Rising Together

Lifting the lid on the experiences of family/carer lived experience workers

Final Report
2022

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Executive summary

The Rising Together study was a co-produced study funded by the Centre for Mental Health Learning (CMHL) and led by the University of Melbourne. The study sought to investigate the experiences of family/carer lived experience (LE) workers within the Victorian mental health system, with the aim of better understanding what is needed to ensure the safe and sustainable development of this workforce.

People with a lived experience of being a family member or carer of a person using mental health services have been employed in lived experience roles within the Victorian mental health sector since 1999. Family/carer LE workers have played several roles within the service system including enabling family/carer perspectives to be represented in service planning, delivery, and evaluation; assisting in improving the responsiveness to family/carer needs; and using their lived experience to connect to and support families and carers (Department of Health, 2013). While research in other lived experience roles indicates a high level of those workers feeling unsafe in the workplace (Edan et al., 2021), at this time, there has been very little research or evaluation of family/carer lived experience roles. With growing investment in family/carer lived experience roles there is a need to better understand the experiences of family/carer LE workers. The Rising Together study was co-produced with a team of family/carer LE workers and university academics, including a consumer academic. They formed the Rising Together Action Group (RTAG), which was responsible for deciding on the research questions, designing the study and research tools, implementing the research, analysing the findings, developing recommendations, and writing this report. The RTAG designed and implemented the following:

Survey: Family/carer LE workers were invited to complete an online survey. Participants were asked about their perceptions of support, inclusion, workload, and training related to their work as well as their perceptions of how families and carers were included in mental health service delivery. A total of 62 participants completed this survey.

Photovoice: Family/carer LE workers were also invited to participate in a photovoice process which involved participants selecting up to three images that represented their experiences as family/carer LE workers. Participants could choose to create these images themselves or select copyright free images from stock image sites. They were then invited to share and discuss these images in a three-hour Share and Reflect workshop (“S&R workshop”). Two workshops were run with a total of 10 participants. The workshops were audio recorded and transcribed, and the transcriptions were analysed using a co-produced approach to thematic analysis.

Recommendations Focus Group: Participants were presented with a summary of the findings of the first two stages of this study. They were asked to brainstorm solutions to issues identified in the findings. This was used to inform the recommendations for this study. A total of 16 participants engaged with this stage of the study.

Key Findings

The multilayered and complex experience of being a family/carer LE worker was an overarching theme present across all stages of data collection. Family/carer LE workers reported a passion for their work and a belief in the positive impacts they had on the lives of families/carers and the mental health system more broadly. However, they also detailed a range of issues that made it difficult to realise the vision of family/carer LE work and to remain in the workforce. At the same time, participants identified a range of features of the work that sustained them in their workplace. The themes below detail the nature of these complex experiences.

The vision

Participants highlighted the vision they had for family/carer LE work. They detailed entering the workforce with a sense of hope and optimism that they could effect change in the lives of families, carers, consumers, and the mental health system more broadly.

Participants detailed the positive impact they felt they had on the lives of families and carers within the mental health system. They saw their role as providing a unique connection with families and carers and a voice for families and carers within the mental health system. They also saw themselves as change makers who use their lived experience to challenge the accepted ways of doing things within mental health services.

A key element to the vision of family/carer LE work was the explicit value that working from a lived experience perspective can bring.

The reality

While participants spoke highly of their vision for family/carer LE work and their belief in the positive impacts they can make, much of the discussion in the S&R workshops and input in the survey focused on the difficult reality of working in these positions. The following themes highlight the challenges that family/carer LE workers face in their roles.

Working relationally in an individualistic system

A key theme in the S&R workshops and survey was the clash between the models of practice that inform mental health services and the work that family/carer LE workers are trying to do. The mental health system is focused on treating individuals and is not well designed to take into consideration the relational context those individuals exist in. Participants noted that this was a key barrier to them being able to do their work effectively.

Participants described a sense of “not fitting in” to their workplaces because of this clash. By representing the interests of families and carers they felt they were perceived as “being a spanner in the works” or “disruptive”. This led participants to feel like they did not have a place within mental health services.

Undervalued and poorly understood

Participants reported that while family/carer LE colleagues, consumer LE colleagues, and their line managers often had a good understanding of their role and valued their work, this was less evident amongst colleagues who were not employed in designated lived experience roles and their organisation more broadly. Participants reported a degree of tokenism whereby they would be invited into settings as a “tick box” measure but their input was not meaningfully used. Part of this lack of understanding can be seen as resulting from the unique and emerging nature of the family/carer lived experience discipline. While there has been substantial research into consumer lived experience roles and investment in the development of consumer lived experience models of practice, this is not the case for the family/carer LE workforce.

Isolation and marginalisation

A proportion of survey participants had limited contact with other family/carer LE workers, with 45.2% reporting having formal contact with family/carer LE workers monthly or less, and 32.3 % having informal contact with other family/carer LE workers monthly or less. Participants spoke about the struggles of being a solo family/carer LE worker in a program, and how this created feelings of loneliness and made it difficult to effectively represent the interests of families and carers. Some participants also detailed explicit marginalisation, including experiences of bullying, discrimination, and social exclusion.

The work is beautiful but fragile

Participants spoke about the complex nature of bringing one’s lived experience of supporting and caring into their work roles. As detailed earlier, the use of lived experience was seen as a crucial strength of the family/carer LE role, however, the reality of using lived experience required family/carer LE workers to be vulnerable with their colleagues in a way that is not expected of mental health professionals in non-designated roles . This sometimes made participants feel exposed and unsafe in their workplaces. Participants also spoke about parallels that existed between their caring role and their work — not fitting in, being marginalised, and feeling isolated were often features of both their caring experience and their experiences in family/carer LE roles. Participants also described the emotionally taxing nature of the family/carer LE role that arose from connecting with families and carers, particularly where the experiences raised were similar to their own experiences.

Workplace conditions

Workplace conditions were commonly cited as a significant challenge for participants. A total of 80.5% of survey participants felt that their workplace conditions were different from their non-designated colleagues. The most common difference cited was being paid less than their colleagues. Most participants did not agree that they were paid adequately for their work despite it being complex and highly stressful.

The survey indicated a very high number of part-time roles among family/carer LE positions, with 88.7% of survey participants being employed part time. Almost a third (29%) reported that they wanted to work more hours. In addition to this, participants spoke frequently about having an unmanageable workload, with the majority (65.3%) reporting that they worked at least 2 or more hours of unpaid work per fortnight.

Almost half (49.2%) of the survey participants reported that they did not have enough training to do their jobs to the best of their ability and there was an identified need for family/carer LE specific training. In addition to this, over two thirds (68.4%) felt there was a lack of a clear pathway for professional development.

Negative impact of the work

Participants described various negative impacts of the challenges identified in this study such as feelings of loneliness, anger and disillusionment. Almost half of the survey participants (52.6%) reported that they had considered leaving their roles, and 10.5% had already left a family/carer LE role. The most common reason for leaving or considering leaving was feeling unvalued in the workplace (37.1%), feeling unsupported in the workplace (37.1%) and not being paid enough (32.3%).

What is currently sustaining the work?

While participants detailed the challenges inherent in the work, they also highlighted some notable positive aspects of the work that enabled them to remain in the role. These included:

- **Connection to other family/carer LE workers:** Participants highlighted the importance of regular contact with family/carer LE workers which enabled them to debrief, share difficulties, and share resources amongst a network of peers. Participants spoke very highly of the Carer Lived Experience Workforce (CLEW) Network as a crucial form of support.
- **Safety and inclusion:** Participants detailed a range of practices that made them feel safe and included in the workplace including having respectful relationships with colleagues and management, having structures in place that ensured that family/carer perspectives were included, and having colleagues and management amplify family/carer perspectives.
- **Flexibility and reasonable adjustments:** Participants highlighted the importance of flexible workplaces and the ability to access reasonable adjustment provisions.
- **Family/carer LE specific supervision:** Participants highlighted the importance of being supervised by someone who works from a family/carer LE perspective as such supervisors were able to better understand the nature and complexity of the work.
- **Passion for the work:** The passion and commitment that participants had for making change in the lives of families and carers was cited as a major factor in sustaining them in their work, and the use of lived experience as a key mechanism for facilitating positive change for families.

Recommendations

The Rising Together Action Group have developed four overarching recommendations that need to be implemented to support the development and sustainability of the family/carer LE workforce. These were drawn from the findings detailed above. Each recommendation contains several actions that need to be undertaken to achieve the recommendation. These recommendations are designed to be implemented in conjunction with the others – without holistic implementation all run the risk of not meeting their inherent potential.

There are parallels between the recommendations detailed below and some of the work being undertaken as part of the reform process under way in Victoria's mental health system. The recommendations put forward here are meant to both support the current initiatives being implemented by suggesting approaches for best practice and provide unique approaches that could be added to the reform process to best support the development and sustainability of the family/carer LE workforce.

Recommendation 1: Mental health organisations need to change to better incorporate Family/Carer Lived Experience Workers

This study found that organisations needed to do more to shift organisational culture, policies and practices to better incorporate family/carer LE workers and embed family/carer LE perspectives. Organisational change should take a two-pronged approach that targets leadership and governance as well as frontline staff. The following actions will enable this recommendation to be achieved:

1.1 Revise the leadership and governance of mental health services to better incorporate family/carer LE workers at all levels.

1.2 Develop a suite of training aimed at educating clinical staff in non-designated roles on the role and purpose of family/carer LE workers. This training, to be developed by family/carer LE workers, should become part of mandatory training for all staff.

1.3 Update program level processes and procedures to ensure that family/carer LE perspectives are included in standard practice.

1.4 Organisations to improve the workplace conditions of family/carer LE workers to ensure that they are equitable with non-designated mental health workers and fully resourced to undertake their roles.

1.5 Organisations must create meaningful and supported career pathways for family/carer LE workers.

Recommendation 2: The family/carer LE workforce needs to be developed and sustained

The findings of this study highlight the need to develop the family/carer workforce by building clearer frameworks for practice, creating meaningful career pathways and investing in the knowledge and skill development of the family/carer LE workers. The following actions are designed to achieve this recommendation:

2.1 Invest in the creation of more family/carer LE positions so that no family/carer LE workers are employed without regular contact with others in the discipline. In addition to this there needs to be investment in establishing family/carer LE leadership positions throughout the sector.

2.2 Develop a clear discipline framework for the family/carer LE profession.

2.3 Develop a clear pathway of training and support to assist family/carer LE workers across their career trajectories.

2.4 Establish and strengthen programs or organisations that support the development and networking opportunities for the family/carer LE workforce.

2.5 Ensure all family/carer LE workers participate in supervision, reflection and professional development activities as part of their paid role.

2.6 Investment is needed to create an evidence base for family/carer LE work.

Recommendation 3: The mental health system needs to better incorporate relational orientated practice into standard models of care

A key finding of this study was the way in which mental health services position families, carers and supporters as adjunct to the core business of mental health service delivery and how this creates challenges for family/carer LE workers to effectively perform their roles. Consequently, there is a need for mental health models of care to shift away from seeing consumers as individuals with a mental illness towards seeing people experiencing distress as interconnected and interdependent with valued and valuable social roles. The following actions will work to achieve this recommendation:

3.1 Funders must take into consideration how services plan to engage with families and carers when funding programs.

3.2 Establish a Centre for Relational Orientated Practice in mental health service delivery that utilises both consumer and family/carer LE experience perspectives to develop and implement models of relational orientated practice.

Recommendation 4: Authentic co-production must guide all work involving the family/carer LE workforce.

It is crucial that all work done to build and sustain the family/carer LE workforce utilise co-production. Lived experience perspectives are often marginalised from decision making processes within mental health settings and family/carer LE workers or are “consulted with” after processes have already been developed. Authentic approaches to co-production are a way of re-centring the perspectives of those who are most affected by the decisions being made. We strongly suggest that any efforts to co-produce in the family/carer lived experience space utilise Roper et al’s (2018) approach to co-production in mental health settings as a means of implementing authentic co-production, ensuring that those most impacted by a project or initiative are privileged. The following actions can contribute to this recommendation:

4.1 Training in co-production must be developed by lived-experience workers and implemented across all programs of work that are attempting to utilise co-production.

4.2 Funders should assess project designs against Roper et al’s (2018) approach to co-production when funding projects and programs.

The Rising Together study has found that while there is great potential in family/carer LE work to affect positive change in the lives of families, carers, and supporters, as well as the mental health system more broadly, this is at risk unless there is strategic investment in a range of initiatives that can support the sustainable, and safe development of the family/carer workforce.

1. Introduction

Family/carer lived experience workers are employed by mental health services to support families/carers by utilising their personal lived experience of caring for family or friends who experience mental health challenges and/or use of mental health services.

They have been employed in mental health services in Victoria since at least 1999, when the first carer peer support roles were created through the Carers Offering Peers Early Support (COPES) program at Maroondah Hospital and EACH community services. The first Carer Consultants in Victorian public mental health services were employed soon after in 2000 at St Vincent's Hospital Melbourne (Our Future Project Partnership, 2021).

Family/carer lived experience work has been included in The National Lived Experience (peer) Workforce Development Guidelines which describes lived experience work (LE work) as "a unique and separate discipline that offers a valuable contribution to the mental health sector" with "distinct values, principles, and theories that define Lived Experience work and the way it is practiced" (Byrne et al., 2021, p. 4). The Guidelines articulate family/carer LE work as the second perspective of this work, stating:

> Designated roles have two distinct perspectives and ways of working and are informed by either:
>
> 1. Personal experience of mental health challenges, service use, periods of healing/personal recovery; or
> 2. Experience of supporting someone through mental health challenges, service use, periods of healing/personal recovery (Byrne et al., 2021, p. 13).

Lived experience as a family member or carer is an essential requirement of family/carer LE work, alongside other skills and knowledge depending on the role.

The definition of 'family/carer' for this workforce is broad, including families of choice and those who may or may not themselves identify as carers. Support is provided to families and carers in a range of ways including directly through peer support or advocacy, or indirectly through systemic advocacy, education of clinicians about families and carers, research, or policy work.

In 2019-2020 the Department of Health Lived experience workforce positions report identified 98 family/carer LE positions (56 FTE) in Victoria's publicly funded mental health services. Since this time, the growing investment in lived experience roles since the Royal Commission into Victoria's Mental Health Services has seen a significant increase in family/carer LE leadership roles.

However, despite this seeming growth in the workforce, there has been limited research which elevates the voices of workers in family/carer LE roles and the systemic and organisational structures required to support them.

Unlike consumer lived experience work, which has benefited from a long lineage of literature detailing the perspective, values and practices that guide consumer workers (Byrne et al., 2019; Davidson et al., 2012; Edan et al., 2021; Gillard, 2022; Ibrahim et al., 2019; Mancini, 2018), there is very little for the family/carer LE workforce in this regard. In order to further family/carer LE work, a similar investment in research and an evidence base for practice is required.

The Rising Together study set out in this report is a first step toward better understanding the current nature of the family/carer LE workforce in Victoria. The following report outlines the various stages of the co-produced research undertaken including findings from the initial literature review, the workforce survey and the workforce focus groups which used photovoice methodology to capture rich stories illustrating the family/carer LE worker experience. It concludes with a set of recommendations aimed at furthering systemic support for these roles. It puts forward a strategy for change that can occur at practice, organisational and systemic levels but ultimately suggests that to consider these recommendations individually is to negate their value as integrated parts of a wider whole – to ignore one is to undermine all.

2. Existing research into family/carer lived experience roles

A scoping review of Australian and international literature was completed to establish any existing evidence base for the development, efficacy, and experiences of family/carer LE workforces. The review outlined below found that while there was a growing body of research, it was far less developed than that for the consumer lived experience workforce. It found that the existing research lacked consideration of the experience of family/carer LE workers, the complexity of the practice undertaken, and, with the exception of a few studies, were not conducted with the family/carer LE workforce or had not centred their voices through co-produced research.

A systematic search strategy was conducted with ten databases chosen to ensure coverage of the literature: CINAHL complete, Global health (Web of Knowledge), SCOPUS, PsychInfo, ASSIA, Emcare, Family-ATSIS, Medline, Web of Science, and SocIndex. A wide range of search terms was used to encompass the different terms used in different jurisdictions. The included papers had to specifically focus on paid roles where the employee was hired because of their lived experience of being a family member or carer for someone with a mental illness. The review generated 42 papers that were all published between 2007 and 2022. Most (28) of the papers were from the United States where the Substance Abuse and Mental Health Services Administration (SAMSHA) recommends the expansion of peer specialist roles, including peer roles for those with lived experience of being a family member or caregiver of someone with mental illness (Hyde, 2013). A further 11 papers were from Australia which is a jurisdiction which also has government policy encouraging the inclusion of family/carer LE workers in mental health service delivery (Commonwealth of Australia, 2010; State of Victoria, 2021). A further two were from Canada and one from the United Kingdom. The geographical spread of these papers indicates that the hiring of family/carer LE workers is far more disparate than the hiring of consumer/service user lived experience workers and are focused on jurisdictions where there is government level policy recommending and funding such roles.

Family/carer LE workers were described using a wide variety of role titles. These included family peer workers (Acri et al., 2013, 2014; Chacko et al., 2020; Hoagwood et al., 2018; Horwitz et al., 2020; Jamison et al., 2017; Olin et al., 2010; Rodriguez et al., 2011), parent support providers (Anthony et al., 2019; Davis et al., 2011), lived experience researchers (Banfield et al., 2021), carer consultants (Barkway et al., 2012), peer family advisors (Cavaleri et al., 2010), carer peer support workers (Barr et al., 2020), peer workers (Chisholm & Petrakis, 2020; Ehrlich et al., 2020), parent advocates (Davis et al., 2010), peer family support specialists (Glisson et al., 2014), parent peer navigators (Godoy et al., 2019), family support specialists (Hoagwood & Burns, 2014; Olin et al., 2014), family peer support workers (Hopkins et al., 2021; Leggatt, 2007; Leggatt & Woodhead, 2016), parent advocate with lived experience (Markoulakis et al., 2018, 2022), carer lived experience workers (Mercuri et al., 2022), family community navigation specialists (Myers et al., 2015), parent peer specialists (Olin et al., 2016) and professional family peer advocates (Wisdom et al., 2011). There was no research into family/carer LE supervision or management and no research into family/carer LE workers employed in policy roles. Given the wide variety of role titles, this study will use the term family/carer lived experience (LE) worker as a means of capturing the wide variety of role types.

The papers were wide ranging in their focus. Several papers investigated the perceptions family/carer LE workers had on their role. Family/carer LE workers perceived their roles as focused on providing emotional support for families and carers (Leggatt & Woodhead, 2016; Rodriguez et al., 2011; Wisdom et al., 2011, 2014), providing information and connection to supports (Mercuri et al., 2022; Rodriguez et al., 2011; Wisdom et al., 2011, 2014), advocating for families and carers and representing the interests of families and carers (Mercuri et al., 2022), and educating clinicians around the concept of recovery (Chisholm & Petrakis, 2020). Family/carer LE workers identified that they were motivated to work in such roles as they had negative experiences within the mental health system and wanted to contribute to change (Barkway et al., 2012).

A proportion of the papers investigated the feasibility and effectiveness of programs incorporating family/carer LE workers. There was evidence that family/carer LE workers were effective in providing emotional support for families/carers, increasing a sense of effectiveness in obtaining required services (Kutash et al., 2011; Visa & Harvey, 2019), increasing engagement with services (Kutash et al., 2011), increased perceptions of care (Radigan et al., 2014) and increased social connectedness of caregivers (Radigan et al., 2014). There was also evidence that family/carer LE workers could feasibly deliver to families and carers psychoeducation training that was developed by non-lived experience professionals (Acri et al., 2013, 2014; Chacko et al., 2020) and that psychoeducation packages co-produced with families/carers could be effective in improving the wellbeing of families and carers (Chiocchi et al., 2019).

There was also evidence that families and carers particularly noted the value of being supported by staff who had a lived experience of being a family member and/or caring for someone who had used mental health services. This was related to feeling as though staff with lived experience better understood family/carer experiences, that they could provide care in ways which were different from the medical model, and that this care was less stigmatizing (Markoulakis et al., 2018; Myers et al., 2015; Nayak et al., 2021; Visa & Harvey, 2019). The use of lived experience of caring was also described as particularly useful to incorporate into mental health research (Banfield et al., 2021).

While none of the papers focused specifically on identifying challenges for family/carer LE workers, many identified several issues faced by family/carer LE workers in a range of roles. Family/carer LE workers reported that the work can be isolating (Banfield et al., 2021; Barkway et al., 2012) and that the role can be emotionally challenging due to the use of lived experience (Hopkins et al., 2021). There was an identified need for family/carer LE specific training (Hoagwood & Burns, 2014; Hopkins et al., 2021; Scheer & Gavazzi, 2009) and specialised supervision (Kutash et al., 2014). There were issues identified in relation to a lack of organisational support for the roles (Chisholm & Petrakis, 2020), challenges working with families in services that were focused on responding to individuals (Hopkins et al., 2021), challenges with being seen as a "legitimate" profession (Ehrlich et al., 2020; Kutash et al., 2014), and issues navigating privacy and confidentiality processes within services (Hopkins et al., 2021). There was an identified need for all staff to be trained in how to best to incorporate family/carer LE work (Wisdom et al., 2011), and a need for more funding to best support the development of family/carer LE roles (Chisholm & Petrakis, 2020; Scheer & Gavazzi, 2009). Finally, there was an identified need to recruit more diverse staff into the roles, particularly those from non-English speaking backgrounds (Visa & Harvey, 2019).

