:

- The development of a 'living library' in which people with lived experience could share their recovery journey with others.
- Personal recovery plans for all consumers.

- The introduction of TRIP which assessed recovery practices with families and friends and a coproduced information package for families.
- The introduction of a Peer Support Worker on the ward (Repper & Perkins, 2013).

Repper and Perkins (2013) assert that TRIP is most successful when the organisation fosters a culture of, and commitment to, recovery-oriented approaches. While TRIP helps to create recovery-focussed services, it is framed as one component in the process of achieving organisational change (Repper & Perkins, 2013).

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KEY MESSAGES: ImROC AND TRIP

❖ Programs such as ImROC and TRIP demonstrate the meaningful involvement of consumers and families is possible if a systemic, comprehensive and integrated approach is adopted.

❖ Coproduction, co-delivery and co-design are essential ingredients to create cultures of inclusion.

❖ Successful implementation of TRIP is dependent on organisational cultures strongly committed to recovery-oriented practice.

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Comprehensive Continuous Integrated Systems of Care (CCISC)

The Comprehensive Continuous Integrated Systems of Care (CCISC) is a model which claims to advance service capacity for individuals experiencing multiple unmet needs within systems of all sizes and complexities, across all cultural backgrounds and locations (Minkoff & Cline, 2004b). Eight principles were co-developed with consumers and families and drive the implementation of the CCICS:

1. Multiple unmet needs should be expected and not framed as an exception or unusual.
2. Consumers experiencing multiple unmet needs are not a homogenous group.
3. Relationships characterised by empathy, hope and 'integrated treatment' contribute to successful outcomes.
4. A case management approach characterised by "empathetic detachment, expectation, contracting, consequences and contingent learning" (Minkoff & Cline, 2004b, p. 72).

5. Considering both mental distress and substance misuse as concurrently primary (rather than applying a hierarchal assessment to the issues and trying to ascertain which came first).

6. Interventions are diagnosis-specific and relevant to the consumer's phase of clinical recovery and stage of change.

7. Interventions are individualised according to diagnosis and levels of 'functioning'.

8. Clinical outcomes are individualised based on 'treatment' interventions (Minkoff & Cline, 2004a, 2004b).

The CCISC is underpinned by a twelve step implementation process covering funding, philosophy, regulations, program standards, design, clinical practice and interventions (Minkoff & Cline, 2004b). Consumer, family, funder and service provider empowerment and involvement are emphasised. The CCISC has been implemented in more than 24 states and regions across the U.S, and it is reported that a range of outcomes have been achieved, including welcoming service environments, improved practices and integrated service delivery responses (Minkoff & Cline, 2004a).

KEY MESSAGES: CCISC

❖ Considering multiple unmet needs the norm rather than the exception can create welcoming service delivery environments and practices.

Mental Health Experience Co-Design (MH ECO)

The Mental Health Experience Co-Design (MH ECO) is a Victorian based program involving "a collection of structured methods that assist organisations to utilise consumer and carer experience to improve mental health services" (Victorian Mental Health Awareness Council & Tandem Inc, 2014). The program is based on four steps, starting with data collection by consumers and family member researchers with other consumers and family members. The phone surveys, in person interviews and focus groups elicit data on consumer and family experiences of, and issues with, the relevant mental health service. The lived experience researchers are from the Consumer Research and Evaluation Unit of the Victorian Mental Illness Awareness Council and the Carer Research and Evaluation Unit which is based at

Tandem Inc. (the peak body for mental health 'carers' in Victoria). Based on the analysis of data collected, the second step is implemented and involves the delivery of training by lived experience researchers to consumers, family members and staff. Examples of training previously provided which emerged from data collected include meeting procedures, communication and collaborative approaches (Victorian Mental Health Awareness Council & Tandem Inc, 2014).

Step three involves the formation of a Collaborative Group which prioritises the issues identified in the research. The membership of this group is unclear from available literature, as is the type and extent of influence enacted by consumers, family members and practitioners. The final step involves Co-Design Groups comprising consumers, family members and service providers. These groups focus on one issue identified as a priority by the Collaborative Group and consider the key issues, good practice examples and an action plan to address the issue (Victorian Mental Health Awareness Council & Tandem Inc, 2014).

While the MH ECO appears a step in the direction towards consumer and family involvement, it emphasises co-design, rather than coproduction in relation to consumer and family experiences of service delivery. This suggests that service providers may still be positioned as leading the project; rather than people with lived experience being positioned as equal partners or leaders in the process. Similarly, other key elements of coproduction such as a blurring of boundaries, reciprocity and mutuality and viewing people with lived experience as having capacity and ability (New Economics Foundation, 2013) do not appear to be addressed in documentation on MH ECO reviewed by the research team.

> **KEY MESSAGES:** MH ECO
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> ❖ MH ECO provides a structured process for consumers and family members to raise issues and concerns related to their experience of service delivery.

RESEARCHER REFLECTIONS

Family inclusive practice, partnerships and culture change have been the primary and initial foci for this literature review. It became clear as we engaged with the literature that each

time an individual enters a system, their identity is constructed by an 'expert' based on a classification of their perceived 'deficits' or 'problems'. The review revealed that the category of multiple unmet needs is one of these deficit-based identifiers which, when enacted, limits access to, and excludes people from services. This review has highlighted the need to reorientate the gaze from what is wrong with individuals and families, and instead critically consider the ways in which service delivery systems pathologise and problematise the people they are supposed to be assisting.

There have been a number of attempts to improve family involvement yet any culture change achieved tends to be superficial and short-term. Notably, there is a lack of evaluation driven by families or consumers which critically reviews and monitors implementation. Instead, researchers and academics evaluate interventions often failing to acknowledge critical issues of staff attitudes and professional positioning and privilege. This is made explicit by a number of authors who state that the effective implementation is highly dependent on service providers' willingness and commitment to improving family partnerships. As researchers we find this situation troubling and antithetical to recovery practices. We are left with the sense that the unspeakable (i.e. why so many practitioners do not involve families) remains protected and unspoken.

