Setting priorities for mental health family carer research and advocacy in Australia

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Introduction

This article reports on the recent priority agenda for mental health family carer research and advocacy developed by a new Australia–based network of stakeholders and researchers with lived and living experience of supporting someone experiencing
mental distress. The Family and Carer Research and Advocacy Network (FaCRAN) emerged in the context of the Royal Commission into Victoria’s Mental Health System (RCVMHS) (State of Victoria, 2021) and subsequent reforms regarding new services for carers and a focus on carer lived experience in participation and leadership in research. Such large-scale transformation requires greater understanding and responsiveness to the needs and experiences of carers, who are critical to the mental health system yet often marginalised, poorly supported and misunderstood. This article outlines an agenda addressing the urgent need for family carer-led and -focused mental health research based on six core research priorities identified by FaCRAN: carer contributions and experiences; identity; rights; the carer workforce; pathways and capacity building; and growing the evidence base. This agenda reflects global challenges regarding the epistemic injustice inherent in the under-representation of carer knowledge in mental health research and practice and calls for further work that illuminates and centres lived experience and addresses the systemic issues carers face.

There are many terms for those who walk beside and provide unpaid support to those experiencing mental distress. We draw on the term ‘carer’, predominantly used in the Australian context, to refer to such supporters and family (of biology, culture or choice).

Background

Health and social welfare systems internationally depend on carers to support people experiencing mental distress. Deinstitutionalisation, involving a shift from hospital to community care, and related policy changes led to fewer, shorter psychiatric admissions (Wilkinson and McAndrew, 2008). A scarcity of adequate community-based services resulted in health systems becoming largely reliant on the informal support of carers (Lawn et al, 2013; Yeandle, 2016). The economic value to governments is significant. In Australia, Diminic et al (2017) report that the taxpayer-funded equivalent of unpaid carer labour in 2015 would have been 1.7 times the national expenditure on all mental-health-related services that year. While governments and health services depend on carers’ emotional and physical labour, this relationship has been largely one-sided, leaving families and carers to rely on their own resources to navigate the complexities of providing support.

Chronic underfunding and reliance on carers to address system shortfalls has recently been identified as a global phenomenon (Yeandle, 2016) and as harming and marginalising carers, as well as those experiencing mental ill-health (Katterl et al, 2023). Families and individuals from diverse contexts are impacted, with experiences shaped by life stage, gender, cultural and linguistic background, socio-economic status, and other factors. Understanding the intersectionality of carers’ everyday lives and needs is central to informing best practice in meaningful engagement, support and system change (Walters et al, 2023a). Carers’ contributions and predicaments are often rendered invisible, largely occurring in private rather than public domains and typically seen as personal, resulting in minimal public recognition of their unpaid role in reducing public healthcare responsibility. While carer recognition acts exist internationally, much of the legislation is vague and does not meaningfully address carers’ enduring support or recognition needs (Yeandle, 2016).
The marginalisation carers experience within health services largely stems from how services frame the carer role and rights. Goodwin and Happell (2006: 138) described nurses’ positioning of carers ‘as secondary to the needs of the consumer, because the consumer was the person to whom nurses owed a legal duty of care’. This positions unpaid carers’ roles and needs beyond a service’s core work, except when carers offer intake information or alleviate services’ responsibilities through discharge. While the person-centred approach promotes consumer rights and autonomy, the primacy of individualised over relational care fails to address the significant implications for carers and the complexity of caring relationships (Wyder and Bland, 2014). The rights and needs of carers and consumers are often construed as binary and in tension, creating a perceived conflict when it comes to information sharing and confidentiality and leading to a default approach that limits practitioners’ engagement with carers, compounding their exclusion and reducing advocacy pathways for consumer rights.

Consequently, carers’ knowledge and expertise in supporting an individual can be underutilised, minimised or denied completely by services and not included in decision making. Wyder et al (2018) highlight this dynamic, noting that family members of people admitted involuntarily are often reduced to the singular role of information givers rather than partners in care. UK research on carers’ perceived level of involvement in acute inpatient settings reported core themes of ‘powerlessness, feeling isolated, needing to be recognized and valued, and a desire for partnership’ (Wilkinson and McAndrew, 2008: 395). Carers felt limited in their capacity to influence or be seen as equal partners, often resulting in a lack of information, explanation and involvement in decision-making processes.

These dynamics have broader implications for the realisation of carers’ rights, compounded by minimal clarity regarding carers’ rights within health services and by carers themselves (Wyder and Bland, 2014). While much of the research on carer rights focuses on information and inclusion in healthcare, there has been little broader identification of carers’ human or civil rights and how care planning and inadequate support can impede these (Walters et al, 2023b). Being identified as a carer has implications for the recognition of personhood, rights and equity (Wyder and Bland, 2014). Walters et al (2023b) have argued that family members cease to be viewed as people with their own rights when operationalised as carers. Such systemic, structural marginalisation and neglect have significant costs to the carer and to their relationship with the person they support, including gendered impacts given that most mental health carers are women (Walters et al, 2023a).