Several papers documented strategies to support and evidence the work that family/carer LE workers do. This included a range of training packages for family/carer LE workers (Hoagwood et al., 2018; Horwitz et al., 2020; Leggatt, 2007; Olin et al., 2010), family journals to document progress of work with families and carers (Anthony et al., 2019), quality indicators for family/carer LE workers and programs implementing family/carer roles (Olin et al., 2014) and scales to assess quality of peer work (Otto et al., 2022).There was also a consideration of the organisational context of family/carer LE work. Positive organisational culture and climate were found to be related to higher job satisfaction amongst family/carer LE workers as well as higher ratings of quality indicators for both family/carer LE workers and the programs they work within (Glisson et al., 2014; Olin et al., 2014). Based on this, and the challenges involved with embedding family/carer LE workers within mental health services, Olin et al. (2016) detailed a two-pronged approach to organisational change with the aim of shifting organisational culture to be more family focused and consequently better able to integrate family/carer LE workers. This approach involved a series of interventions and training sessions targeted at leadership within organisations, followed by a range of initiatives targeted at frontline staff.

Most of the papers identified in the scoping review documented research that was conducted by academics and it was not clear whether family/carer LE workers were involved in design, implementation, or writing of the papers. This indicates a need for a greater focus on co-produced research when investigating the role, impact, and experiences of family/carer LE workers.

Overall, the scoping review indicated a small but growing body of research into family/carer LE roles that indicate an emerging body of evidence supporting the implementation of such roles along with a range of initiatives to support this growing profession. While several studies identified a range of challenges faced by family/carer LE workers, there has been no study specifically investigating the experiences of family/carer LE workers within mental health settings. Nor is there the breadth of literature detailing models of practice, theory, and complexity of family/carer LE work that exists within the body of consumer LE literature.

Based on the literature review, and the RTAG member's lived experience of being family/carer LE workers, the RTAG chose to focus on the following areas for investigation with the Victorian Family/Carer LE workforce:

1. What are the experiences of family/carer LE workers within Victorian mental health services?
2. What are the workplace conditions experienced by family/carer LE workers?
3. How do family/carer LE worker's personal lived experience of caring intersect with their work?
4. What do family/carer LE workers need to make their roles sustainable?

The following section details the co-produced approach to research design and implementation that was used to answer these questions.

3. Methods

The Rising Together study drew on the lack of existing research centred around the voices of family/carer LE workers, to propose a co-production methodology that elevated the experience of family/carer LE workers at all stages of the study. The methodology set out below outlines how co-production was undertaken, the stages of team development, data collection and analysis, and the use of co-production aligned data collection methods such as photovoice. The process of co-production undertaken in this study represents a further stage of development of co-production methodology in mental health.

3.1 Co-production as methodology

Co-production is an approach to partnering with communities that has gained a significant amount of traction in recent years. Co-production was first articulated by Elinor Ostrom (1973) who used the term in a series of studies of the Chicago police in the 1970s. The key to Ostrom's thinking was that public services function best when they are designed and run by a combination of community members who have a localised understanding of context, and professionals who have technical expertise. This has become the grounding concept of co-production today. Co-production embeds the value of citizen participation outlined by Arnstein (1969) and aims to move citizen engagement beyond consultation and participation, to partnership and delegated power. Co-produced research entails a collaborative approach between academics and community members to design, implement, and evaluate topics that directly impact the community members participating in the research (Lambert & Carr, 2018; Lignou et al., 2019; Pinfold et al., 2015). In the mental health sector this commonly involves partnering with consumers (service users) and/or family/carers as lived experience experts to investigate topics that directly impact them.

Within the context of this study, co-production was informed by the principles and frameworks outlined within Co-production: Putting Principles into practice in mental health contexts (Roper, Grey, and Cadogan, 2018), with adjustments made to fit a family/carer LE perspective. Roper et al (2018) stress that authentic co-production is the confluence of four distinct phases of project design and delivery: co-planning, co-design, co-delivery, and co-evaluation. Co-planning ensures that lived experience experts are involved in any project from the very start.

They play a role in setting the agenda of the project, deciding on the approach the project will utilise, as well as influencing decisions around timeframe, funding and governance arrangements. Co-design centres lived experience experts within the design of the project. Here the nature of the problem is defined by those with lived experience expertise, and ways of addressing the problem are developed and tested in partnership with people with expertise in other areas. Co-delivery maintains lived experience involvement in a co-produced project by ensuring that lived experience experts are involved in the delivery of a project. Finally, co-evaluation involves ensuring that lived experience experts drive any evaluation of the project including deciding how to measure implementation success.

Roper et al (2018) also stress that the following key principles of co-production are embedded in to all four stages:

- **Lived experience experts are partners from the outset –** It is crucial that lived experience experts are involved at the start of any co-produced project in a meaningful way, and should be instrumental in setting the agenda and priorities of the project.
- **Power differentials are acknowledged, explored, and addressed –** Power imbalances within co-production partnerships are inevitable and if unaddressed can lead to less powerful members of a co-production team having less capacity to meaningfully influence decisions within the co-production process. Consequently, it is crucial that power differentials are clearly acknowledged, the impact of them explored, and that strategies are implemented to address their impacts.
- **Lived experience leadership and capability is developed –** While co-production aims to meaningfully embed lived experience expertise in projects resulting in a high-level participation illustrated within Arnstein's 1969) ladder of citizen participation, it ultimately falls shorts of the top rung of citizen control. For this reason, it's important to embed opportunities for capacity building within any co-produced project as this works to build the skills and capabilities of the lived experience partners so that there is a greater capacity to lead such projects.

The Rising Together study aimed to embed these principles into practice whilst ensuring that family/carer LE experts were instrumental in the project planning, design, delivery, and evaluation of the study.

Scaffolding co-production – the importance of process

Roper et al.'s (2018) approach to co-production is ambitious as it requires academics and practitioners to upend their usual way of practicing, to enable a working environment where all parties involved in the co-production process feel safe and supported to meaningfully contribute to, and potentially lead, all aspects of the project. The Rising Together team implemented a range of strategies to create such a work environment. These were initially instigated by the research leads, however, over time all group members took up responsibility for creating a safe and supportive environment to work and learn in. The following strategies and process were implemented across the life course of the group to achieve this aim.

Setting up co-production

It needs to be recognised that the way a project group is constituted can contribute to project outcomes. Careful consideration was made when forming the RTAG. Membership included the academic research lead, family/carer LE community lead, four family/carer LE workers, a consumer academic, and an academic with no experience in the mental health space who filled the role of a provocateur. The group also invited a staff member from Tandem to provide insight to industry developments impacting on the family/carer LE workforce. The academic research lead and consumer academic both had extensive experience in co-produced research and had a focus on building the capabilities of co-researchers to enable them to conduct research in future projects. The consumer academic was also able to draw on expertise in the consumer LE discipline at times, in order to examine differences and similarities in the workforces. In selecting lived experience members, diverse work experiences and contexts were sought. The membership included experience of child and youth, adult services; publicly funded services and community services; and consultants, advisors, project officers and peer support worker roles.

THE ROLE OF THE PROVOCATEUR

Within a co-design methodology, the role of the provocateur, or curious questioner, is to bring an authentic curiosity to the research process and findings analysis (Tindall et al, 2021). This authenticity comes from being detached from or having very limited experience of the sector or lived experience central to the research. While ensuring that lived experience co-researchers remain at the core of a co-design research project, the introduction of a provocateur, inserts a researcher into the team to be curious about assumptions or unspoken understandings between co-researchers with similar lived experiences. This assists co-researchers to explore and question processes or findings, to articulate meaning behind statements or descriptions, and to explore how they sit within the research process. In this research project, the provocateur role was taken up by a researcher with experience in social work, human service systems and law. Throughout the co-design process, the provocateur posed questions about how lived-experience family/carer LE roles work in different settings, the workplace cultures of different mental health settings and the connection between consumer and family/carer LE concepts and personnel.

The group was structured so that there was a clear majority of members who had lived experience as family/carer LE workers. It was both by design (well-considered recruitment), planned exercises, group discussion and a bit of luck that the RTAG ended up with members complementing one another in skills, experience, interests and temperament. But then it was up to the group to decide how best to turn this to its advantage by allowing everyone to build on their strengths and contribute in a way best suited to them.

Finally, consideration was given to finding collaborative and creative ways of working together. This study commenced during Covid restrictions, so the group worked remotely for the bulk of the study. In the absence of whiteboards, sticky notes, and flipchart paper, the project leads decided to use Padlet which is an online collaborative platform that creates virtual bulletin boards. This platform is highly interactive and allows for a range multimedia to be included within boards. Padlet was used as a way of setting agendas, documenting discussion and decisions, icebreaking activities, brainstorming, and later analysis, allowing project members to be involved as much as possible.

Bringing the group together

Early in the study time was invested in developing strong relationships within the group. It was important to ensure that all group members had a shared understanding of co-production and the RTAG worked together to discuss what the team could do to ensure that Roper et al.'s (2018) principles of co-production could be implemented. Key to these discussions was the importance of feeling safe to be vulnerable in the group in order to try out ideas without fear of getting things wrong, and to be able to consistently reflect on how the team was working together. Several processes were developed to enable this to occur:

- **Check in:** Each meeting started with "check in" where group members were able to bring up interesting ideas or questions they had for the group, with discussions ranging from topical news, personal stories, current challenges, and personal joys. This prompt ensured relationships and connections were fostered throughout the study, creating safety for group members. It also highlighted the idea that group members were not solely stepping into the study within their associated roles but were encouraged to bring their whole selves to the space.
- **Reflections:** Each project meeting agenda included time for reflections, inviting feedback on the meeting. Within these reflections, barriers to contributions and power dynamics within the group were regularly discussed. Consistent reflections enabled continual iteration of meeting and group processes, responding to the needs and preferences of group members.
- **Creating space for constructive criticism:** Early on in the study the academics shared work that was in development rather than a finished project and the group were encouraged to openly critique. This helped group members feel more comfortable putting forward their own ideas and being open to constructive criticism.
- **Sharing meeting roles:** The group took turns to lead different aspects of the meeting such as keeping time, leading check-ins or delivering the acknowledgement of country.
- **Collaborative tool:** Using Padlet to document group agendas and processes became a tool to democratise the study. All group members could add to the Padlet each week and could set agenda items and issues to discuss. Options to use the Padlet anonymously to reflect at the end of each session as to what worked well, what could be different and what group members would like discussed at future sessions allowed for open and honest discussion.

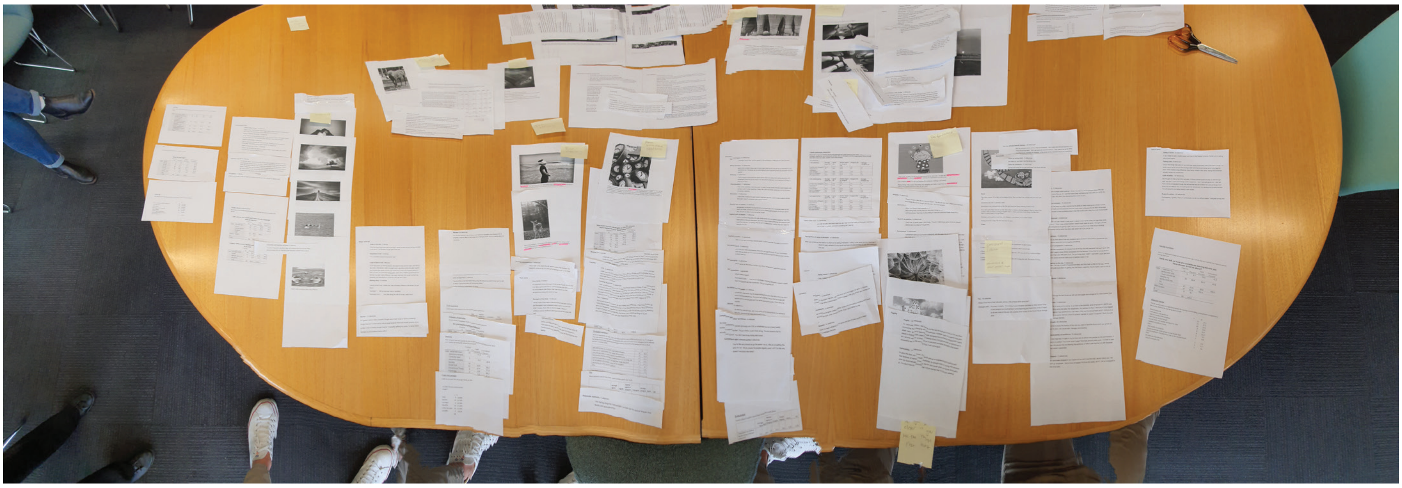
The group also worked together to create a clear vision for the study. When doing this, the research leads were transparent about the roles that everyone had and the constraints to the study (ie: time, money).

LISA'S REFLECTION ON THE CO-PRODUCTION PROCESS:

"I entered this project with some trepidation about my ability to meaningfully participate in and contribute to academic research. Co-production was also new for me, but it was reassuring to have other family/carer LE workers in the group. After writing my first, short story to share with the group, I was encouraged by positive feedback from everyone as well as from having this piece of work shared more publicly on our website. It told me that my work was good enough and gave me confidence to continue. As we went on to collectively develop the survey, website content, presentations, blogs and the report, we took turns in leading and editing sections of work. There was time to question, suggest and rewrite many iterations of copy. This co-production process really taught me that it was safe to have a say, and when everyone did not agree with something, it simply prompted further thinking which was often valuable. Notably, this process also involved 'letting go' of some content or a style of writing that I may have been attached to as it was far more important to consider and utilise the views and contributions of all group members."

Performing as a group

The work done in the early stages of the study was successful in creating a safe and supportive environment that enabled the group members to take risks, share ideas, and contribute to, and receive constructive criticism. Consistent reflection allowed for the group to adapt processes to best suit the needs of individuals and the study as a whole. When decision making was needed, the group aimed for consensus with the understanding that the incorporation of conflicting opinions often results in a stronger outcome. Co-researchers were encouraged to take ownership of several key elements of the study and were supported to build skills in specific areas of research. For example, co-researchers developed the project logo and website, wrote blogs about the research process, and analysed transcripts. Co-researchers also jointly presented the work at forums and conferences and have been involved in co-writing this report.



Co-analysis

BRONWYN'S REFLECTION

"The absolute standout for me in being part of this project as a person with family/carer LE and experience as a LE worker, has been the people I've gotten to know and the value that's been placed on the voice of lived experience at every stage of the project. But how did that happen?

Check-ins at the start of each meeting meant I got to know other team members outside of the content of the project and reflections at the end of each session, where we identified what worked well, what we could do better and incorporated those ideas into the subsequent meetings was an important part of that process. Those two things, amongst many others, meant that when it came time to have more difficult conversations, we had established relationships with each other and an established process for making change. It also meant that when it came to decision points where we might disagree and need to have robust conversations, I felt heard, even when the outcome sometimes wasn't what I had originally wanted.

Every meeting (mostly held online) was purposeful, productive and active and had form and purpose – there was no sitting there just listening – we were all actively working on the project while being in the meeting. This meant breaking into small groups to work on a small part of the project, editing documents together, sifting through data or developing survey or share and reflect questions, amongst other things.

For me, the unexpected gift at the end of the project is that for the first time in my life, I'm loving writing, because I've found that when writing is valued and shared (and produced in this case) within a supportive community of people, it adds such a richness to its value and purpose. My hope is that our writing has done justice to the amazing family/carer LE workers who participated in the project and so openly shared their stories with us."

3.2 The research design

The RTAG decided to undertake a mixed-method approach to the research design that incorporated an online survey of family/carer LE workers, Share and Reflect (S&R) photovoice workshops, and a Recommendations Focus Group. This decision was made to enable the study to capture descriptive statistics on broad trends within the workforce, alongside rich stories that illuminated the experiences of family/carer LE workers. The group also wanted research participants to be able to respond to the findings of the study in a way that used their expertise to shape the recommendations of the study. Figure 1 outlines the research design for this study.

Figure 1: Rising Together Research Design

SURVEY
Capturing quantitative and qualitative data about workplace conditions, relationships with colleagues, safety and supports.

+

PHOTOVOICE
Workshops capturing rich stories of Family/Carer LE experiences.

ANALYSIS
RTAG identified key findings from survey and conducted thematic analysis.

INTERPRETATION
RTAG decided on key findings to take to the Focus Group.

FOCUS GROUP
Participants identified key actions in response to findings from Survey and Photovoice.

FINAL REPORT
RTAG used findings from Survey, Photovoice and Focus Group to inform recommendations and final reporting.

Survey

An anonymous online Qualtrics survey was developed by the RTAG for distribution to family/carer LE workers. The RTAG developed all aspects of the survey which covered: demographic data, workplace conditions, relationships with colleagues, safety and inclusion, and support and professional development. To collect relevant quantitative and qualitative data multiple-choice, open-ended questions and Likert scales were used.

Participants were eligible if they had worked in a designated family/carer LE role, in the last 5 years in Victoria. The survey was shared with the Carer Lived Experience Workforce (CLEW) Network and other professional mailing lists. Participants were encouraged to further share the survey with others who met the eligibility criteria.

Share and Reflect photovoice workshops

The RTAG wanted to capture the rich stories of family/carer LE worker experiences and were interested in exploring this through verbal and non-verbal mediums. The group decided to utilise photovoice as a research method to achieve this aim. Photovoice is a research methodology that uses images to enable participants to identify, represent and develop shared understanding of their experiences (Wang & Burris, 1997). This method is commonly used within community based participatory research projects and enables community members to express their life experiences and community's concerns in a way that creates dialogue and knowledge, and works to effect change (Wang & Burris, 1997).

The RTAG implemented this approach by inviting participants to create or find three images that represented their experiences of being a family/carer LE worker. The RTAG ran an online information session to promote this stage of the study and to provide guidance for participants on how to create or select images in a safe and ethical way. Participants were able to create their own images or source images from royalty free stock photography sites. They were provided with the following prompts to guide their selection of images:

Select or create an image that illustrates:

- your experiences in the workplace
- how your service views families and carers
- how you feel about your role
- why you work as a family/carer lived experience worker
- how your lived experience and your role interact.

Participants were invited to share these images in a three-hour S&R workshop that occurred over Zoom. Each participant was asked to share at least one image and discuss what it meant to them, and the group were guided to share their reflections on the image. Participants then wrote short captions to accompany their images. The workshops were audio recorded and transcribed through a professional transcription service.

Analysis of survey and focus group

The RTAG were responsible for conducting the analysis of the survey and S&R workshop transcripts and photos. The quantitative questions in the survey were analysed for descriptive statistics. The qualitative questions and the S&R workshop transcriptions were analysed using a co-produced approach to thematic analysis. This involved the group reviewing one transcript from the S&R workshop and generating a long list of “codes” which described content in the transcript. These initial codes were reviewed by the group and then used to develop a coding framework. This framework was then used by two RTAG members to code the two S&R transcripts using NVivo software. This was analysed for interrater reliability and any different coding was mediated by a third coder. The coding was then grouped under higher level themes that were reviewed by the RTAG. The qualitative data from the survey was also coded using this framework.

The RTAG met in person to review the key findings from this stage of analysis along with the photos submitted by participants in the S&R workshops. This involved having individual themes or statistical findings each on a piece of paper that was spread across a large table along with the photos. The group worked together to decide which findings could be grouped together into macro level themes. Images that mapped well to each of these themes were also selected. This analysis shaped the key findings that were presented to the Recommendations Focus Group.

Recommendations Focus Group

The findings developed in the above stage of analysis were used as the focus for the Recommendations Focus Group. Participants who registered for the focus group were sent a brief summary of the findings. The focus group was run online, and participants were invited into breakout rooms to discuss their ideas for actions that could address the issues identified in the findings. They were asked to note their ideas on a Padlet.

To analyse the focus group data the RTAG reviewed the Padlets created and grouped suggestions together. These are reported in the findings section and were also used when the RTAG were developing the recommendations for this study.