Furthermore, despite literature arguing for meaningful family involvement, families are positioned secondary to consumers; indicating a binary of needs and interests. This further marginalises families which can, in turn, inhibit personal recovery for individuals. While acknowledging that the experiences, needs and recovery journeys for families and consumers are different and can at times be in conflict, they are also intimately linked. Consumers and their families need to be viewed simultaneously as co-existing, interdependent and representative of unique needs and experiences.

The most successful instances of family inclusion have involved a focus on dialogue. Meaningful and equal partnerships require widespread attitudinal change where service providers are willing to step out from behind their professional positions and privilege and join in a process of coproduction, co-delivery and co-review between providers, consumers and their families (New Economics Foundation, 2013; Repper & Perkins, 2013). This review has affirmed that family inclusion is not simply an approach to practice that is easily implemented by following policy or standards. Instead, meaningful partnerships underpinned

by principles of coproduction are driven by a deeply ingrained belief in the power of family inclusion.

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Legislation

Western Australia: *Carers Recognition Act 2004*

South Australia: *Carers Recognition Act 2005*

Queensland: *Carers Recognition Act 2008*

Northern Territory: *Carers Recognition Act 2009*

New South Wales: *Carers Recognition Act 2010*

Victoria: *Carers Recognition Act 2012*

Australian Capital Territory: *ACT Carers Charter*

APPENDIX 1 - METHODOLOGY

The aim of this review was to locate published literature addressing family inclusive practices for people considered to have multiple unmet needs including mental distress, substance use and criminal justice involvement. Key concepts such as service delivery practices, 'good' practice, service provider attitudes, lived experience, family recovery and mental health system change were the focus in the search. A systematic approach was adopted which proved helpful given the multiple key concepts and lack of specifically relevant literature and conceptual frameworks on the topic. This meant that the topic needed to be broken down into key concepts and related topics and each area systematically searched for relevant literature.

A search strategy was developed to ensure a comprehensive search of the topic area and a briefing paper of the strategy was provided to the Partnership Group for feedback. Recommendations and feedback from this group were incorporated into the final search strategy. An example of the terms searched relating to family inclusion included:

- Family or carer inclusion
- Family or carer involvement
- Family or carer collaboration
- Family or carer engagement
- Family or carer inclusive practice
- Family or carer participation
- Family or carer leadership
- Family or carer recovery

Phrases searched relating to multiple unmet needs included:

- Multiple unmet needs
- Co-occurring disorders (or diagnosis)
- Complex needs
- Comorbidity
- Dual diagnosis
- Complex unmet needs

Added to the above were the multiplicity of terms used to refer to individuals, such as:

- Consumer
- Client
- Person with lived experience
- Service user
- Patient

Electronic searches included five databases consisting of PsychInfo, Science Direct, Informit, Proquest, CINAHL and Google Scholar. Synonyms were searched using the OR operator and results were combined using the AND operator. Additional sources of interest were identified through purposive examination of cited references. Grey literature (non-peer reviewed), books, reports and other relevant documents were included. A total of 1115

abstracts were identified and screened for relevance with 300 articles identified as meeting the inclusion and exclusion criteria. 89 articles and reports were read for this review. Articles meeting the inclusion criteria included exploration or discussion of:

- Family inclusive practice and mental distress, substance use and/or criminal justice involvement.
- Service provider attitudes, practice, skills and knowledge relating to multiple unmet needs.
- Service provider attitudes, practice, skills and knowledge regarding family inclusion.
- Policy, programs and strategies aimed at achieving family inclusive practice.
- Policy, programs and strategies aimed at improving services for people with multiple unmet needs
- Culture change in mental health aimed at improving service delivery through family inclusive practice for individuals with multiple unmet needs.

It is important to note that given the paucity of literature in this area, studies relating only to mental distress and family inclusion constitute the majority of those included in this review. Mental health appears to be the focus in research while interrelated issues of substance use and involvement in the criminal justice system are neglected or unacknowledged, and rarely are the three linked and conceptualised as inter-related in one document. Government policy and program initiatives addressing multiple unmet needs are scarce.

Exclusion criteria for this review included:
- Family recovery (in this context this term refers to parenting and child protection matters) and substance use.
- Consumer involvement and substance use (and no reference to mental distress and/or criminal justice involvement).
- 'Dual diagnosis' and 'co-morbidity' which represented a clinical, bio-medical and pharmaceutical treatment paradigm with no reference to social, cultural or political contexts.
- Multiple unmet needs and service integration where there was no mention of family or consumer involvement.
- Family psychoeducational groups.

- Carer 'burden' or 'gains', with no reference to family involvement, recovery and multiple unmet needs.
- Studies of family support deemed 'helpful' to the consumer with no reference to family involvement, recovery and multiple unmet needs.

Qualitative and quantitative methodologies were included and no time limits were placed on the search given the paucity of relevant literature. Furthermore, quality assessments of articles were not conducted, however the researchers cross referenced and reviewed the articles and reports in accordance with inclusion and exclusion criteria. Emerging themes were documented and reviewed by researchers on an ongoing basis. An analytical approach was employed to examine the literature using personal recovery as a framework to identify central features. Literature discussing family therapy, psychoeducation, clinical treatment and bio-medical focussed practice was excluded on the basis that these approaches usually pathologise and problematise families, arguing that families 'need education' or have deficits which 'need' to be addressed. Such approaches discredit and invalidate the knowledge and experience families hold and were assessed as not reflecting the philosophy of the In Community project.