The current state of carer research

There is little research that has been led by carers or centred their voices and perspectives. How research is conceived and who conducts it impact how carers are understood and represented. Recent scoping reviews highlight a lack of partnership and co-design with carers (Larkin et al, 2019; Rising Together Action Group, 2022) and note that the current literature fails to capture intersectional and relational aspects of mental health carers’ experiences, leading to epistemic injustice, a form of discrimination whereby marginalised people are rarely afforded the opportunity to create knowledge and solutions or generate meaning from their lived experiences (Okoroji et al, 2023).

In Australia and internationally, there is a move towards co-produced, co-designed and participatory action research led by and involving carers to promote meaningful
carer participation at all stages of research (Maybery et al, 2021; Walters et al, 2023a). Ensuring a voice for people with lived experience in research increases the validity and relevance of findings for translation into policy and practice (Okoroji et al, 2023). The RCVMHS recommended carer-led research and family-focused funded initiatives, including eight family and carer-led centres (State of Victoria, 2021). Similarly, a recent report for the National Mental Health Commission (Petrakis and Walters, 2022: 58) recommended that the Australian government establish and fund collaborative hubs to ‘foster, mentor and disseminate family leadership in service redesign, evaluation and research’. These recommendations demonstrate momentum in the Australian context towards the development of a comprehensive carer research agenda.

FaCRAN research and advocacy priorities

FaCRAN was formed in late 2022, bringing together 12 advocates, community and government researchers, academics, and allies at a roundtable, the majority of whom have lived and living experience as carers and supporters of people experiencing mental distress. The overarching purpose was to identify key research and advocacy priorities. The discussion was recorded, transcribed and analysed to identify key themes, presented further in the following. There was consensus that mental health carer-led research has historically been underfunded, not well publicised or disseminated, and often located in the grey rather than academic literature. Participants also highlighted the poor connection between formal and informal research, the lack of a ‘home’ for carer-led research, and minimal resourcing, opportunity or structures for building carer research and advocacy capacity. Consequently, carer-led research is often misrecognised as being in its infancy. The roundtable highlighted the need to address decades of epistemic injustice and invisibility through a more systematic and sustained approach that would both recognise the history of carer research and advocacy and address contemporary priorities. The FaCRAN agenda seeks to promote the leadership of carer lived experience in research and advocacy and address the aforementioned challenges by focusing on the priorities outlined in the following.

Carer lived experiences

Roundtable participants identified the pressing need to document and promote the lived experience and support needs of diverse carers within and beyond mental health systems. This documentation serves to address carer invisibility and enhance the informal and formal supports offered to both families and consumers. A better understanding of carers’ diverse and intersectional experiences will help address the marginalisation produced by systemic epistemic injustice, leading to better policy and practice outcomes.

Carer identity

Key questions regarding carer identity were identified; they included understanding factors shaping identity formation and how a carer’s identity influences relationships and roles in private and service-related spheres. As the literature suggests, the
conceptualisation and recognition of identity have implications for relationships, support and the realisation of rights.

**Carer rights**

The promotion of carer rights, through relational, individual and citizenship lenses, was identified as a key priority. As the literature suggests, the exercise of power within the mental health system, created through legislation and other structures, impacts carer rights and their interaction with services. This priority seeks to understand how rights are experienced through intersectional prisms: factors underpinning carer rights; the nature of rights in relation to services; whether carers are aware of their rights; and how services manage competing rights.

**The carer workforce**

The past two years in Australia have seen a rapid expansion of the carer lived experience workforce. A recent review found that while there has been some initial research in this area, the evidence base lacks breadth in comparison to other lived experience workforces and is troubled by epistemic issues (Rising Together Action Group, 2022). To develop the workforce, this research priority seeks to better understand the workforce’s impact, experiences and challenges.

**Pathways and capacity building**

This priority presses for carer-led and co-designed research that creates new pathways and conditions for capacity building. These aspirations require funding and policy commitment to ensure that research and the creation of new knowledge meaningfully engage and centre the expertise and experience of carers as active research partners. As best practice suggests, fostering such equity and leadership in research will counter epistemic injustice and lead to better, more sustainable outcomes for carers, consumers and service providers.

**Growing the evidence base**

This priority underpins each of the aforementioned themes and seeks to document and grow the evidence base for carer research. It considers how this can be driven by carers and service providers so that it does not remain on the margins of mental healthcare and lived experience research. Importantly, this priority urges the identification of research gaps, the honouring of the unrecognised carer history and deeper thinking about promoting equity in future research.

**Conclusion: Agenda for action**

The critical role of carers and families in Australian mental health systems is gaining increasing recognition in legislation and practice, and it is anticipated that this may
influence legislation, policy and practice internationally. While recognising and engaging with carers and their expertise has benefits for consumers, families and services, this must be supported by systematic, sustainable and carer-led and -engaged research and advocacy. Advancing the FaCRAN priorities requires carers’ and supporters’ lived experience, needs and rights to be better acknowledged, understood and promoted. Practice-based research that builds on existing knowledge and expertise will be key to this agenda, alongside authentic partnership and co-designed approaches that provide richer, nuanced and comprehensive findings to inform family- and carer-inclusive policy and practice. Operationalising these priorities will require the conditions and partnerships that dissolve the boundaries between carers, consumers, practitioners/clinicians and public and private sectors, with the aim of promoting improved outcomes for all.

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**Conflict of interest**

The authors declare that there is no conflict of interest.

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