Ethics

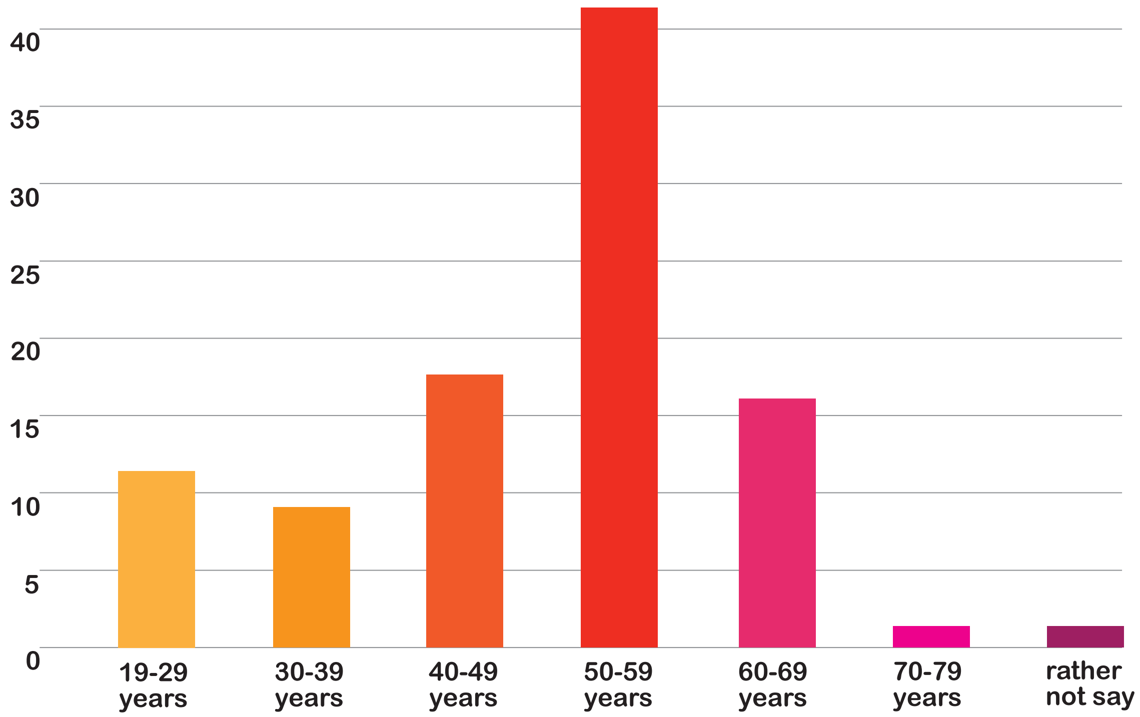
This research design was approved by the University of Melbourne Human Research Ethics Committee Application No: 22395.

3.3 Participant demographics

Survey

A total of 62 participants completed the survey. Participants had the option to complete the survey more than once if they wanted to report on more than one role. A total of 5 respondents filled out the survey more than once to detail separate roles. This represents a substantial proportion of the workforce. While the exact numbers of family/carer LE workers are not known, the Carer Lived Experience Worker (CLEW) network reports having 170 members. This may include members who have left the workforce and there may be family/carer LE workers who have not joined the CLEW. The survey participants predominantly identified as female (88.7%) and over the age of 50 (61.7%) (see Figure 2). This demographic spread would seem to be very similar to what is known about family/carer LE workforce (Our Future Project Partnership, 2021) and as such could be considered as a representative sample of the wider workforce.

Figure 2 Age of Participants



Share and Reflect Workshops

The S&R workshops had 10 participants, with four participating in the first session and six in the second session. Age was not recorded for the participant group, however no younger members of the workforce (19-29) were in attendance. All participants were female.

Recommendations Focus Group

The Recommendations Focus Group had 16 participants. Age was not recorded for the participant group, however no younger members of the workforce (19-29) were in attendance and all participants were female.

The low numbers of male participants in all stages of this study has made it difficult to analyse whether the experience of male family/carer LE workers is different from those of female family/carer LE workers. This is an avenue for future research.

4. Findings

The analysis of the survey, S&R workshops, and Recommendation Focus Group resulted in the following themes that detail the experiences of family/carer LE workers. These themes include the characteristics of the family/carer LE workforce, the vision held by family/carer LE workers, the reality of working in these roles, the negative impacts of these roles, and what sustains the workforce.

4.1 Characteristics of the workforce

The study drew on the findings from the survey to understand the current nature of the family/carer LE workforce in Victoria. These understandings of the workforce more generally have been used in the report recommendations to give context to the needs of the workforce and how best to support workers to sustain the work they do.

Personal characteristics, education and experience

As indicated in Figure 2, the majority of survey participants (61.7%) were over the age of 50, while only 11.3% were aged 19-29, 9.7% were aged 30-39 and 17.7% aged 40-49. The survey also indicated a highly feminised workforce with 88.7% of survey participants identifying as female, suggesting a workforce predominantly made up of women over the age of 50.

A fifth (22.58%) of survey participants reported that they were either CALD or of Aboriginal descent.
A total of 8.06 % reported being LGBTIQA+. Almost a fifth (19.35%) of survey participants reported that they were living with mental illness or psychological distress. While discussions of the workforce generally may at time seem homogenous, these findings suggest it is important for organisations and policymakers to also consider the broader intersections for this workforce, particularly in the context of bringing lived experience to the work undertaken.

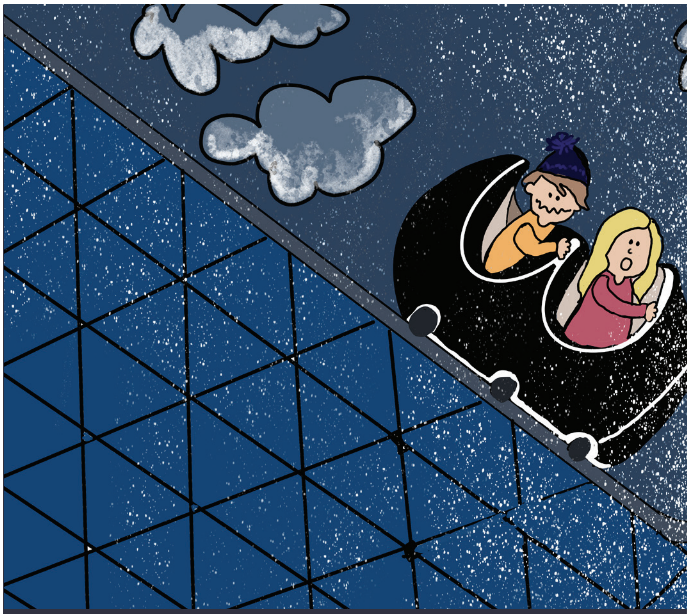
Participants were generally highly educated with 67.7% having an undergraduate degree or higher. A further 29.1% had vocational qualifications. As indicated in Table 1, the focus of the qualifications varied significantly. The most common qualification was a Bachelor of Arts or Social Science, but many participants had also completed health related qualifications such as mental health, social work, peer work, and nursing.

Table 1 – Qualification

QUALIFICATION	N	%
Arts/social science	13	21.0%
Counselling or Psychology	8	12.9%
Community Services and Community Development	7	11.3%
Vocational – health (Eg: aged care, allied health, remedial massage etc)	7	11.3%
Applied Science/health science/public health/science	6	9.7%
Education and Training and Assessment	6	9.7%
Cert IV Peer Work	6	9.7%
Nursing	5	8.1%
Other (eg: public policy, art therapy, youth work, creative arts)	5	8.1%
Mental Health	5	8.1%
Social Work	5	8.1%
Business/Commerce	4	6.5%
Theology	3	4.8%

Almost a third (29%) of survey participants had worked in another non-designated role in the mental health sector. Of this group 38.9% had worked as community mental health workers/support workers, a further 27.82% held allied health or allied health adjacent positions, and 16.67% had worked in nursing.

There were a variety of caring experiences reported in the survey. The majority of survey participants (64.5%) had experience caring for children or adult children. This was followed by 33.9% having experience caring for parents, 33.9% having experience caring for friends, 29% having experience caring for partners, 29% having experience caring for siblings and 9.7% caring for other family members. The majority of participants (71%) reported that they were currently in a caring role.

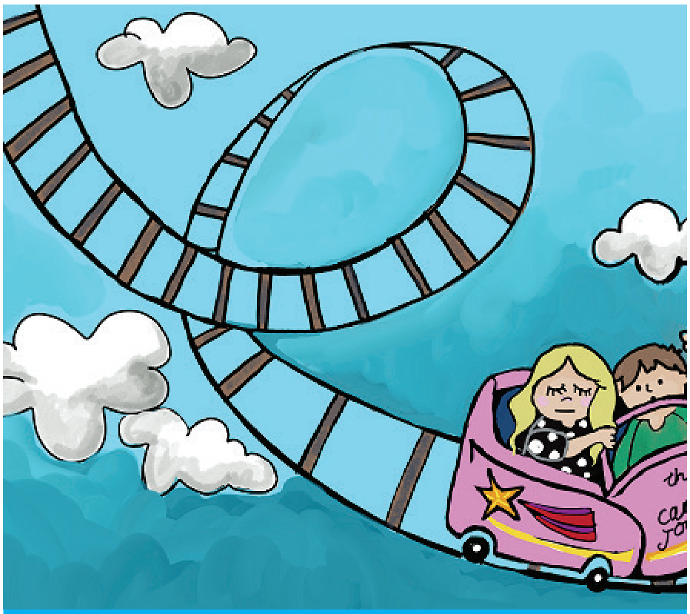


APPROACHING A CRISIS

The roller coaster. It's a ride you're strapped in for. But you didn't buy a ticket and you can't get off. Sometimes the ride is pleasantly calm. Sometimes your stomach drops as the ride gets faster and faster, hurtling toward crisis. You can't get off the ride, but you can learn. Here is where a little dip happens. Here is where you scream. Here is where you hang on tightly. Here is where you know it [will] not always be like this. Here is where [you] know it will get better. Helping your loved one, your son, your daughter, your partner…it's a roller coaster.

Caring is not for wimps.

We do it because we care.



LIGHT

Sometimes we ride the roller coaster with other people. Sometimes we ride it alone. Understanding the journey and sharing our experiences shows they're not all bad. Choose to enjoy some moments. Outbursts of laughing tears, allowing ourselves to acknowledge a sense of peace when loved ones are feeling better. Celebrate and remember these moments. Be proud that you're taking the ride.

Be proud of being a carer.

Roles and Organisations

Most participants (72.6%) reported working in a metropolitan centre, with 16.1% indicating that they worked in a rural location, 6.5% reporting that they worked for a state-wide service, and 4.8% for a national service. The vast majority of participants (85.5%) worked in publicly funded mental health services. Of this group, 69.8% worked in adult mental health services, 15.1% in child and adolescent services, 5.7% in aged services, and 9.4% in a state-wide program. These findings reflect the current mental health system which is likewise focused on metropolitan, public and adult services. As the mental health system develops to be more accessible in regional/rural areas or for youth or older consumers, it will also be important to ensure a similar development in family/carer LE workers across the diversity of the sector.

As indicated in Figure 3, most participants (38.7%) reported working as a family/carer LE worker for 3-5 years. Most participants were either family/carer consultants (38.4%) or family/carer peer support workers (41.1%). A smaller proportion worked in other positions such as managers, educators/trainers or researchers (see Table 2).

Figure 3 – Time working in the family/carer LE workforce

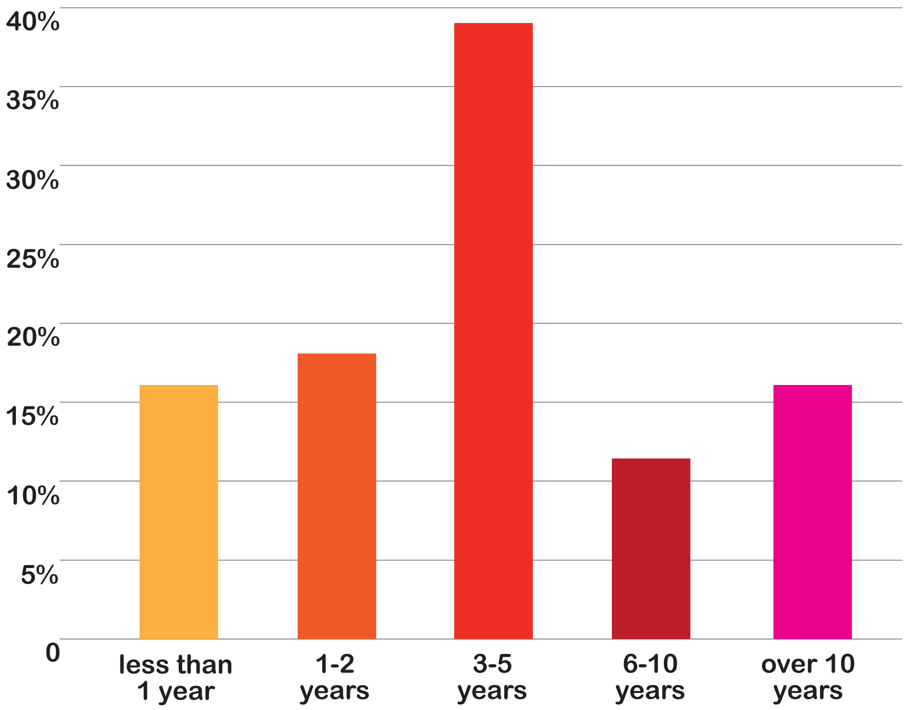


Table 2 – Type of Role

TYPE OF ROLE	N	%
Family/Carer peer support worker	30	41.1%
Family/Carer consultant	28	38.4%
Coordinator/manager	4	5.5%
Other	5	6.8%
Family/Carer representative	3	4.1%
Educator/trainer	3	4.1%

Image sourced from: https://pixabay.com/photos/beeches-part-winter-autumn-way-3638277/

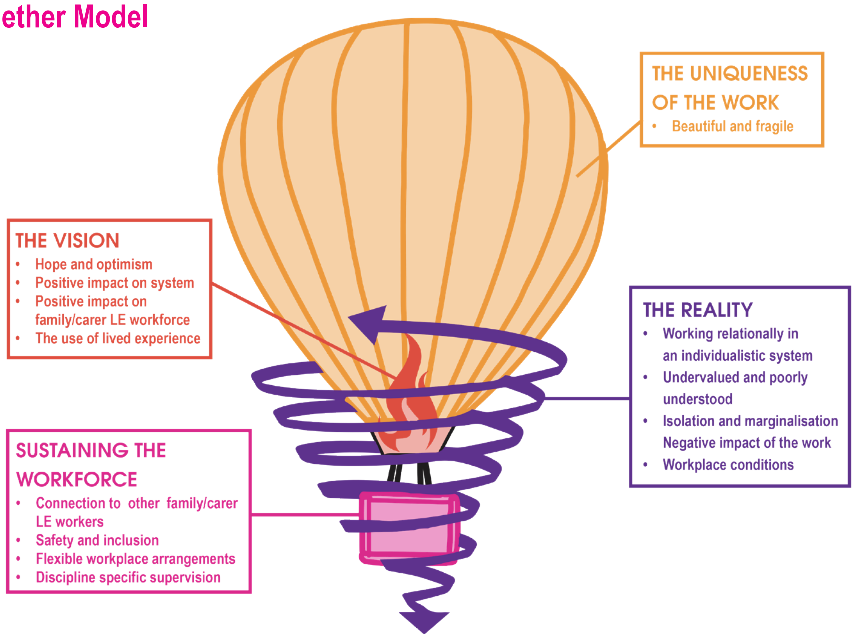
> ***I searched to find a messy image of mixed pathways rather than one lone pathway that does not allow many choices. For me, this image landed well, as it is uphill, rocky, uneven and would be tough going.***
>
> ***But the achievement of reaching the view at the top or of just successfully working through the journey was worth the effort.***

4.2 A multilayered and complex experience

Through the survey and S&R workshops, the research team was able to explore in further detail the experience of family/carer LE workers. An overarching theme in the findings is the multilayered and complex nature of the experiences of family/carer LE workers. There is hope and optimism and the work is meaningful and seen as having a positive impact. However, the work has inherent challenges that make it complex and difficult to sustain.

The following model illustrated in Figure 4 was developed by the RTAG as a way of capturing the findings of this study that detailed experiences of family/carer LE workers.

Figure 4 – Rising Together Model



This model drawn from the research findings uses hot air balloons as a metaphor for the family/carer LE workforce employed in a mental health service. Each workforce, or balloon is unique, and like the specific descriptions from participants, both are at once beautiful and fragile.

The vision

Family/carer LE worker's vision and passion is the fire that heats the air to keep the balloon aloft. This fire is ignited by family/carer LE workers' lived experiences of interacting with mental health services and fuelled by the positive impact their work has on families (including carers and consumers) and on the broader mental health system. Without this vision and passion, the work would not take off nor be able to transcend the challenges faced by the family/carer LE workforce.

The reality

The success of this passion in lifting up the workforce is mediated by forces in the environment. The challenging reality of working relationally in an individualistic system, feeling undervalued and poorly understood, isolation and marginalisation, poor workplace conditions, and the negative impact of the work are illustrated in the model by a large cyclone-like spiral. Without change to these environmental and cultural conditions the workforce is likely to be dragged down.

Sustaining the workforce

However, there are forces that are sustaining and elevating the workforce – connection with other family/carer LE workers, discipline specific supervision, flexible workplace arrangements, and practices that support safety and inclusion all work to keep the workforce afloat.

MY MULTIFACETED ROLE

This work highlights some of the problems I experience – having two roles, being siloed, not being invited to join the meetings for peer workers because I'm not a consumer peer.
I often feel out of place, as I'm not a clinician. When I started, I was a hero; they were really happy with what I was doing, but 8 years later I'm invisible.

I know I'm doing good work and there are some positive moments. People tell me I have made a difference, but only I hear that. There are so many factors to consider and I feel like I'm banging on an empty door. I'm trying to fix things and I don't know where to start. I feel like a dinosaur being the oldest person here.

Do I smash it all and just walk away?

4.3 The vision

The findings of the survey and the S&R workshops highlighted the vision that family/carer LE workers had for their work. Many entered the workforce hopeful and excited to make a meaningful impact in the lives of families and the mental health system more broadly. The themes below detail the different aspects of the family/carer LE vision.

Hope and optimism

Participants spoke about entering the workforce with a sense of hope and optimism about their ability to use their lived experience to support others through their journey of caring and contributing to systemic change.

> *"I started in a project which was about introducing peer support into the clinical service, and it was a big project and it had a lot of people behind it. I was a rock star, you know? I was kicking goals. I went off to TheMHS [conference] and I felt like I was really making a difference."* **PARTICIPANT 6**

"I looked at the photo of the rainbow and the photo of the sun and when I looked at both of those they actually brought up for me all of the floods and things going on north and I was thinking, 'well, these things do happen and recovery does come one day and the rainbow appears after the rain and the next day the sun will come through.'" PARTICIPANT 4

These feelings of hope were often deeply connected with a belief in recovery – that things do shift for people experiencing distress – and that family/carer LE workers had a role to play in this journey.

Participants also spoke about the hope they had for change within the mental health system with the current reform process.

> *"We're creating transparency and removing the rug and just saying 'well let's deal with everything and let's look at everything freshly' and I think that's a really exciting thing to look at going forward."* PARTICIPANT 8

This hope and optimism, particularly in the context of the current reform process, can also be seen as a factor that drives family/carer LE work.

The positive impact on families and carers

Part of the vision described by participants was the belief that family/carer LE work had a positive impact on families and carers.

Survey participants felt strongly that they were valued by the families and carers connected with the services they work in, with 88.3% of respondents reporting that they strongly agreed or agreed with the statement "I am valued by the families and carers who are connected with my service" and 96.8 % reported agreeing or strongly agreeing with the statement "I make a difference to the families and carers that I support on in my role".

Within the S&R workshops participants detailed the ways in which they felt they supported families and carers.

Connection with families and carers

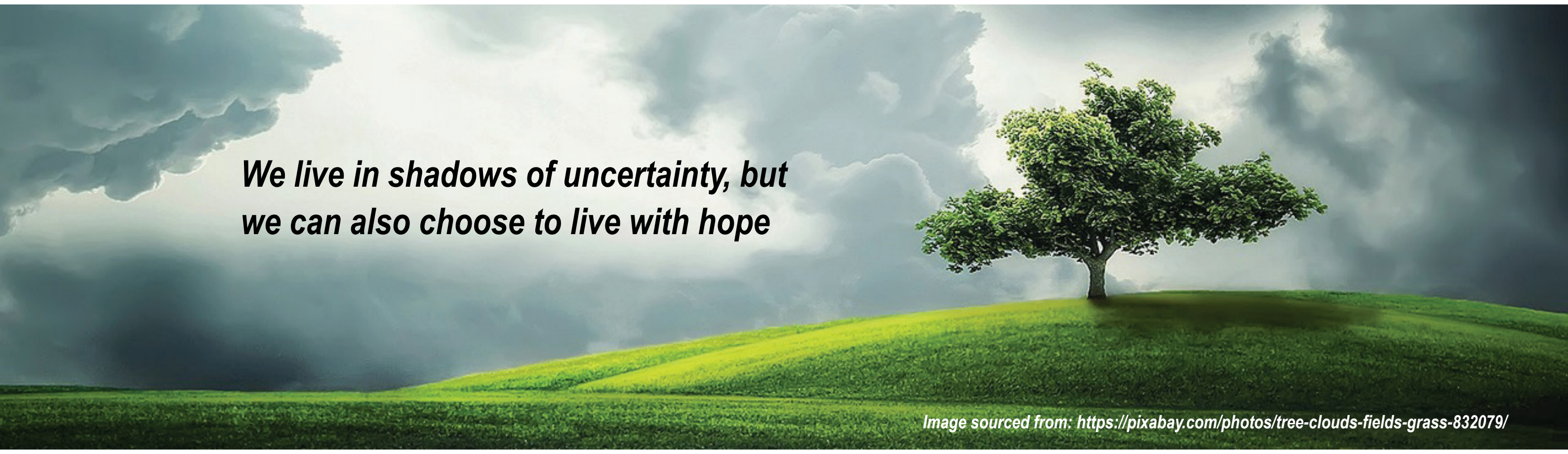
Connecting with families and carers to provide emotional support, information and encouragement was seen as a key part of the role. The words that participants used to describe this connection include:

"precious" "being a witness"
"speaking from the heart"
"validate and encourage"
"walking alongside" "nurturing"
"holding them so they don't fall"
"sharing their journey"

Being the voice of carers

Participants spoke strongly of the value of being the voice for families and carers. It was identified that families and carers are often not valued by clinicians nor factored into mental health service provision, and that there was strength in occupying a space that could help give them a voice.

> *"But also creating a space for the carer through family meetings and empowering them. So before a family meeting I'll connect with a carer and actually talk to them to get a sense of what's happening for them and also encourage them to jot down issues or concerns they have, so that when they're at the family meeting and I'm attending I can support them, and I let them know beforehand it's okay for you to tell it like it is and share what you're experiencing or ask certain questions that you may have."* **PARTICIPANT 5**



We live in shadows of uncertainty, but we can also choose to live with hope

Image sourced from: https://pixabay.com/photos/tree-clouds-fields-grass-832079/

> *"I resonate more now with this idea of fallen trees because I just think that sometimes you know how they say if a tree falls in the forest do people hear it? It's us. If we're not there are they going to hear that voice? Are they going to have that person to say, hey, wait a minute, no wait a minute. Have you thought about this? Have you thought about the carer's perspective?"* **PARTICIPANT 2**

The role of family/carers LE workers as advocates is important here. Participants commented that part of their roles involved "challenging norms" or being a "spanner in the works" to ensure that the views of families and carers were considered within mental health service delivery.

> *"That spanner in the works – well, part of our role, I believe, is to be a bit of a spanner in the works at times. Not that we intend for it to be disruptive but a little bit of disruption can be good, I think, as well, and sort of that resonates with me in the sense of sometimes we might bring things up that people don't want to have discussed but they're important."* **PARTICIPANT 5**

The impact on the service system

Participants in the S&R workshops saw themselves making a positive impact on the organisations and broader service system and described themselves as change makers. Participants noted the potential for family/carer LE workers to play a role in seeing and addressing problematic aspects of the mental health system. For example, one participant spoke about the importance of continually questioning things within her service to challenge the “taken for granted” ways of doing things:

> *“I agree, I think questioning things, whether it’s to do with the consumers or the carers or that side of things, but even around the way we do things and policies and procedures and sometimes things have been done a certain way for a long time and fresh eyes come in and speaking from experience, we question why we do something a certain way to create change and improve things as well.”* **PARTICIPANT 9**

One of the key ways in which participants described making change in the system was to create more transparency within organisations. One participant spoke about how she felt that clinicians would sweep the reality of the experiences of consumers, families, and carers under the rug, and that family/carer LE workers played a role in bringing these experiences to the surface.

> *“But I do remember thinking to myself that it feels like sweeping things under the carpet rather than actually – you know, when someone gets discharged prematurely and they end up back in hospital a week later, it’s like, well you weren’t listening to the person that’s providing care. You’ve swept it under the carpet and they’ve re-presented. They’ve gone through the trauma of having to have another admission and their loved ones have had to go through triage and trying to get their loved one into hospital when they become unwell. So maybe the next time around, we need to see what’s really happening and it’s okay to actually see what’s happening and to actually talk about it and to have that carer, have that voice heard, because their voice is important. Because they’re the ones that actually provide that frontline support when they’re at home and what’s happening at home obviously has a big impact on – and the support that they receive is really important in terms of if we get it right when they’re in hospital, there’ll be a less likely chance of them needing to re-present and go through all that trauma again.”*
> **PARTICIPANT 5**

Positive impact on family/carer LE workers

Participants also spoke about the positive impact that working in a family/carer LE role had on their own wellbeing. Participants described the joy of connection with other family/carer LE workers, the ways in which connecting with families and carers had helped them grow in their personal lives, and how using their own lived experience to support others was a deeply rewarding experience.

> *"My own reflection on this was how we listen to them and we create a safe space for them to be their best and to have a go and to thrive. Ultimately, that's what we want. We can see examples of when we do that. I see examples of when I do that and there is thriving and it's just such a joy. There's smiles, there's laughter, there's insight, there's just such beautiful recognition of self in a way that is so temporary and so fragile and yet so beautiful."* **PARTICIPANT 10**

Participants reported a high degree of satisfaction with their work with three quarters (75.9%) of survey participants reporting that they agreed or strongly agreed with the statement "I am satisfied in the work that I do as a family/carer worker".

The use of lived experience perspectives

Key to all of these positive impacts was the use of lived experience perspectives. Participants described using lived experience as a key form of expertise that is unique from other expertise in mental health services. Participants spoke about the strength of sharing their caring experience with the families and carers that they were supporting, and this enabled them to build a quality of connection that clinicians who are not working from a lived experience perspective struggled to achieve.

> *"But at the same time, I really feel super honoured to be able to share parts of my story with people and say, do you know what? I get parts of what you're going through. I've gone through parts. No one's story's the same. I'd never say I know what you're going through. But I'm a carer as well. I've been supporting someone as well. That immediate relief or that immediate [sighs] that people feel that oh God, you get it, you're not – do you know? It's horrible to say, in that, you're not a clinician."* **PARTICIPANT 10**

Image sourced from: https://pixabay.com/photos/drop-of-water-drop-impact-ripples-578897/

Ripple effect, one drop can make a big difference.

Participants also identified that bringing in their lived experience perspectives was like a “fresh set of eyes” that viewed things more broadly than other professionals in the system.

> *“When you come from that lived experience it’s like you have a fresh set of eyes or a lived experience set of eyes on what’s going on around you. What you’re feeling, what you’re experiencing, what you’re sensing and holding space with carers that often share things with you also when things are going wrong and when there are barriers to them feeling involved and supported.”* **PARTICIPANT 5**

Finally, they described how using their lived experience perspective helped to bring authenticity into the highly structured world of mental health services.

> *“It was very much around that a lot of the lived experience sort of approach is telling it like it is and bringing that messiness of real life into an environment that is often very structured, very power-driven, very hierarchical.”* **PARTICIPANT 5**

The use of lived experience to positively impact on the lives of families and carers, and the mental health system more broadly, can be seen as the guiding vision for family/carer LE work. This vision brings people into the profession and plays a role in sustaining family/carer LE workers in their roles.

The participants in the Recommendations Focus Group made a range of suggestions in response to participant descriptions of their vision for the role, focusing on ways in which this vision could be maintained and sustained:

- Ensure family/carer LE workers receive discipline specific training and supervision
- Support family/carer LE workers’ need for regular networking with others in the workforce
- Use co-design and co-production tools when developing workforce strategies for family/carer LE workforce
- Develop a strategy for promotion of the work and engagement with families and carers who might be interested in joining the workforce – with a focus on targeting culturally diverse groups
- Use media and social media to educate public on the role and value of the role in order to increase interest in joining the workforce.

The vision of family/carer LE work is made clear by the participants in this study. There is potential for the family/carer LE workforce to provide much needed support to families and carers and help lift their voices within the mental health system. This vision can be sustained by the investment in lived experience supervision and training along with the promotion of the value of the role both within, and outside of the mental health sector.

From before, reminders that each life is chaotic and messy and beautiful in its own unique way,

it is a discovery, never more than in the now.

Long road, blue sky (all of the potential for growth and improvement)

Image sourced from: https://pixabay.com/photos/heaven-panorama-field-grass-nature-3122143/

4.4 The reality

While participants spoke highly of their vision for family/carer LE work, much of the discussion in the S&R workshops focused on the difficult reality of working in these positions. These were reflected in key findings in the survey. The following themes detail the nature of the challenges inherent with working as a family/carer LE worker.

Working relationally in an individualistic system

> *"It's not rocket science, guys. We all know this. If someone in a family is not doing well or in a support group or network and all we do is give attention to that one person…But everybody who has been holding them up is now crippled, absolutely devastated, has no supports, has been treated like crap in many cases and we expect somehow that this is all going to be okay."* **PARTICIPANT 3**

A key theme that was present in both the survey and S&R workshops was a clash between the models that inform clinical practice and the work that family/carer LE workers are trying to do. This creates a difficult tension that family/carer LE workers need to negotiate.

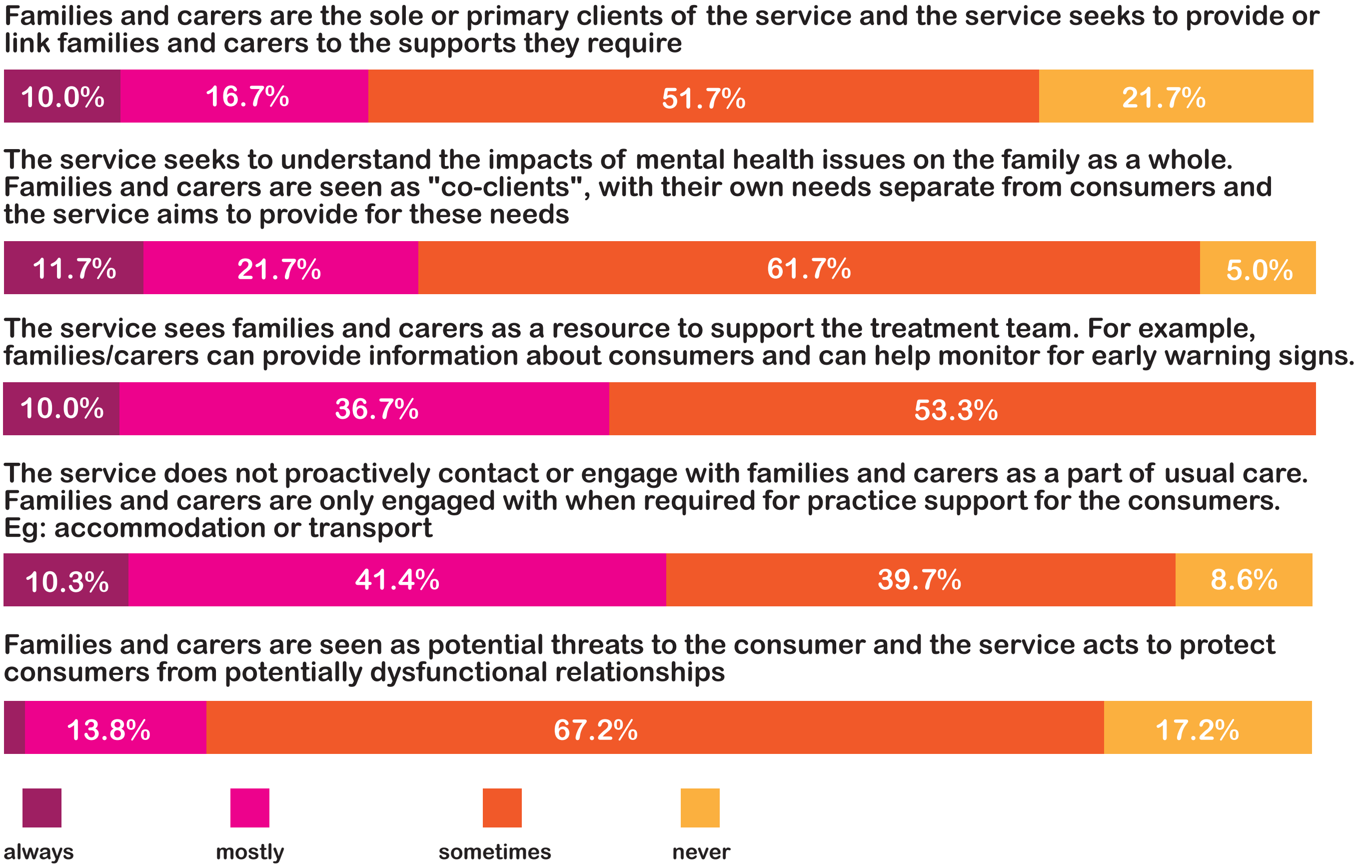
The positioning of families/carers

Family/carer LE workers are employed to support the interests and needs of families, carers and supporters, yet they are working in a system that is highly individualistic and does not have the discourse, policies, funding or procedures to adequately work with families and carers. As indicated in Figure 5, the survey asked participants how frequently their organisation mirrored a range of descriptions of how mental health services can engage with families. Participants were more likely to suggest that their services engaged with families as resources to support the treatment team, or only as a means of providing practical support to consumers. Services were less likely to position families as their sole or primary clients, or as co-clients alongside consumers.

Complexity, diversity. Broken connections. In pieces.

Image sources from: https://unsplash.com/photos/3y1zF4hlPCg

Figure 5 – Service Positioning of Families



This positioning of working with families and carers as something that is peripheral or outside of core business was noted as a key barrier to family/carer LE workers doing their work effectively. This was exacerbated by negative perceptions of families and carers held by other mental health professionals.

> *"It is hard to work in a role where notes written by clinicians often appear to question the role of families and whether they are in fact part of the problem for the consumer."*
> SURVEY RESPONDENT

> *"The audacity of her cleaning the daughter's home because it made the consumer a little bit more distressed and it was more work for them… I said, "can you not understand that mum could be so distressed herself and that's the only thing that she thinks that she can do right at this moment to help her daughter?". And they're like "oh!" It's like a constant battle of trying to change the way people see carers as not just more work, too much attitude, or not important enough… They're good for a bit of collateral information and then I don't want to know anything."* PARTICIPANT 2

Participants felt that their work was seen as an added extra and not as a core focus of the service. In addition to this, participants described their experience as workers in ways that mirrored this positioning of families as peripheral.

> *"Am I safe to share in all these spaces? Sometimes you're not, and sometimes I've found in my experience I've not been safe and I've actually been, oh my God! You know, someone's hit back at me in a meeting with a bunch of clinicians about 'why should we listen to you, you're just a carer?'"* **PARTICIPANT 10**

> *We're told a million times a day in many ways that not only are we not as important in our workforce but the people we are advocating for and supporting aren't as important, and it's painful.* **PARTICIPANT 3**

Take the blinkers off and see everything. The good, bad and the challenging. The journey is worth witnessing.

One of the images brought to the share and reflect session that elicited quite a bit of discussion was that of the blinkered horse. This photo is of a purebred horse that had been badly treated and was destined for the slaughterhouse before being rescued. The image was chosen as it represented having a second chance; that there was still hope.

The blinkers over the horses' eyes also evoked the idea of being blinded. Participants reflected that sometimes they have no idea where they are going, but are hoping that there's 'someone there to lead me and vice versa' (Participant 3). There seemed to be a camaraderie in that statement, but also a note that 'we're put into these roles and we don't know our role, we don't have real clarity, structure, support or direction' (Participant 1).

It was also observed that many carers are alone, but that 'when your senses are that heightened' when you're blindfolded or don't have clear support or direction, 'you're alone and you're really allowing yourself to think these things... one of the purest emotions of scared...deathly scared' (Participant 2).

Not fitting in

Participants described this sense of “not fitting in” as partly a result of the nature of their role. Representing the interests of families and carers often meant being “disruptive” or being like a “spanner in the works” that goes against the status quo within mental health services.

> *“Part of our role, I believe, is to be a bit of a spanner in the works at times.*
> *Not that we intend for it to be disruptive but a little bit of disruption can be good.”*
> PARTICIPANT 5

This feeling of “not fitting in” was also a product of the role itself not “fitting in” within mental health services. As detailed earlier, participants described a clash of the models of practice between the family orientated practice of family/carer LE work and the individualised focus of mental health service delivery. The result of this clash was often described as a feeling of not having a place, being outside of the way things run, or being othered.

> *“A spanner in the works is like the scalpel that’s been left inside the body or the thing that’s kind of stuffing everything up. Someone’s left something. The tool that sort of gets left behind and no one can quite work it out, what’s causing this trouble. Or this has to be moved.”* PARTICIPANT 6

> *“Clinicians who are actually involved and part of their work, so they do the clinical morning meetings and things. So there’s a real sort of like, yeah, you’re one of us but you’re not kind of but we kind of like you. We would like to have you but we’ll get there.”*
> PARTICIPANT 2

Power and hierarchy

The professional hierarchy that exists within mental health exacerbates the positioning of families and carers as peripheral and family/carer LE workers as an add-on rather than a core part of mental health service. Participants reported feeling as if they were at the “bottom of the pile” within the medical hierarchy.

> *PARTICIPANT 7:* *“You didn’t have to put up with that though.”*
> *PARTICIPANT 6:* *“No, absolutely not. Look, I’ve been bullied in the workplace before.”*
> *FACILITATOR 1:* *“...the type of work you do – is that related to being peer support worker?”*
> *PARTICIPANT 6:* *“I don’t think so. I just think it’s the status of the peer support worker. The level of respect or disrespect that you get, because you do feel like you’re on the bottom of the pile.”*

Participants reported it was difficult for them to influence decision making within their organisation, make the changes that they felt were inherent to their role, and hold other professional groups accountable to families and carers.

> *"I was told today that the head of our service, who is in charge of all the psychiatrists, I said, 'why can't he just go and talk to the other psychiatrists, especially one in particular, and just say, no, I'm sorry, this isn't our model of care. This isn't the way we're doing things anymore. We are absolutely, positively going to make sure that we're doing relational recovery, that a whole system is going to be around that', and I was told he doesn't have the power to do that and I'm like, 'what? Come on, man.' So that's frustrating because people you're hoping for can't do it."* **PARTICIPANT 3**

The tensions between worldviews held by family/carer LE workers and the dominant worldview that is embedded within mental health services presents itself as a real challenge to the successful implementation of family/carer LE work within mental health services. This is exacerbated by the hierarchies that exist within mental health services that favour the status quo.

The participants in the Recommendations Focus Group came up with several suggestions in response to these descriptions of working in an individualistic system. These included:

- Organisational culture needs to change to enable organisations to better respond to the needs of families and carers.
- More guidance is needed for clinicians on what is expected in terms of working with families; this needs to go beyond the Office of the Chief Psychiatrist Guidelines (State of Victoria- Office of the Chief Psychiatrist, 2018).
- Family/Carer LE workers should design interview questions for incoming clinical workers and sit on interview panels to ensure that new staff are orientated towards working with families and carers.
- Family/Carer LE workers should play a role in assessing or auditing services. Funding should be allocated based on these assessments.

Undervalued and poorly understood

This positioning of family/carer LE workers is related to a perceived lack of understanding of the nature and scope of family/carer LE work. This manifested as other professionals not respecting or valuing family/carer LE worker's knowledge and skills.

> *"You're not important enough to actually want to know exactly why you do it or what you do or how you do it."* **PARTICIPANT 2**

Image sources from: https://unsplash.com/photos/GYumuBnTqKc

"Deer in the Headlights – A deer stops in the middle of the road and stares at the oncoming car but doesn't move – represents non-lived experience leaders, their stunned faces as they try to understand the philosophy of the Carer Lived Experience Workforce."

This image generated a range of ideas for discussion. It was initially chosen as representing the reaction of non-lived experience leadership to lived experience philosophy. The deer freezing in the headlights relates to "why we do what we do and how only we know what it is that we're doing, and that's difficult for them to grasp." (Participant 1). This suggests more needs to be done to educate the broader workforce about the nature of family/carer LE work. The hope is that the need to support the supporter becomes more universally acknowledged and understood as the impact of not doing so is too great.

Another perspective explored was that the deer is the family/carer LE workforce "and we have been stopped in our tracks and we can't cross the road, we can't back up, we can't go anywhere. We're kind of trapped…in this time warp." (Participant 3). There is a tension between wanting the reform to speed up – for the workforce numbers to be increased to reduce isolation, yet wanting it to slow down so things can be co-designed properly. It was also expressed that it feels like there is a great divide between the promise of future reform and a perceived lack of interest in moving towards this change by services.

This cute little deer also sparked conversation about how feelings of anger are often evoked and how expressing this anger may be necessary to achieve equality and justice in various workplace conditions, "the deer got fangs" (Participant 3). It was thought that perhaps the family/carer LE workforce is viewed by services like the cute deer "Oh, you're so nice. You're so good. It's so amazing what you do but… you're not important enough to actually want to know exactly why you do it or what you do or how you do it." (Participant 2). This treatment, together with disparaging attitudes openly expressed towards families and carers, a lack of effort focused on improving relationships between families/carers and their consumers, and the constant fight in trying to change these attitudes continues to foster this sense of anger.

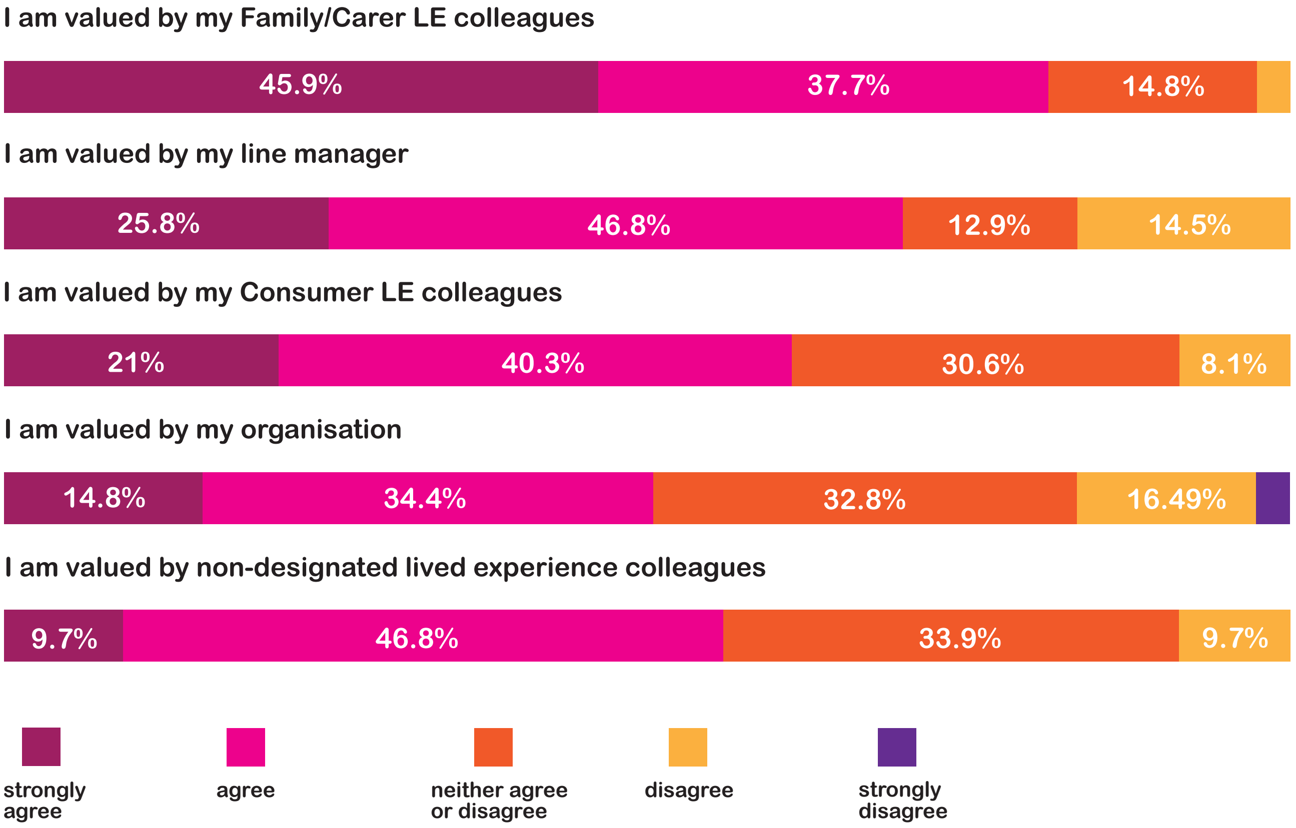
> *“You had to make a way and you had to prove that you were going to make a difference, and that took years. It really did.”* PARTICIPANT 4

Themes relating to feeling undervalued and poorly understood were common in both the survey and the S&R workshops.

Undervalued

Participants in the survey were asked to what degree different colleagues and their organisation valued them. As indicated in Figure 6, while most participants strongly agreed or agreed that they were valued by their family/carer LE colleagues (83.6%), their line managers (72.6%), and their consumer lived experience colleagues (61.3%), there was less of a sense that they were valued by their non-designated colleagues (56.5%) and their organisation more broadly (49.2%).

Figure 6 – Feeling valued



This was supported in the qualitative answers in the survey and S&R workshop, where participants detailed the frustration that their organisations did not appropriately value their work. This was often evident in organisations incorporating family/carer perspectives into service delivery in a way that was tokenistic, making it difficult for family/carer LE workers to effect change.

> *"We have all this knowledge. We're going to all these amazing reform things and we're aware of the way things are headed. We are so super aware, but I go back to my service and it's like you said. It's like going back into the dark ages. They don't want that. They don't care. They're not interested."* **PARTICIPANT 3**

Importantly, feeling unvalued was the most common reason participants cited when asked why they had considered leaving their family/carer LE role.

When asked about what advice participants would give to organisations seeking to employ family/carer LE workers, participants highlighted the need for organisations to value the unique expertise and contribution that family/carer LE workers bring.

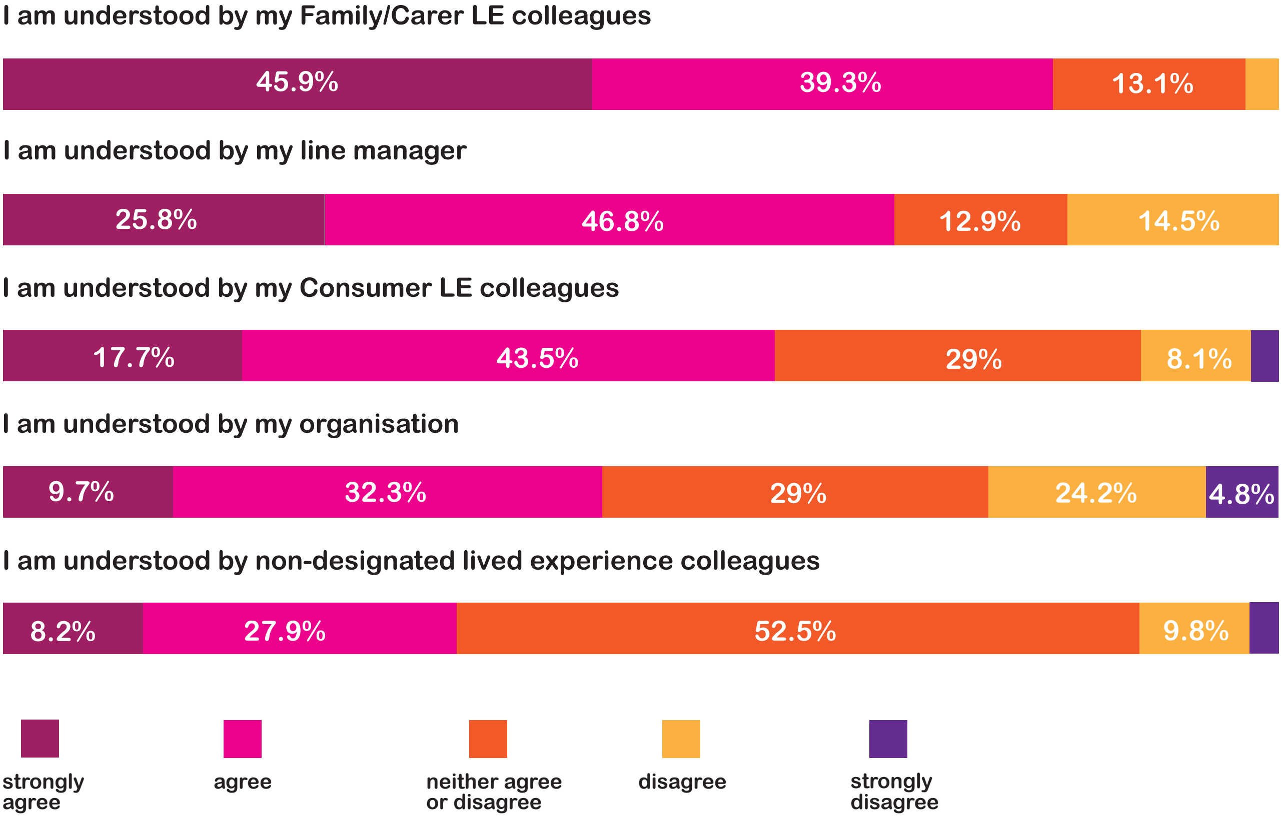
> *"The organisation needs to understand support and value not only the family carer workers but the carer LE discipline and working with carers and families in general."* **SURVEY PARTICIPANT**

> *"Make sure the team the family peer worker is part of understands the benefits of having a lived experience worker [as] part of their team."* **SURVEY PARTICIPANT**

Poorly understood

As indicated in Figure 7, participants in the survey were asked to what degree different colleagues and their organisation understood them. While most participants strongly agreed or agreed that they were understood by their family/carer LE colleagues (85.2%), their line managers (72.6%), and their consumer worker colleagues (61.2%), there was less of a sense that they were understood by their organisation more broadly (42%) and their non-designated colleagues (36.1%).

Figure 7 – Feeling understood



The participants in the survey and S&R workshops spoke of their colleagues often not having a good understanding of what they do and of a general lack of clear role definition for family/carer LE work. This often resulted in family/carer LE workers being asked to perform duties that were not in their role. This was reflected in the survey with 54.4% of participants agreeing or strongly agree with the statement “I am often asked to perform roles outside my job description”.

Participants often felt they themselves were unclear about the organisational expectations of their role, which led to their colleagues not having a clear understanding of what to expect from them and how to best work with them.

In the absence of a clearly understood role and scope of practice, participants felt obliged to educate others about their role and purpose within the organisation.

> *“It was the same thing really, just we’re put into these roles and we don’t know our role, we don’t have real clarity. We could be walking out in the ocean, we’re that blind that we don’t know our direction. There’s no structure or support or direction.”* **PARTICIPANT 1**

> *“Love it, but it’s frustrating that a lot of my role is dedicated to promoting and educating the clinicians and nurses.”* **SURVEY PARTICIPANT**

Family/carer work as a unique and emerging discipline

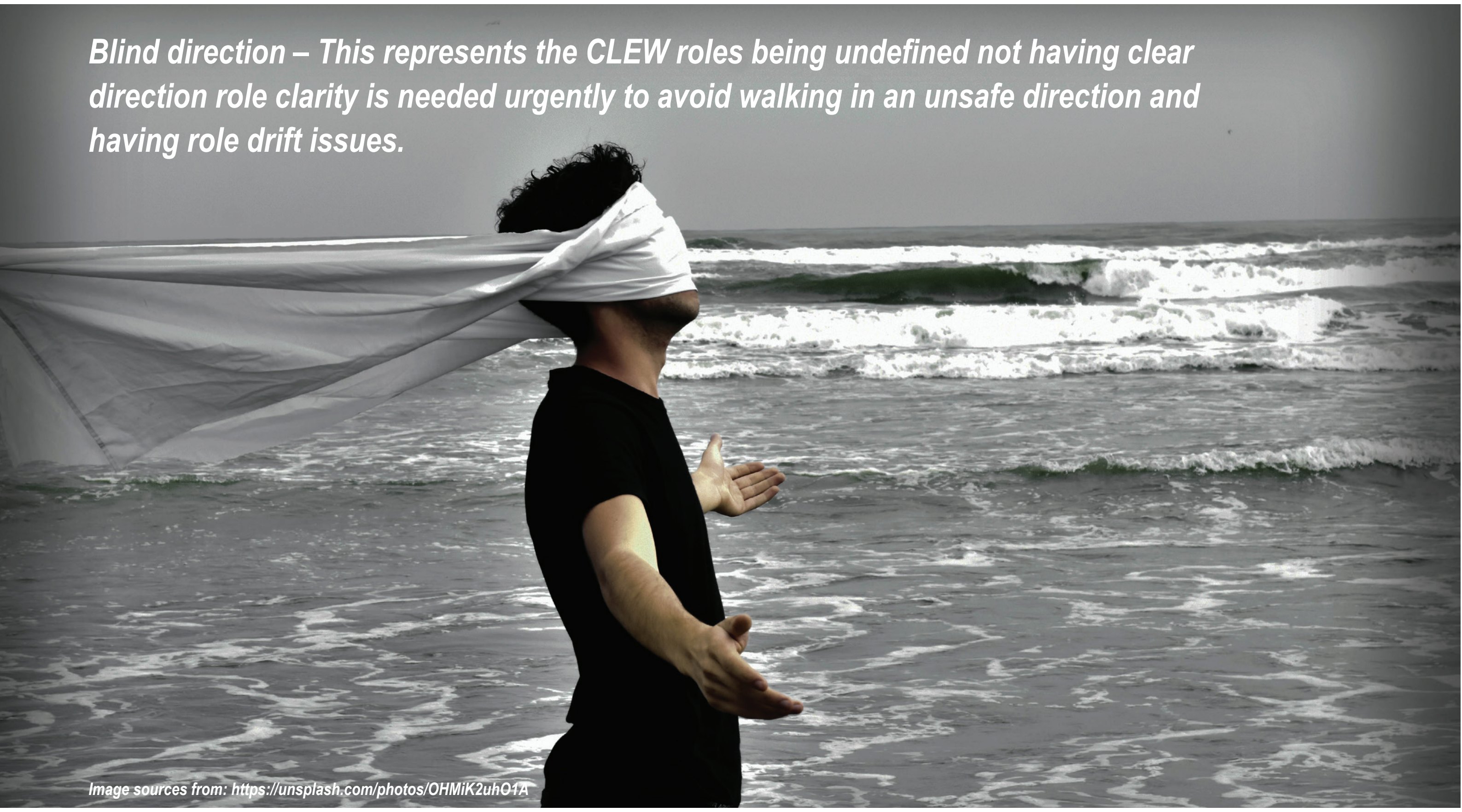
Consumer and family/carer LE roles were established in Victorian mental health services in the 1990s in response to the First National Mental Health Strategy requirement that consumers and carers be involved explicitly in service planning and delivery. The first consumer LE workers were employed in Victorian mental health services in 1996 and the first family/carer LE workers were employed in Victorian mental health services in 1999 (Our Future Project Partnership, 2021). This means that family/carer LE work is a relatively new discipline in the mental health sector. Participants described a struggle in having their work recognised as part of a unique discipline, particularly one that was separate to consumer lived experience work. For example, Participant 10 noted the importance of “being acknowledged as a discipline in ourselves rather than that add-on, we need to tick a box and have a lived experience”.

Participants described how the newness of the discipline made them feel like they had to prove their worth, something that other mental health professionals did not have to do.

> *“I guess because I was one of the first carer consultants, so there wasn’t any ground rules or guidelines. We just got in there and did what we thought we could and the whole time you’re probably battling the system itself, having to – and I call it earn your stripes. You had to make a way and you had to prove that you were going to make a difference, and that took years.”* **PARTICIPANT 4**

Finally, participants highlighted the importance of resisting being enculturated into the clinical way of working.

> *“It’s important that I don’t become a part of that culture where we walk past that mat or over it or allow someone else to trip over it. I think it stems back to that culture of if you become so enculturated into that clinical space, that you can lose that sense of that fresh perspective and being able to see what’s in front of you.”* **PARTICIPANT 5**



Blind direction – This represents the CLEW roles being undefined not having clear direction role clarity is needed urgently to avoid walking in an unsafe direction and having role drift issues.

Image sources from: https://unsplash.com/photos/OHMiK2uhO1A

The participants in the Recommendations Focus Group contributed the following suggestions in response to these descriptions:

- Develop mandatory training for non-designated lived experience staff – this should include an orientation to family/carer LE roles and how to be conscious of power sharing with lived experience workers.
- Develop a discipline framework that defines the scope of practice for family/carer LE work – this must be separate from consumer LE worker frameworks.
- Develop clear role descriptions that can be tailored to particular programs.
- Include family/carer lived experience perspectives in clinical meetings as standard practice.
- Employ skilled family/carer LE managers to help protect role drift.
- Co-design a lived experience commitment statement where LE workers and clinicians agree on a number of priorities and commitments.

Being undervalued and misunderstood was a key feature of the family/carer LE worker experience described by participants. The newness of the discipline, combined with a lack of value given to supporting families and carers resulted in family/carer LE workers feeling as if a large part of their role was to educate others about the value of their role. This ultimately detracted from their capacity to best support families and carers. The investment in developing discipline frameworks and clear role descriptions along with training for non-designated LE workers and organisational change initiatives will help address this experiencing of being undervalued and misunderstood.

Isolation and marginalisation

Isolation was a theme present in both the survey responses and S&R workshops. Almost a third (29.9%) of participants reported that they agreed or strongly agreed with the statement "I feel isolated in the workplace because of being a family/carer worker".

A proportion of survey participants had limited contact with other family/carer LE workers, with 45.2% reporting having formal contact with family/carer LE workers monthly or less, and 32.3 % having informal contact with other family/carer LE workers monthly or less.

Participants often spoke about the struggles of being a solo family/carer LE workers in a program. They reported feelings of loneliness and a difficulty representing family/carer interests without support. They also spoke about not having anyone to adequately debrief with about the realities of supporting families and carers and using their lived experience.

> *"There's always been supportive people but it hasn't stopped the feeling of aloneness and doing things alone and you think you make some headway because for the majority of my 20 years I've worked solo and you think you make headway and then something happens and you think nobody is even listening."* **PARTICIPANT 4**

> *"It takes courage every day to speak up, to reflect and comment when I'm the sole voice for families, carers and supporters in the room. To be told it looks effortless doesn't help."*
> **SURVEY PARTICIPANT**

> *"So it really feels like you're the one lone army in your armour ready to defend and have that voice for the carer."* **PARTICIPANT 2**

Participants also described experiences of marginalisation. While the above experiences of "not fitting in" were examples of implicit marginalisation resulting from the clash of practice models and the reality of being part of an emerging discipline, there were also examples of explicit forms of marginalisation expressed by participants.

Participants described instances where they felt an explicit social exclusion in the workplace because of not sharing the same position and experience as their work colleagues.

> *"On a personal level, I have felt like I have been discriminated against, being left out of general conversation and unable to build potential friendships, due to not sharing the same training or job position. Feeling like I don't belong because my role is misunderstood."*
> **SURVEY PARTICIPANT**

> *"I don't want to throw out discrimination but it's the first time since I've been a kid and had the wog, you've got stinky food, you're talking weird, that I've really felt that in a long time. Yes, I am white and privileged in many ways but I suddenly feel like I'm in this place where I'm the minority again and it's icky and you feel like you're squashed and you're not as important."*
> **PARTICIPANT 2**

There was also mention of specific incidents of intimidation, bullying, stigma and discrimination, as illustrated in the following quotes:

> *"He was just angry and he turned it back on me like the narcissistic type of thing of gaslighting me and telling me why it was all my fault, which included the comment about being disruptive."* **PARTICIPANT 6**

> *"Even though I was from a carer perspective lived experience very strongly, I also have severe depression and have had to manage that for a very long time and I was told very clearly by many people in the service never, ever to share that because no one would look at me the same again... We work in mental health and we're not allowed to disclose that we have mental distress."* **PARTICIPANT 3**

The participants in the Recommendation Focus Group suggested the following actions as ways to combat marginalisation and isolation in the workforce:

- Ensure a minimum number of family/carer LE workers are employed with teams.
- Have designated family/carer LE managers to lead teams of family/carer LE workers.
- Implement exemplar structures for LE worker teams across different organisations.

Being connected and included within workplaces is key to feeling safe and supported at work. These findings indicate that more needs to be done to ensure that family/carer LE workers are not isolated within non-lived experience teams and feeling marginalised within their workplaces.

The work is beautiful and fragile

Participants spoke in depth about the complex nature of bringing one's lived experience into their work role. It was depicted as inherently "beautiful" and "precious" work but also "fragile". Part of this fragility was related to the issues detailed earlier around a clash of practice models and the role not being embedded, but part of it was also connected to vulnerability that is at the heart of using lived experience. Being in designated roles within mental health services means that colleagues automatically have knowledge of some difficult life experiences that participants had been through. This was described as an essential part of the work, but one that often made participants feel vulnerable and sometimes even unsafe.

> *"As I work with carers, I see that the journey can be tough and painful. Our form and theirs is morphing and changing with the challenges. However, there can be beauty as we grow, adapt, learn, as we're learning to walk alongside the uncertainty or the discomfort. There's beauty in finding hope, even if it's fleeting. Even if it's just one bloom and then we have to let it fall and wait for another. So just those short moments, the fragility of that, doesn't necessarily last in the same form but it will come again."* **PARTICIPANT 7**

> *"So I think that in that sense, it creates a certain sense of fragility in that how am I held and how do I hold myself, how am I held and supported in that space to do the work, and about my choice? Do I have choice about how I share parts of my life?"*
> **PARTICIPANT 10**

Participants spoke about parallels between their caring role and their work. The experiences of not fitting in and being isolated and marginalised detailed earlier often mirrored their experiences of being unseen or devalued as a family member or carer of someone seeking or receiving mental health treatment. Additionally, there was a sense of relentless crisis within the mental health sector, and the world more broadly, that mirrored the stress that is associated with supporting someone who is grappling with mental health issues.

> *"The image for me is like the parallels that exist in our work, the beauty, the fragility, but also fraught often with pain and part of that journey is that discomfort and it's very much like a lot of the journey that carers take as well. So it's sort of like, it's okay that they coexist somehow."* **PARTICIPANT 5**

> *"Also, the waves just keep coming. It's just one hit after another after another. So there's no peace in the horizon. There's just something else coming. You're always poised for that. So it's that poise of the waiting as a person just standing but there's something happening all around you."* **PARTICIPANT 2**

Participants also spoke about the challenges involved with doing the work while caring for someone who is currently in a crisis.

> *"It's scary. It's weighty. You're having to give compassion and listen to other stories when in the background you know that there's turmoil happening and there's this sense of need to do even more and that's why time – watches, those clocks, it's like there's never enough time and this sense of so many hats and trying to be the hat in the moment of trying to put that hat off and be a carer peer worker and then once you get home you've got to be the carer for not only your mum but make sure that she's doing the right things to help my brother and then it's mum and it's wife."* **PARTICIPANT 2**

Participants described the work as emotionally taxing, and this highlighted the emotional labour that is inherent in working from a family/carer lived experience perspective. While specific emotions raised by participants are expanded on in *Negative impact of the work*, participants described feeling a complex range of emotions as a result of or arising from specific features of the work. Such emotions resulted from emotionally connecting with a family or carer, especially when their experiences were similar to the participant's own lived experience. This was particularly challenging when clinicians didn't adequately see or respond to a family's distress and suffering. Advocating for family and carers and trying to improve the mental health system were also described as eliciting challenging emotions. Finally, participants described the difficult emotions associated with realising that others in their workplace didn't understand or value the work that they did.

> *"Why can't the clinical team see it? Why is it so hard to recognise distress when it's a family member or a carer or supporter? But your job is to manage distress. To me that's a wilful blinker, the horse or the blindfold. It really is probably the thing that tears my heart out the most in my role, that I spend day after day, week after week trying to advocate on behalf of people that it should be so easy for people to understand and be compassionate towards."* **PARTICIPANT 3**

Participants also spoke about feeling a need to perform certain emotional states in their roles – there was a pressure to remain positive and calm in the face of workplace pressures. This is illustrated in the following interaction between a facilitator and three participants.

> *PARTICIPANT 2: That's me. A smile hides thousands of things. There's a thousand things going on but you always need to put on a face of – I've got this.*
> *FACILITATOR 1: There's a performance element there?*
> *PARTICIPANT 2: Yes.*
> *PARTICIPANT 1: You're on a stage. It's like a stage performance.*
> *PARTICIPANT 3: That really resonates with me.*

Wonderful teamwork , an image to behold, appreciated yet open to change in climate at any moment.

This image sparked conversation around the beauty and fragility of carer lived experience work. But what exactly is meant by describing the work as fragile?

Image sourced from: https://www.istockphoto.com/photo/card-house-against-blue-skies-gm93112680-5871903

The participants spoke about how the work is not yet embedded within services. They are still an added extra, dependent on allies and the strength of individual family/carer LE workers to push for change, "creating some turbulence around how things are done." (Participant 5). Confidence to push into this discomfort grows over time. While it is difficult to step up as the voice of carers in the current power structure, "breaking through this barrier can be victorious." (Participant 8).

Central to this conversation was the idea that the family/carer LE role is unique as you can bring your whole self to work and share your own experiences in a genuine way. There is a sense of beauty and honour in being able to share parts of your own difficult story with other carers, creating a "precious space between two people." (Participant 8). However, the requirement to share parts of your personal life in a professional space is inherently dangerous and creates a sense of fragility, even anger at times at the lopsidedness of it – "you automatically know my life but I don't know yours." (Participant 8). This experience, together with fighting to be heard, is a recipe for heavy emotional labour.

The participants highlighted an urgency for family/carer LE workers to be better supported to do the work safely. While the CLEW Network helps with this aim, some other elements were identified to strengthen the foundations of this house of cards making it more sustainable and less fragile, while still maintaining its beauty. This included an emphasis on building support structures, educating the broader workforce about the roles, and improving safety to make it easier to invite other carers to work in the space and expand the workforce. It would also help to be acknowledged as a discipline, separate from Consumer LE; be genuinely welcomed to contribute; be well supported by more senior family/carer LE staff; have opportunity to work with colleagues in the same role and be shown compassion with reasonable adjustments provided to accommodate their caring role as needed.

Participants in the Recommendations Focus Group suggested a variety of actions in order to assist the workforce negotiate this concept of the beautiful and fragile. These included the following:

- Increase opportunities for family/carer LE workers to connect with each other to share and debrief their experiences.
- Ensure that there is time allocated for co-reflection and support within work hours.
- Develop training for family/carer LE workers around sharing own lived experience with colleagues and in peer work, and what their rights are within this space.
- Ensure that family/carer LE workers receive discipline specific supervision.
- Offer to create safety plans for family/carer LE workers when they are in crisis.
- Ensure that family/carer workers are taught the principles of peer work before they begin their work with families carers.

Working in lived experience roles is inevitably a vulnerable position. Utilising some of the most difficult times of your life as a key feature of your role results in lived experience work being uniquely different to other roles within the mental health sector. This vulnerability contributes to the power and effectiveness of lived experience work, but it is something that needs to be well supported by others who have had the experience of navigating the use of lived experience in the mental health sector.

This is me. A carer. I'm the one to step up and be the advocate. I'm the one juggling many hats and emotions. I'm the one on display – wearing my experiences for all to see.

On a platform alone. I'm the one battling for validation, battling to be heard.

Being strong with a smile. Promoting our strengths, our truths. Exposing our vulnerabilities so others may benefit and know they are not alone.

One of the noticeable observations of the S&R workshops was how a family/carer LE worker's experiences in their workplace were closely aligned with their own personal lived experience of being a family member or carer. This image represents this parallel experience.

'Trying to be the amazing carer' but at the same time 'juggling one thousand things at once' (Participant 2) was reflective of not only the experience of being a family/carer LE worker, but also the experience of caring – an experience so closely linked that it was reflected on by some participants interchangeably. The family/ carer LE workers who engaged in this session reflected that 'we're stepping up on the pedestal...always juggling' (Participant 1), but that the smile 'hides one thousand things' (Participant 2), because 'there's one thousand things going on but you … need to put on a 'I've got this' face' (Participant 1).

‘Stepping up’, being the ‘strong one’ (Participant 1) saying ‘I’m the carer’ (Participant 1), was said to be so like the experience of ‘stepping up into this role’ which was ‘always a lot’, where there’s ‘identification’, ‘exposure’ and ‘nakedness’. That close linking of the carer experience and the experience in the roles drew out a vulnerability of the experience in these family/carer LE worker roles.

The group reflected that the experience was like a ‘staged performance’ (Participant 1), and that it was ‘a lonely place to be’ (Participant 3). The juggling image portrayed this loneliness, by being on display on a pedestal so small that only one person can fit on it. Sometimes feeling so alone and juggling everything, contrasted with other times of ‘relying on your wing mates’ (Participant 3) and was a contradiction that seemed to sit easily with participants.

Workplace conditions

Workplace conditions were commonly cited as a significant challenge for family/carer LE workers, often related to descriptions of being undervalued, marginalised and a fragile workforce. This varied from challenges around pay and part-time roles to issues around workload and unpaid work.

Different conditions

A total of 80.5% of participants felt that their workplace conditions were different from their non-designated colleagues. As indicated in Table 3, the most common condition was being paid less than non-designated colleagues (56.5%) followed by having minimal career advancement opportunities (53.2%) and only having part-time or casual positions available (43.5%).

Table 3 – Workplace conditions

CONDITION	%
I get paid less than my non-designated colleagues	56.5%
I have minimal opportunities for career advancement	53.2%
I only have part-time or casual positions available to me	43.5%
I have access to flexible working arrangements due to my caring role	22.6%
I don’t have study leave or have to negotiate to take study leave	17.7%
I am not allowed within certain areas of the workplace	9.7%
I am employed on a fixed -term contract	6.5%
Other	3.2%

Pay

Participants in the survey reported a range of annual incomes from $32,188 to $113,168, with the median annual income being $67,900. Most participants felt they were not paid adequately for their work, with 67.3% reporting that they disagreed or strongly disagreed with the statement “I am paid adequately for my work as a family/carer worker”. Participants highlighted that the highly stressful nature of the work warranted a higher rate of pay.

> *“My concerns are around pay. Many family/carer workers deal with highly distressed families with complex needs. Our roles have expanded and evolved over the past years and no longer resemble the PD’s that we were employed on.”* SURVEY PARTICIPANT

They also commented that they didn’t feel the pay matched well with their education levels and past work experience.

> *“I feel underpaid, especially as my service benefits from the knowledge and communication style I utilise, which partially comes from having a post-grad tertiary qualification, but they currently don’t have to pay for that experience.”* SURVEY PARTICIPANT

Some participants commented that the low rate of pay resulted in them having to take up other roles to make ends meet.

Workforce positions

The survey indicated a very high level of part-time roles among family/carer LE positions, with 88.7% of survey participants being employed part time and 11.3% being employed full time. In addition to this, almost half of survey participants (43.5%) reported working in more than one role concurrently, the majority of which worked in the same service in different roles. A total of 29% of participants indicated that they would like to increase their hours.

Participants spoke about the low number of family/carer LE workers in their service compared with the number of consumer LE workers.

> *“There are two Carer Consultants and two Carer Peer Workers in our entire adult and aged service and we have 20 consumers (lived experience workers).”* PARTICIPANT 3

> *“The CLEW have substantially less workers employed and less FTE than the consumer workforce. Who is gathering info on demand/need/projected growth needed to sustain this workforce?”* SURVEY PARTICIPANT

When asked what the impact of the difference in FTE between consumer and family/carer LE workers was, S&R workshop participants spoke of impacts on their perceived value and importance, power and workload.

> *"There's a power imbalance in time. So all my Consumer Peer Workers have more FTE than I do. So that alone gives a lot of power to them and they have been allocated a team, so they only have to look after three or four (consumers) maybe and I have a potential of 28 that change over all the time and it's like "oh well, whatever you can do in your time" … My hours have increased but they're still not at the same level as my (consumer) counterparts and it just shows to me that there's only one of me, there's so many of them, they have more hours, I have less hours, then you are not as important, and that is the problem."* PARTICIPANT 2

Workload

S&R workshop and survey participants spoke frequently about the challenging nature of managing the workload. Participants characterised the nature of their workload using the following terms:

"really emotionally taxing" "just one hit after another" "turmoil" "weighty"
"I'm juggling 1,000 things at once" "onslaught" "the waves keep coming"
"I just think that it's always juggling" "so many projects" "constant barrage"
"mind is jumbled- I don't know what to tackle first" "never enough time"
"you have to bend over backwards and twist yourself inside out and give up your own time what do I drop?"

There were a number of reasons participants identified as contributing to this challenging workload. This included the difficulty of managing workload in part-time roles, working flexibly to accommodate the needs of carers (who they might only be able to meet outside of office hours), the complexity of the work, not being embedded as part of the team, and the pace of current reforms in the mental health sector.

> *"I think it's much like that, isn't it, after the Royal Commission, the constant, constant barrage of things to do and to get involved in."* PARTICIPANT 1

Unpaid work

Almost three quarters of survey participants reported doing unpaid or out of hours work relating to their family/carer LE role. The majority (44.7%) did between 2 and 5 hours of unpaid work a week, and 17% did between 5 and 10 hours. As indicated in Table 4 the most common task participants did in unpaid hours was checking and responding to emails (51.6%), followed by reading and reviewing documents (48.4%), learning more about systems, policies etc (41.9%), training that was essential to the role (40.3%), and reflective practice (38.7%).

Table 4 – Types of unpaid work

TYPE OF UNPAID WORK	%
Checking and responding to emails	51.6%
Reading or reviewing documents	48.4%
Learning more about systems, policies etc	41.9%
Training that you see is essential to your role	40.3%
Reflective practice (external supervision, journalling)	38.7%
Attending meetings or consultations that fall outside my paid hours	32.3%
To keep on top of my workload or complete my required tasks	30.6%
Attending meetings or consultations that my workplace does not pay me to attend	22.6%

The survey asked participants what their motivations were for doing unpaid work. The most common response was that it was necessary to keep on top of workload, and the next most cited reason related to the passion for the work. Participants also commented that they felt they needed to work outside of working hours to meet a family or carer's needs, or to attend training or meetings that fell outside their paid hours.

Resources

While over half of survey participants (53.1%) agreed or strongly agreed with the statement: "I have the necessary resources to do my job", over a quarter (26.3%) reported that they disagreed or strongly disagreed with this statement. Most commonly cited was a lack of designated space for them to do the work, particularly one that allowed for the privacy needed when engaging with families and carers, and purposeful use of their own lived experience to support a family/carer or educate a colleague about carers' experiences and needs.

> ***"Office space is not adequate for private and confidential conversations with carers and to be able to share my own lived experience challenges without co-workers hearing about my personal life."*** **SURVEY PARTICIPANT**

Adequate technology was also cited as a needed resource, particularly when required to work from home.

> ***"Tech has been and continues to be a problem area. Covid has exacerbated these challenges to work from home with insufficient tech. A laptop and a phone that works and integrates with everything else and that has the latest upgrades would be fab."***
> **SURVEY PARTICIPANT**

Image sourced from: https://unsplash.com/photos/FlHdnPO6dlw

Ticking time bombs –

this represents the time pressures of the Royal Commission implementation of the recommendations and the time frames placed on the carer lived experience workforce that is already stretched being very small to the time to be involved in co-designing.

This also represents the carer workforce wanting to hurry things up and employ more colleagues in their teams to break the isolation as lone workers.

Training and development

The findings indicate significant issues relating to access to training for family/carer LE workers. Almost half (49.2%) strongly disagreed or disagreed that they had enough training to do their jobs to the best of their ability. This was reflected in the qualitative answers in the survey.

> *"I have not received any training, or offered supervision – externally or internally. I have essentially worked out this role on my own."* SURVEY PARTICIPANT

> *"I feel that I have not been provided adequate training to effectively complete the responsibilities of my role."* SURVEY PARTICIPANT

Participants highlighted a lack of appropriate training developed specifically for family/carer LE work. While some participants said that their workplaces were very supportive of them accessing internal and external training, others said that their access to training was restricted.

There was also a perception that there were limited opportunities for career development. A total of 68.4% of survey participants disagreed or strongly disagreed with the statement "As a family/carer lived experience worker there is a clear pathway for professional development".

When asked about what advice participants would give to organisations hiring family/carer LE workers, ideas around learning development were frequently cited. Survey participants wanted family/carer LE workers to have opportunities for training that was supported and paid for by their workplace.

Participants wanted better orientation and on the job training as well as training that was specific and relevant to support them in their family/carer LE role.

> ***"Create appropriate and comprehensive training and orientation programs for all family/carer positions – similar to an entry level clinician program, and the program must recognise that new family/carer workers have not had 3+ years training at uni, with multiple placements, and reflect what would be equitable training."***
> **SURVEY PARTICIPANT**

The participants in the Recommendations Focus Group suggested a range of actions to address issues of workplace conditions. These included:

- Ensure that the future Enterprise Bargaining Agreements (EBA) increase pay rates for family/carer LE workers.
- Create more full-time roles for family/carer LE workers.
- Ensure that family/carer LE workers have access to confidential workspaces to enable them to have private conversations with families/carers.
- Develop more family/carer led training that sets up a solid foundation for the roles.
- Develop clearer role descriptions that are shared across services and set up standard expectations and allowances.
- Ensure that flexibility is part of employment for family/carer LE workers as the work can be complex and many family/carer LE workers have current caring roles.

These challenging workplace conditions can be seen to further exacerbate the challenges that family/carer LE workers have in terms being isolated and not well understood or valued. This reality of what it is like to be a family/carer LE worker puts a significant strain on individual workers and threatens the sustainability of the workforce as a whole.

4.5 Negative impact of the work

The challenges detailed above can be seen to have several impacts on family/carer LE workers. There is also potentially an impact on the broader mental health system due to a lack of sustainability in the family/carer workforce.

Impact on Family/Carer LE workers

Participants described a range of negative emotions that they experience as a result of the challenges they experience in their role. Participants used such phrases as:

“it’s extremely challenging” **“diffiicult for us as workers”**

“it’s hard, it’s been a tough few months” **“It’s very diffiicult”**

“as I work with carers, I see that the journey can be tough and painful”

“it can be a pretty thorny road at times, definitely”

“there’s negativity, there’s layers, there’s a bit of spiky”

“but it’s very hard. It’s very hard not to become resentful.”

Specifically, participants described feelings of loneliness as a result of working in isolation or with limited connection with other family/carer LE workers.

> *“When you think about it, we are constantly back and forth in that world... sometimes you feel so alone and you’re juggling everything.”* PARTICIPANT 3

> *“Looking at the forest, I just thought sometimes my mind is so jumbled I don’t know what to tackle first. It just bought me back to that feeling of, not impossible, but feeling that you’re all alone, tackling something which you can’t see a positive end result yet.”* PARTICIPANT 4

Anger was another emotion that was present in the survey and S&R workshops. This related to anger at how families and carers were seen by and treated in the mental health system, as well as anger about how the family/carer LE workforce is not being better supported.

> *“That sort of anger could come up. When I’ve heard in clinical spaces, where they talk about carers… I get that mama bear sort feeling like how dare you speak like that! I said, ‘why aren’t you discussing this in front of me? I can be here supporting a family’.”*
> PARTICIPANT 2

> *“It’s just so precious and it is so fragile and it gave me this sense of beauty that I hadn’t seen before because I guess I’d been a bit angry about how fragile it is.”* PARTICIPANT 8

Feelings of disillusionment were also present in the survey and S&R workshops. Participants spoke about feeling hopeful when entering the workforce but increasingly feeling disillusioned by the role as time went on. This related to the challenges detailed above and the feeling as if efforts to make change are not progressing.

> *“I started off really positive about the role but this has significantly changed in the last three months, and feeling unmotivated and somewhat disappointed.”*
> **SURVEY PARTICIPANT**

> *“I wish I could quit my job.”*
> **SURVEY PARTICIPANT**

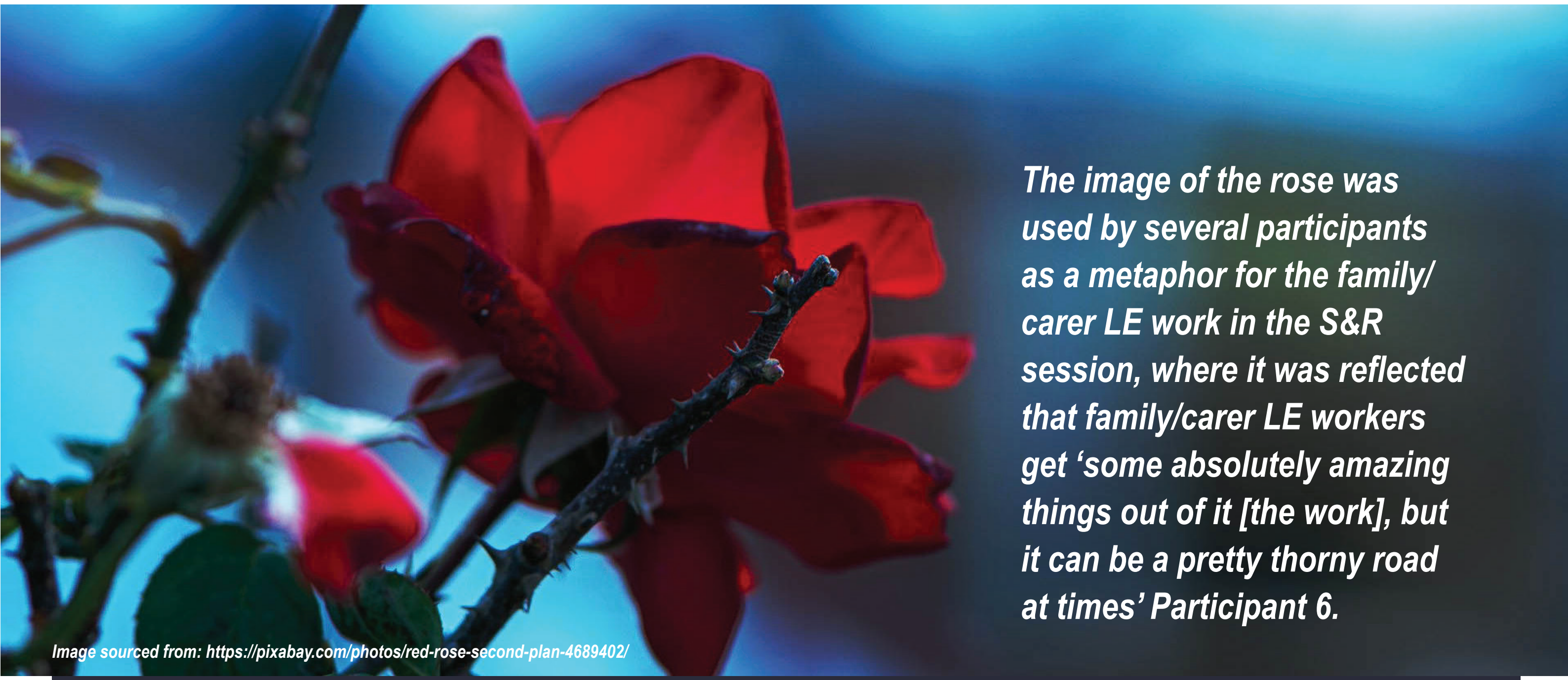


Image sourced from: https://pixabay.com/photos/red-rose-second-plan-4689402/

The image of the rose was used by several participants as a metaphor for the family/carer LE work in the S&R session, where it was reflected that family/carer LE workers get ‘some absolutely amazing things out of it [the work], but it can be a pretty thorny road at times’ Participant 6.

Reflections included ‘in order to enjoy the beauty of the rose, you need to tackle the thorns which can prick or tear the skin, can cause pain, damage and bleeding’ and that ‘the rose forms small but the bloom changes form, expanding to reveal exquisite beauty and fragrance’. Not only that, but that in the ‘work with carers, I see that the journey can be tough and painful’, and that ‘our form is morphing and changing with the challenges, however, there can be beauty as we grow, adapt, learn; as we’re learning to walk alongside the uncertainty or the discomfort’ (Participant 7).

A further observation was that the bloom may be fleeting, like finding hope, and that we may need to let the bloom fall and wait for another. As with the family/carer lived experience work, there is fragility in the rose bloom, but it will bloom again.

System impact

> *"I felt heavier looking at this. I think that's what it was; it's all of this stuff coming, and you don't really know from one minute or one day to the next what you're doing and how you will manage and not quit."* PARTICIPANT 1

The negative impacts of the work can be seen to influence the sustainability of the workforce more broadly. The survey results indicated that a large proportion of participants had considered leaving the workforce, if they hadn't left already. A total of 10.5 % of participants have left a family/carer LE role, and half (52.6%) reported that they have considered leaving their role.

As indicated in Table 5, the most common response regarding reasons for leaving involved being unvalued in the workplace (37.1%) and feeling unsupported in the workplace (37.1%), followed by not being paid enough (32.3%).

Table 5 – Reasons for leaving

REASONS FOR LEAVING	%
I felt unvalued in the workplace	37.1%
I felt unsupported in the workplace	37.1%
I felt that I was not paid enough	32.3%
I found another more suitable family/carer role	12.9%
I needed a job with more hours	12.9%
Other	16.1%
I felt unsafe in the workplace	9.7%
I found another role	9.7%

In addition to speaking about how they were considering leaving the workforce, participants also spoke about not wanting to encourage others into the workforce as they couldn't guarantee that it was a safe, supportive work environment.

> *"If I don't feel like I'm safe in my job, how can we attract more people into this workforce, if there's no safety? You know what I mean? Word gets around pretty quick. I'd hate to see, even the people that are leaving the workforce, I'd hate to see that they've left because they weren't supported."* PARTICIPANT 10

> *“I won’t be looking out for expansion… I‘m looking at it for others and I do develop this protectiveness. I’ve witnessed it and talked about it with others. There’s a real sense of well if I’m a bit tough and I’m also very fragile, I know that about myself. I know my sensitivities and so on. But if there’s this sense that I’m being excluded and I’m dealing with myself about that, I’m working out what to do about it, I’m not going to be inviting others to come and do a version of that too. It has lots of ripple effects but I struggle to articulate it. But it’s very real.”* **PARTICIPANT 8**

The turnover of family/carer LE staff can be seen to perpetuate the negative impacts on the remaining workers.

> *“Other lived experience workforce leaving and not being replaced. Promises of restructuring lived experience workforce never being followed through.”*
> **SURVEY PARTICIPANT**

The participants in the Recommendations Focus Group suggested several actions in response to these findings. These included:

- Establish clearer pathways for career progression for family/carer LE workers. This could include encouragement to apply for higher level positions, training to support career progression and having annual reviews of career progression targeting specifically at family/carer LE workers.
- Enable family/carer LE workers to access a range of training tailored to the role.
- Ensure that family/carer LE workers have discipline specific supervision.
- Work towards pay parity with other non-designated staff to recognise the difficulty and emotional toll of the role.
- Ensure that family/carer LE workers are included in the process and decision making around any decision related to LE workers.
- Ensure that organisations are well equipped to employ family/carer LE workers-this should involve a focus on organisational readiness and a focus on supports needed for family/carer LE workers.
- Encourage others to join the workforce by offering training to carers interested in gaining employment.
- Introduce mandatory training for clinical staff focusing on skilling them up to work effectively with LE workers.

The negative impacts of the work on family/carer LE workers poses a threat to the sustainability of the workforce as a whole. More needs to be done to better support workers in their roles to enable them to continue working in the sector and to create an environment that attracts new family/carer workers into the workforce.

4.6 What is currently sustaining the workforce?

While survey and S&R workshop participants detailed the challenges involved in working as a family/carer LE worker, there were notable aspects of the work that were positive and sustained them to remain in the work.

> *"Now, however, there's been a bit of a shift in terms of, I feel less like it's batten down the hatches and more it's actually, there has been a shift. Creating that space for my role and actually having others value the input, to me it's a beautiful thing. I can't describe it any other way. It's just really a shift that I never expected would come."* **PARTICIPANT 5**

Connection to other family/carer LE workers

Participants highlighted the importance of having regular contact with other family/carer LE workers. A little over half (51.6%) of survey participants had formal contact with other family/carer LE workers on a weekly basis or more frequently, and 61.3% reported having informal contact weekly. Participants stressed the importance of working in teams with other family/carer LE workers for several reasons. Working in close contact with other family/carer LE workers created opportunities for debriefing and discussion about the nature of the work that was difficult to obtain from colleagues working in non-designated roles. Having contact with other family/carer LE workers also allowed for sharing of resources and information. Finally, specifically having other family/carer LE workers in a team meant that there was power in numbers which better enabled the family/carer perspective to be heard.

> *"You're not alone. You're not alone is what was really strong in that picture for me. I put in the picture of the brooms and it was a really silly one. Actually, it was an opposite metaphor for me because it represented – normally you only see one broom and it represented having colleagues and not being alone as well. Something that you don't normally see is a lot of brooms all together. You would hope that we see a lot of workers side by side. We hope that that grows."* **PARTICIPANT 1**

Some participants in the survey and S&R workshops spoke of the value of mentoring by a more experienced family/carer LE worker.

> *"I have a really good mentor, I guess, my colleague who is my senior. One of the best things that she said to me when I came into the role was just give yourself a year just to – not acclimatise, but get used to the role – and she would throw lots of opportunities my way of training that would be really good to support my role. So I feel really fortunate to have someone who was knowledgeable about training that would be really good to support me."* **PARTICIPANT 10**

While some of the contact came from within the organisation, participants highlighted the vital role that the Carer Lived Experience Workforce Network (CLEW) and Tandem provided in scaffolding the connection to other family/carer LE workers in other organisations.

The CLEW is a long-standing, volunteer-run network for people working in family/carer LE workforce roles in Victorian mental health services. Originally established in 2001 with a just a handful of Carer Consultants, at the time of writing this report the CLEW has 170 members. The activities of CLEW include members' meetings, group co-reflective supervision every two months, an annual 2-day professional development forum, an online community of practice, and opportunities to have a voice on issues that affect families, carers and the family/carer LE workforce, as required. CLEW is supported through an auspice arrangement with Tandem, the peak body for family and friends in mental health, with secretariat support provided by CMHL (Our Future Project Partnership, 2021).

The CLEW was the most commonly cited source of informal support by survey participants. Family/carer LE workers in the S&R workshops were similarly very positive about the CLEW. It is not always possible to tease out which services and supports participants were referring to as participants used 'the CLEW' to refer to varied activities of the CLEW, as well as other CLEW members and the workforce in general.

The following quotes illustrate the benefits participants gained from the CLEW in reducing isolation, providing mutual support and learning, sustaining morale, helping with role clarity, and connecting new members with potential mentors:

> *"Because especially for those who are working alone it feels like actually the feelings that I'm feeling, the things that I'm experiencing you're not alone and that all your values, all the emotions are reflected back to you. So there's a strength and there's a warmth in that that is just like the biggest hug ever and it gives you a bit of, yeah, we can do this."* **PARTICIPANT 2**

> *"I'm just so moved to be in a workforce, honestly, that is – nobody has a workforce like this. The most compassionate, the most kind, the most supportive. If we could all only just be together how great would it be? I've said this a million times. I don't know what I would have done without CLEW. I don't think I could have continued in this role, and that goes for CMHL and that goes for everybody who is working so tirelessly to help us continue. Tandem, oh my gosh."*
> **PARTICIPANT 3**

> *"Mentoring from a colleague in a similar position was invaluable as a peer-to-peer support. The CLEW has offered so much support and guidance that is also invaluable ongoingly. Whilst service staff other than lived experience are supportive, nothing is as good as this peer support."* **SURVEY PARTICIPANT**

Image sourced from: https://unsplash.com/photos/rZId_qIS8-c

Safety in numbers – representing a supported CLEW workforce in teams and structures with supervision and discipline leads.

The discussion about this image centred on hope for the future growth of the family/carer LE workforce, and the development of a more supportive environment. The image sprang from the irony, that like family/carer LE workers, it is not common to see many brooms all together. But what if there was a room full of brooms? Sharing the load in family/carer LE work, as in caring, would significantly lighten the load. The parallels between the two were not lost on participants. Limited recognition of the carer lived experience discipline and relatively few family/carer LE positions (including leadership roles) create fertile ground for power imbalance and inequity in the workplace. Participants identified that there are many more consumer LE workers than family/carer LE workers in services, who were also perceived to be better supported. This unfairness is a source of ongoing resentment, "I've got the same role as you…why do you have five people alongside you and I don't?" (Participant 2). Discussion was also held about the difficulty of working in a team as a lone family/carer peer worker. "It's like…we like the idea of you and we will grow as an army, like the brooms, but we just don't know where you fit…it really feels like you're the one lone army in your armour ready to defend and have that voice for the carer." (Participant 2). This highlights that more needs to be done to provide clarity about the purpose of the roles and truly embed the roles into the system.

There was general consensus that in trying to meet some of the carers needs with limited FTE, it is challenging to keep up with service developments, know what work to prioritise and get to know staff members. This often results in working extra hours without pay and changing work days to attend meetings or meet with carers. A lack of service wide supports exacerbates poor understanding of the value of the work and is reflected in inequitable position descriptions. The message received is "not only are we not as important in our workforce, but the people we are advocating for and supporting aren't as important and it's painful." (Participant 3). The injustice of it all, makes it difficult to imagine wanting to attract more family/carer LE workers into the workforce, even though they are very much needed.

Walk a mile in my shoes –

Carer workforce understand what it's like and are best placed to connect their community and break the isolation while also building trusting relationships that lead to participation in service development and better still a pathway to the carer workforce.

Safety and Inclusion

There were some positive markers of safety and inclusion found in the survey. A total of 58.6% of survey participants agreed or strongly agreed with the statement "I feel part of the team in my workplace". In addition to this 60.4% agreed or strongly agreed with the statement "I am free to express my opinions in the workplace".

Participants detailed practices in the workplace that made them feel safe and included. Having respectful relationships with colleagues and management was highlighted as an important aspect of a safe and inclusive workplace.

> ***"I've been reflecting about this a bit lately. So number one is respect and intention to be respectful, even. Sometimes people muck up. But you can feel the respect was intended. That's 80 per cent there. The rest is valuable but I think for me that's the bottom line. There's certainly things about the way people speak and the types of speaking, even the interruption or the non-interruption. But there's ways of interrupting that are respectful and ways that are just – I'm looking after me and I'm saying what I want to say and I have no attention on you."***
> **PARTICIPANT 8**

In addition to this, participants spoke about having structures in place within organisational processes that ensured that family/carer perspectives were represented. For example, one participant detailed a proforma used in clinical reviews that sought each discipline perspective including family/carer LE workers. This was seen as a move away from the tokenism that is often experienced by family/carer LE workers.

> *“But I think for me, recognising that in clinical reviews that I can speak up and in fact that there actually is – just in the past 12 months or so proformas have been developed where in clinical review every discipline gets some input and I make full use of that. I never used to attend many clinical reviews but I find that I attend a lot more now because there is that space that has been created and I’m not competing to speak over others because I tend to hang back. But if I’ve got that space that’s been created then I know that I do have some input.”* **PARTICIPANT 5**

Participants also spoke about feeling included when their work is valued within their organisations. This is something that is seen as changing over time and being amplified by the Royal Commission reforms. Being valued looked like family/carer support being a routine part of practice, having colleagues seek out family/carer LE worker input, and having management support and amplify family/carer LE perspectives.

> *“The clinical workforce has developed a far greater understanding and value of the lived experience role, as well as the experience of families/carers. Family peer support is now a routine part of care in my workplace. My work is very valued by both my clinical colleagues and families. The feedback from the Victorian Royal Commission around the LE workforce has been validating and heartening. The lived experience/family voice is now being listened to within the mental health system, rather than a “token” appearance after all the important decisions have been taken. I find my work far more enjoyable now than I have over the previous years.”* **SURVEY PARTICIPANT**

> *“One of the things that came to my mind was being supported, even if the team’s small. I’m pretty new to all of this but still having a peer and having someone senior who has my back I think makes a big difference.”* **PARTICIPANT 7**

Participants in the survey and S&R workshops shared the impact team leaders and managers could have on feeling safe, included and valued.

> *“When I first commenced in the role, the line manager only had minimal time to devote to connecting, giving the impression that he was not interested in the role and what it could bring to the team. A new line manager was able to give more time to catching up which made me feel more valued.“* **SURVEY PARTICIPANT**

PARTICIPANT 9: I do have a good network of supervisors and managers who obviously have their own lived experience as well...

FACILITATOR: Do you think that's an important point or not, that your supervisor and manager have lived experience?

PARTICIPANT 9: Oh absolutely, because they recognise and understand where you're coming from. When they are supporting you...it's just come and reflect and come and share and just be you. You don't have to put a hat on each time you talk to someone else. You just keep the same hat and be yourself.

Participants highlighted the importance of having a line manager with lived experience, however, only 17.2% of survey participants were managed by someone with lived experience, with the majority being managed by nursing staff (32.8%) or social workers (22.4%).

Joy, hope and promise for a better tomorrow for our CLEW and families/ carers/ supporters.

Image sourced from : https://unsplash.com/photos/2PODhmrvLik

Flexible, family and carer friendly workplace arrangements

Participants in the survey and S&R workshops highlighted the importance of flexibility in their workplaces as well as access to carer leave. Participants noted that these arrangements were necessary because of their living experience of caring and were needed to enable them to remain in their roles. Many participants highlighted that their workplaces offered the required degree of flexibility in their role, however some participants reported that their employers were reluctant to support flexible hours.

> *"I feel like it's almost on that same level, that if I'm a carer and I'm living, this is my living experience. So there's times when I have to be pulled out of my work or things are happening and I need to have a reasonable adjustment for that. I don't feel like there's always the supports for that and safety in that."*
> **PARTICIPANT 10**

> *"If they took that (flexible hours) away from me I don't think I would still be working, and that can happen at any time."* **PARTICIPANT 4**

Family/carer lived experience specific supervision

Supervision was noted as an essential aspect of a supportive work environment. Specifically, participants highlighted the importance of having supervision from a lived experience perspective as supervisors with lived experience were better able to support the complexity of the work done by family/carer LE workers.

> *"Provision of group reflective supervision within the family/carer lived experience workforce in our organisation has been a great addition and has enhanced my work."*
> **SURVEY PARTICIPANT**

Unfortunately, not all participants reported receiving regular supervision. Almost a third of participants (29.8%) did not receive supervision.

Participants commented that the workforce was so small that there was limited availability of family/carer LE supervisors and pointed to the need for more supervision training to be provided to the family/carer LE workforce.

> *"It is important to have the opportunity to discuss and debrief with someone who is knowledgeable of the lived experience role and able to provide constructive feedback/strategies and support."* **SURVEY PARTICIPANT**

In addition, survey participants spoke of the value of having external supervision, or at least having a choice of supervisor.

> *"The pool of lived experience family/carer supervisors within our organisation is very small. I feel that the organisation should pay for our external reflective practice supervision if that is what we prefer."* **SURVEY PARTICIPANT**

Passion for the work

Many participants in the survey and S&R workshops spoke of the passion and commitment they had for the work that sustained them through the challenges.

> *"I love my work. I find the system frustrating at times, with its focus on individuals and the medical model, but families are (mostly) incredibly grateful for the support, which provides me with incredible satisfaction in this lived experience work."*
> **SURVEY PARTICIPANT**

> *"Probably a fortnight doesn't go by where I'm signing up to something to expand my knowledge in some area. It could just be reaching out and calling another colleague and asking for input into something which I guess creates growth. I feel that if I've learned something new it's helping me grow."*
> **PARTICIPANT 9**

In addition to this, while the reform process was at times a point of stress, many participants identified that the reform is leading to family/carer LE work being increasingly valued and promoted, which gave them hope for the future.

> *"…one of the main things I wanted to do that brought me into this space was I wanted to hopefully tweak one little part of the system that makes it better for someone else so they don't have to go through what I saw, and what my loved one experienced."*
> **PARTICIPANT 10**

Passion led us here – why we stay in our CLEW jobs even when we don't feel valued and supported

CLEW has been a wonderful place that brings us together and supports us to keep going.

Image sourced from: https://unsplash.com/photos/TamMbr4okv4

Much of the content detailed above was reflected in the Recommendations Focus Group. Some key actions that the group came up with that were not previously identified in the survey or S&R workshops included:

- Support to encourage allyship amongst staff. This could include allyship workshops, identifying ally champions, and ensuring that allies had good connection to leadership.
- Stronger leadership from the Department of Health to develop the family/carer LE workforce. This should include more resourcing for networking and training opportunities and strategic planning for workforce growth.
- Establish an adequately funded lead body charged with supporting the development of the family/carer LE workforce.

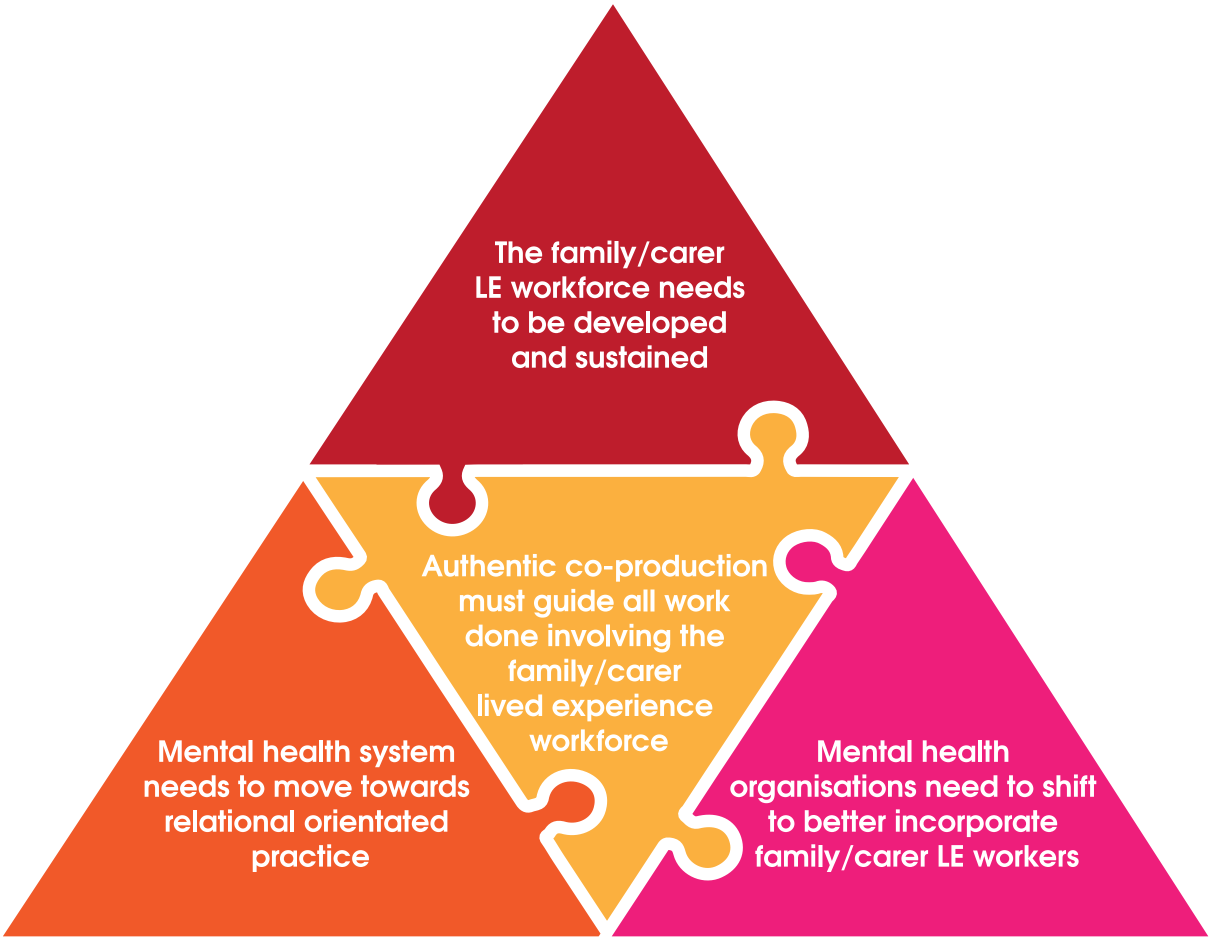
The aspects of the work that can be seen to sustain family/carer LE workers in the workforce provides a good indication of what needs to be further developed in order to ensure the sustainability of the family/carer LE workforce. An investment in family/carer LE led networks and supports and efforts to build safe and inclusive organisational cultures will serve to help buffer against the challenging features of the work detailed earlier in the report.

5. Recommendations

The RTAG have developed four overarching recommendations that need to be implemented to support the development and sustainability of the family/carer LE workforce. These recommendations were drawn from the findings of the survey and S&R workshops as well as the Recommendations Focus Group. Each recommendation contains several tangible actions that are designed to meet the aims of the recommendation. As indicated in Figure 8 these recommendations and actions must be implemented in conjunction with each other. Without this holistic focus, all run the risk of not meeting their inherent potential.

The RTAG are conscious that the Victorian mental health service system is undergoing reform and there is currently significant investment into the lived experience workforces. Consequently, there are parallels between the recommendations detailed below and some of the work being undertaken within the reform process. These recommendations are meant to both support the current initiatives being implemented by suggesting approaches for best practice and to provide unique approaches that could be added to the reform process to best support the development and sustainability of the family/carer LE workforce.

Figure 8 – Recommendations



1. Mental health organisations need to change to better incorporate family/carer lived experience workers

This study found that while some organisations have been increasing their numbers of family/carer LE workers, more work is needed to shift organisational culture, policies, and practices in order to better incorporate and embed family/carer LE workers. Participants reported feeling as if their work was not well understood or valued, that their inclusion into organisational processes was tokenistic, and that they were at the bottom of the organisational hierarchy within mental health services.

This work of organisational change should take a top-down, bottom-up approach with work targeting leadership, governance, and policy being matched with work targeting front-line staff. The work of Olin et al., (2016) provides a strong example of an approach to shifting organisational culture to better embed family-orientated practice within an US mental health service.

1.1 Revise the leadership and governance of mental health services to better incorporate family/carer lived experience work.

This recommendation involves enabling family/carer LE workers to have positions within organisational governance structures such as boards, executive teams, and leadership groups. This must involve at least two or more family/carer LE representatives within these structures to ensure that they are not isolated and to help mitigate tokenism. Decision making groups should move towards ensuring that there is a level of equity between consumer and family/carer LE workers and other mental health professionals in non-designated roles, ensuring that the power balance leans towards those most affected by the decisions being made. There is a need to invest in the development of family/carer LE leadership positions that would feed into these governance positions along with training opportunities to support family/carer LE leaders to build leadership capabilities to enable them to best represent family/carer LE perspectives within these spaces.

1.2 Develop a suite of training aimed at educating staff in non-designated positions on the role and purpose of family/carer LE work. This training, to be developed by family/carer LE workers, should become part of mandatory training for all staff.

This suite of training would target front-line workers who are working alongside family/carer LE workers, and who are instrumental in creating workplace culture and processes that can support the embedding of family/carer LE workers, and relational orientated work within services. It is important that this training specifically focuses on the roles of family/carer LE workers rather than lived experience workers more broadly as there are unique features of the family/carer LE role that need to be well understood by front-line staff. This training suite needs to be designed to both support staff who are already wanting to better assist with family/carer LE work but also to build interest and engagement in staff who are resistant or uninterested in supporting family/carer LE work.

This training would involve:

- Developing an understanding of family/carer LE work and the value this can add to the organisation and day-to-day work
- Developing an understanding of family/carer LE perspectives and discipline framework (to be developed –see recommendation 2.2)
- Building skills and knowledge to equip staff to work effectively with family/carer LE workers
- Learning about how to be an ally to family/carer LE workers and other lived experience workers
- How to use the principles of co-production when working alongside lived experience workers

1.3 Update program level processes and procedures to ensure that family/carer LE perspectives are included in standard practice

Organisations should review standard processes and procedures such as handovers, clinical reviews, and case notes and create opportunities within these processes for family/carer LE perspectives to be included. This may involve adding family/carer LE input into clinical review or handover proformas. In regard to clinical files, there is a need to create a process for documenting contact with families, carers and supporters so that privacy and confidentiality for family members and supporters can be maintained when they are seeking support for themselves or needing to discuss complex aspects of their particular situation and relationship.

1.4 Organisations need to improve the workplace conditions of family/carer LE workers and ensure that they are equitable with non-designated workers.

Participants highlighted that the following workplace conditions needed to be improved:

- Pay parity – Pay rates for family/carer LE workers must recognise the complexity and skill inherent in the work, the considerable knowledge, skills and experience that carers have gained in their caring role as well as during their employment, and be equitable to the pay rates of other frontline workers in adjacent roles that are performing comparable tasks (e.g.: social workers, occupational therapists). This should be embedded in relevant Awards and Enterprise Bargaining Agreements (EBAs).
- Increase opportunities for full-time positions – Organisations must create more full-time opportunities for family/carer LE workers at all levels. Options for job sharing or working part-time could still be supported, allowing for more choice for family/carer LE workers to choose working hours that best suit their life circumstances.
- Protected time for debriefing, co-reflection, training, and networking – Organisations need to recognise that for family/carer LE workers to work effectively they need to engage in these activities within paid hours as an essential part of their role.
- Family/carer lived experience supervision – Ensure all family/carer LE workers have access to at least 2 hours per month paid family/carer lived experience supervision. This is distinct from line supervision which has a focus

on workloads, allocation of tasks, and performance development. In contrast discipline supervision involves reflective practice, support around the impact of the work, and supporting the skills needed to effectively work from a lived experience perspective (Carer Perspective Supervision Co-design Group, 2021). Access to 2 hours per month of discipline specific supervision with a supervisor of their choice is protected for family/carer LE workers employed under the current Victorian Public Mental Health Services Enterprise Agreement 2020-2024. Family/carer LE workers employed under other Awards or EBAs should also have this access.

- Confidential workspaces – Ensure that family/carer LE workers have easy access to workspaces that allow for confidential conversations with families and supporters. This is integral to maintaining privacy of families and supporters but also enables family/carer LE workers to share aspects of their lived experience in a safe way.
- There is a need for the unions involved with negotiating workplace conditions (for example during EBA negotiations and Awards negotiations) or in industrial disputes, to better understand the family/carer LE workforce so that EBAs can be used as a mechanism to achieve the above conditions.

1.5 Organisations must create meaningful and supported career pathways for family/carer LE workers.

Throughout the findings it is evident that one of the issues for family/carer LE workers is a lack of a clear career pathway. Organisations should work to create opportunities for career advancement pathways for family/carer LE workers. This could be achieved by establishing family/carer LE positions throughout organisational hierarchy and supporting family/carer LE workers wishing to move into different roles in the family/carer LE workforce (for example, education or research) to gain relevant skills. Careful succession planning is needed to build the skills of entry level workers to enable them to take up positions in higher roles. This workplace learning also needs to be supported by training, which is explored in recommendation 2.3.

2. The family/carer lived experience workforce needs to be developed and sustained.

Family/carer LE work is a relatively new discipline and one that has expanded rapidly in the past decade. The findings of this study indicate a need to develop the workforce by building clearer frameworks for practice, creating meaningful career pathways for family/carer LE workers, investing in the knowledge and skill development of the family/carer LE workforce, and strategically investing in family/carer LE leadership.

2.1 Invest in the creation of more family/carer LE worker positions so that no family/carer LE worker is employed without regular contact with others in similar roles. In addition to this there needs to be investment in establishing family/carer LE leadership positions throughout the sector.

Participants in this study highlighted the vulnerability that was inherent with being employed as a sole family/carer LE worker in a program. Without support from other family/carer LE workers the work can be isolating and unsafe, and it can be difficult to advocate for necessary change for families and carers as the sole voice representing these interests. Participants also spoke about the inequity they felt with consumer lived experience workers who tended to have higher FTE available in programs.

Providing a sufficient number and variety of family/carer LE worker positions at appropriate FTE to respond to the needs of families and carers was highlighted as a priority in the Our Future: Developing Introductory Training for the Lived and Living Experience Workforces Report (2021) and in the Strategy for the Family Carer Mental Health Workforce in Victoria (2019).

For these reasons we recommend that there is greater investment in more family/carer LE worker roles in mental health services so that there are no sole family/carer LE worker employed within any program. The family/carer LE worker employed within teams should ideally be rostered on at the same time at least one day per week. There will be a need for government funding to support organisations to increase the number of FTE family/carer LE positions.

2.2 Develop a clear discipline framework for family/carer lived experience profession.

The findings in this study highlight the issues involved with family/carer LE work being a new and unique discipline. Present in the findings were issues such as a lack of role clarity, poor understanding of family/carer LE perspectives, and struggles to be seen as a legitimate profession. Within the focus group, participants highlighted the importance of having a clear framework of practice for family/carer LE work that could clearly define the scope of practice for these roles. This is supported by the *Our Futures* report:

> ***The History of lived experience work in Victoria (CMHL, 2019) explains how lived experience positions grew organically in mental health services in Victoria. This organic growth, coupled with a lack of clear organisational understanding of the purpose and activities of the various roles and the recent, rapid expansion of family/carer peer support roles, has contributed to role confusion. Family/Carer Consultant roles in particular vary widely across services. Therefore, there is a need to differentiate the work undertaken by family/carer lived experience workers in their roles.***
> ***(Our Future Project Partnership, 2021, p. 29)***

The *Our Futures* Report identified a lack of information about the family/carer LE discipline in the published and grey literature as a barrier to development of a clear family/carer LE discipline framework. Therefore, it is crucial that this framework be developed with family/carer LE leadership and be grounded in the experiences of the family/carer LE workforce. Further to this, the discipline framework should be used to map out a standard approach to position descriptions that are consistent across the sector, otherwise any work to standardise family/carer LE worker position descriptions risks being inconsistent with the discipline framework and therefore obsolete.

2.3 Develop a clear training and support pathway to assist family/carer LE workers across their career trajectories.

Participants felt strongly that there were minimal opportunities for career advancement and that there was a need for better training opportunities for family/carer LE workers across the career trajectory. This was also a finding of the *Our Future* Project Partnership:

> ***At present, options for career progression are very limited due to limited numbers of family/carer leadership roles. Therefore family/carer workers who wish to increase their earning capacity and have career options in mental health have little choice but to retrain and transition into other roles in mental health such as social work, nursing or occupational therapy. However, considering the age demographics and the challenges of cost, time and juggling work, caring and community responsibilities, this option is only really accessible to those with considerable financial and practical support.***
> ***(Our Future Project Partnership, 2021, p. 33).***

There were also issues evident with the pathway into the profession and the lack of age and gender diversity of people who take up family/carer LE workers roles. We recommend the following staged approach to developing the family/carer LE career pathway.

Recruitment – More needs to be done to promote family/carer LE roles in a variety of communities. This could involve the following:

- Training and support for family/carer consultants in how to facilitate family/carer engagement in mental health services, including promotion of co-production, co-design and participation activities to attract families, carers and supporters into collaborative work.
- Consultation with community organisations supporting people from diverse backgrounds around the enablers and barriers for people from their background joining the profession.
- Development and promotion of short training courses that introduce family/carer LE work as a discipline and supports basic skill development for people who are interested in taking up family/carer LE roles. This should be funded by the Department of Health in an effort to promote the work and ultimately recruit more potential family/carer LE workers into the sector.
- Engagement with family/carer and consumer advisory groups to promote family/carer LE roles in order to recruit advisory group members. Mentoring could be provided to advisory group members who were considering taking up family/carer LE work.

Early years in role – Family/carer LE workers new to the role need to be provided with specific training around their discipline framework, how to work effectively in their role, and how their role works alongside other family/carer LE roles. This training must be augmented with regular family/carer LE perspective supervision, opportunities to be mentored by senior family/carer LE workers, opportunities for co-reflection with other family/carer LE workers, and opportunities to network with family/carer LE workers across the sector. Family/carer LE workers should also be supported to engage with networking opportunities and co-reflection with consumer lived experience workers. As family/carer LE workers progress pass their initial years in the role they should be supported to gain further experience in leadership by acting in team leader roles or other mid-level leadership positions.

Moving towards leadership – Family/carer LE workers need to be mentored and supported to be able to move into leadership roles. This would involve being supported to access training and development in a range of specialist areas including management, co-production skills, project management, supervision, and research and evaluation. Family/carer LE workers entering into leadership roles also need to be supported to develop the “soft skills” of leadership that can be implemented from a family/carer LE perspective.

2.4 Establish and strengthen programs or organisations that support the development of the family/carer LE workforce.

Participants in this study spoke strongly of the importance of connecting with other family/carer LE workers through networking mechanisms such as the CLEW network. The CLEW network was cited as the most important form of informal support that participants received. Such networking structures provided opportunities for supportive debriefing, sharing of resources, and collective action. There is a need for such structures to become more formalised and have greater resources. A formal program or organisation that was auspiced to support the development of the family/carer LE workforce would be useful in creating localised networks that were responsive to geographical needs and could work to promote and advocate for the workforce and the implementation of the above recommendations.

2.5 Ensure all family/carer LE workers participate in supervision, reflection and professional development activities as part of their paid role.

These activities are an essential part of supporting, sustaining and developing family/carer LE workers. With high numbers of family/carer LE workers indicating they are performing unpaid work to keep on top of workload, it is important that workplaces and sector funding factor in professional development time and increase FTE accordingly.

2.6 Investment is needed to create an evidence base for family/carer LE work.

As highlighted in the literature review, there has been limited research to understand the practice of family/carer LE workers. This is particularly the case regarding research into family/care LE supervision and family/carer LE work in policy, management, or research and evaluation roles. This has led to a poverty of evidence base that can be used to inform training and resources for family/carer LE workers as well as frameworks to guide the workforce. This has also resulted in the frequent conflation of family/carer LE work with consumer LE work. While the different

LE workforces have some similar experiences within the sector, there are some notable differences that necessitate nuanced approaches to supporting the development of both workforces. Consequently, there is a need for dedicated resourcing of research and evaluation of family/carer LE work to understand the similarities and differences between this work and consumer LE work, to develop and test frameworks of practice for family/carer LE workers, to develop and test approaches to training and development for the workforce, and to better understand the impacts of family/carer LE roles within the sector.

3. The mental health system needs to better incorporate relational orientated practice into standard models of care.

A key finding of this study highlighted that mental health services in Victoria typically position families, carers, and supporters as adjunct to the core focus of mental health service delivery. The core focus is on the identified consumer and there is limited consideration for the relational context that the person exists within.

This finding is consistent with the findings of the Royal Commission into Victoria's Mental Health System:

> ***Evidence suggests that Victoria's adult mental health system primarily takes an individualistic approach to treatment, care and support without consistently considering the social contexts within which most people live in the community. This individualised approach means that the valuable role families, carers and support networks can play in a consumer's recovery is often overlooked by services, as is the notion that families, carers and supporters have needs in their own right.***
> ***(State of Victoria. Royal Commission into Victoria's Mental Health System, 2021, p. 72)***

Family/carer LE workers in this study reported the difficulties involved with attempting to support and advocate for families, carers and supporters within a system that does not adequately recognise and respond to the relational context of the consumers that they are providing a service to.

To best meet the needs of families and carers, the mental health system itself needs to shift to become more relationally orientated. This requires a paradigm shift for mental health systems and workforce; away from seeing their clients as individuals with a mental illness towards seeing people experiencing distress as interconnected and interdependent with valued and valuable social roles. Again, this is supported by the findings of the Royal Commission into Mental Health Services.

> ***The Commission is satisfied of the need to provide 'a very clear message that family involvement is not an add-on, but is core business', noting that this includes families of choice and broader support networks. (State of Victoria. Royal Commission into Victoria's Mental Health System, 2021, p. 97).***

The Royal Commission into Mental Health Services in Victoria interim report detailed some of the complex and interconnected reasons that families and carers are not well supported by the mental health system, including the complexity of navigating the service system, varying interpretations of privacy and confidentiality legislation, crisis driven services, lack of resourcing, lack of time, lack of opportunities to undertake training, and staff feeling ill-equipped to support families. (State of Victoria. Royal Commission into Victoria's Mental Health System. Interim report, 2019). The Royal Commission Final Report also acknowledges that while consumers, families, carers and supporters "may have shared interests, they speak from their own perspectives and experiences, and at times they may have conflicting views" p. 74). The Commission highlights several models for supporting consumers in the context of their support networks including Open Dialogue, Single Session Family Consultation and Multiple Family Groups, all of which have been delivered in mental health services in Victoria but none have gained traction.

In order to realise the ambition of a paradigm shift towards relationally orientated practice, it must be recognised that this is complicated work and that there are various tensions that exist between consumer and family/carer groups with Victoria. For this reason, any move towards relationally orientated practice must be developed from a partnership between consumer and family/carer groups that is responsive to the perspectives of both groups.

3.1 Funders must take into consideration how services plan to engage with families and carers when funding programs.

When making decisions about the funding of programs or services funders should assess services against their plans to meaningfully engage with families, carers, and supporters. This could involve assessing organisations against the following:

- Action plans that organisations develop to shift their practice towards better engagement with families and carers
- The incorporation of a statement of purpose around engaging with families and carers
- How staff identify and connect with consumers' chosen supports
- The quantity and quality of contacts with families and carers
- The degree to which organisations partner with family/carer specific services and supports

This could also involve assessing organisations against how well they implement the recommendations listed under Recommendation 1 of this report.

3.2 *Establish a Centre for Relational Orientated Practice in mental health service delivery that utilises consumer and family/carer lived perspectives to develop and implement models of relational orientated practice.*

This Centre would be responsible for leading the sector in the research and implementation of relational orientated practice. While the Royal Commission into Victoria's Mental Health Services (2021) and the Office of the Chief Psychiatrist (2018) are clear that family and carer involvement must be part of core service delivery within Victorian mental health services, more needs to be done to shift the paradigm from one that is individual focused and views mental health problems through a predominantly biomedical lens, to one that responds to individuals within their relational context and recognises that there are many ways of conceptualising and therefore responding to mental distress.

This Centre could play a role in co-producing a relational model of practice that could be feasibly implemented within Victorian mental health services. Crucial to the development of a relational model of practice is a consideration of how such a model can intersect with and uphold consumer rights and self-determination, trauma-informed practice, and a focus on personal recovery. This model of practice would be based on research into practice approaches currently being implemented globally as well as input from a community of practice made up of families/carers, consumers, family/carer and consumer lived experience workers, and other mental health practitioners. The model of practice would also take into consideration the diversity of understandings of family within multicultural Australia such as Aboriginal kinship structures, Māori concepts of whanau, and other collectivist cultures.

The Centre would also be responsible for having oversight of the implementation of the relational model of practice across Victorian mental health services. This could involve developing practice standards for organisations, delivering training and support for organisations adopting standards, and auditing organisations against standards. Such work should be led by family/carer LE workers.

Within the current mental health reform occurring in Victoria, such a Centre could fit well within the Victorian Collaborative Centre for Mental Health and Wellbeing.

4. Authentic co-production must guide all work done involving the family/carer lived experience workforce.

It is crucial that all work done to build and sustain the family/carer workforce utilises co-production. Lived experience perspectives are often marginalised from decision making processes or they are "consulted with" after processes have already been developed. Not only is there a moral imperative to meaningfully involve the perspectives of people who have a lived experience of the issue being addressed (Charlton, 1998) but lived experience perspectives can also powerfully illuminate the issues being addressed in ways that are often unseen by people without lived experience (Brooks, 2007).

The terms "co-production" and "co-design" are increasingly used to describe a range of different approaches to consumer and family/carer engagement in the mental health sector. While the intention to co-produce is often present in these initiatives, the reality is that consumers and family/carers are still often brought into projects in a tokenistic manner, or one that does not meaningfully address power differences within project groups (Farr, 2018). We strongly suggest that any efforts to co-produce in the family/carer lived experience space utilise Roper et al's (2018) approach to co-production in mental health settings as a means of implementing authentic co-production, ensuring that those most impacted by a project or initiative are privileged. This means that in issues where family/carers or family/carer LE workforce are most impacted, co-production would involve prioritising and privileging family/carer leadership and perspectives. While this model focuses specifically on co-producing with consumers, the core principles are applicable to co-producing with families and carers. Approaches to co-production should always have a focus on building the capability of lived experience workers in a way that aims to equip them to lead projects in the future. Ultimately co-production should be transitional in that it should work to enable lived experience leadership and self-determination.

4.1 Training in co-production must be developed by lived experience workers and implemented across all programs of work that are attempting to utilise co-production.

In order for authentic co-production to become the norm within mental health services, all parties involved in co-production processes must receive effective training in co-production. A suite of co-production training packages should be developed by lived experience workers that is focused on building the skills and knowledge to implement authentic co-production. There is also a need to produce co-production resources that are responsive to the unique experiences of family/carer LE workers. This may involve adapting Roper et al's (2018) approach to co-production to ensure that it is inclusive and responsive to the family/carer experience.

4.2 Funders should assess project designs against Roper et al's (2018) approach to co-production when funding projects and programs.

As co-production is increasingly being expected from programs and organisations, care needs to be taken to ensure that co-production is implemented authentically. There is risk that the whole concept of co-production will be watered down if programs are labelled as co-produced when they don't match up to the standards of co-production outlined by Roper et al (2018). Funders could play a role in assessing project designs against this approach to co-production and only funding programs that meet a certain standard. This would serve to encourage organisations to strive for authentic approaches to co-production.

6. Conclusion

The Rising Together study has found that the experiences of family/carer LE workers are complex and multilayered. Family/carer LE workers enter the workforce with a vision of helping families and carers within the mental health system and contributing to system change, however, are faced with substantial challenges that inhibit their ability to perform their roles in an organisational context that is safe and inclusive. Family/carer LE work is a relatively new discipline and is one that is focused on understanding individuals within their relational context. From this perspective recovery is enabled when the whole system of relationships is well supported. This way of thinking sits at odds with the individualistic focus of mental health service delivery in Australia and this tension makes the work of family/carer LE workers challenging to achieve. The impacts of this were evident in this study. Participants felt misunderstood and undervalued, they felt like they didn't fit in within the workplace, and they felt that their inclusion was often tokenistic. The experiences of not fitting in were compounded by inequitable working conditions, a lack of lived experience led support, and a lack of clear career progression pathways. The current investment in the family/carer LE workforce is at risk of being jeopardised if strategies are not put in place to better support and develop the workforce. The Rising Together study has put forward four intersecting recommendations that target different levels of the mental health system. If implemented together, we believe that the family/carer LE workforce will be best positioned to realise the potential that working from a family/carer lived experience perspective can have for families, carers, supporters and the broader community.

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