

## History of lived experience work in Victoria

People with lived experience were first employed in Victorian Mental Health services in 1996. Four roles were created at Royal Melbourne Hospital following the completion of the Understanding and Involvement Project. (Epstein & Wadsworth, 1994). These roles, originally called Consumer Staff Collaboration Consultants were initiated in 1996 to lead quality improvement projects in each area mental health service. Within a short time, the funding for the positions became recurrent and the title shortened to Consumer Consultants. These roles were often isolated and evolved in unique ways that were dependant on: the management of the service, the consumers' needs within the service, and the individuals filling the roles.

In 1999 a project was undertaken at Maroondah Hospital that explored the support needs of carers. The project, Carers Offering Peers Early Support or COPES, initiated carer peer support work across both the clinical service and one of the local community services (EACH). In 2000 St Vincent's Hospital introduced the first Carer Consultant and in 2002, the Department of Health permitted services to utilise the Carer Brokerage Fund to employ Carer Consultants in each service. Not all service took up this opportunity and in 2009 the Department reviewed the Carer Brokerage Fund, redistributing it to services and implementing recurrent funding for each service to employ Carer Consultants.

In 2002, North Western Mental Health, implemented the first leadership role for consumer workers. The Consumer Advisor position sat on the executive team and while initially was only for 2 hours a month over time it grew to the current role of .6 EFT. In 2005 Southern Health introduced a Director, Consumer and Carer Relations, this full time executive management position managed the lived experience workforce, led the strategic development of consumer and family/carer participation and involvement, and managed the brokerage funds and consumer complaints. Around 2007-8 North Western Mental Health and Southern Health initiated small projects exploring peer support in inpatient settings, but these projects did not gain recurrent funding and were ceased. In the following years clinical services undertook more explorations of peer support but with no identified funding stream these failed to gain ground. Austin Health also introduced a senior position of Consumer and Carer Coordinator in 2010, with management of the Consumer and Carer Consultants.

Victoria's 10 year mental health plan and Mental health workforce strategy (2015) identified the importance of growing and developing the lived experience workforce.

In **2016**, the Department of Health funded a new program, the **Expanding Post Discharge Support**, which has resulted in a rapid growth in the lived experience workforce in clinical mental health services.

With the implementation of the NDIS, and the lack of a clearly identified funding line for peer support work, organisations in the community sector are exploring how to utilise dedicated lived experience roles. Many services are replacing lived experience positions with generic support worker roles thereby reducing their complement of dedicated lived experience workers.





## Key events in mental health, social justice and lived experience work in Victoria and Australia

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1843	Dangerous Lunatics Act (1843) led to establishment of Yarra Bend Lunatic Asylum
1867	An Act of parliament requires people with mental illness to be sent to asylums instead of prisons
1870s	Lunacy Acts and Insanity Acts passed in Australian states
- 1880s	In 1870, 1 in 397 people in Vic were classified as insane. In 1888 there were 3,634 registered insane people in Vic. Vic was named the 'maddest colony'
1930	Victorian Association for Mental Health established to give public voice to concerns
1945	UN Declaration of Human Rights
1957	GROW, a peer support program for growth and personal development of people with a 'mental illness', founded in Sydney
1958	Mental Hygiene Authority holds the first Victorian Mental Health Week
	Closure of large mental hospitals around the world (deinstitutionalisation) largely driven by economic and political incentives (institutions were costly, in disrepair, and stories of human rights abuses were coming to light)
1960s	New Mental Health Acts in Australian states
_ 1970s	First consumer organisation in Australia - Campaign Against Psychiatric Injustice and Coercion (CAPIC) established
	A range of consumer groups established and supported by small community managed organisations and the university student sector
	Term 'consumer' adopted from physical health consumer movement context
1978	Schizophrenia Fellowship of Victoria was founded and incorporated
1979	Victorian Association of Relatives and Friends of the Emotionally and Mentally III (ARAFEMI) was formed in Camberwell, using the slogan 'You are not alone'
1981	Victorian Mental Illness Awareness Council (VMIAC) was established
1983	The Richmond Report published – a NSW government inquiry into health services for the 'psychiatrically ill and developmentally disabled'
1991 _ 1994	Understanding & Involvement (U&I) – VMIAC's watershed project focused on participatory action research





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1991	The first TheMHS Conference held in Adelaide SA with 170 delegates and featured Simon Champ as a consumer keynote speaker
1992	National Mental Health policy and National Mental Health Strategy First Carers Awareness Week held in Australia
1993	1st National Mental Health plan (1993 – 1998) released with 12 priority areas including consumer rights and the linking of mental health services with other services
	Burdekin Report – National Inquiry Concerning the Human Rights of People with Mental Illness found widespread ignorance and discrimination and also stated that consumers and carers should be actively involved in decision-making Carers Association of Australia (CAA) launched
1994	Victorian Mental Health Carers Network began informally with the support of Carers Victoria, the Schizophrenia Fellowship (now Wellways), SANE Australia and ARAFEMI (now part of MIND Australia)
1995	VMIAC won National Mental Health Strategy Innovative grant for research. The Lemon Tree Learning Project explored ways consumers could be involved in education and training of mental health clinicians
	Schizophrenia: teaching relatives the 14 principles of coping manual published. This was one of the first family education courses developed by a family member (Ken Alexander)
	First consumer consultants employed at Royal Melbourne Hospital Jon Kroshel, Cath Roper, Robert Blake and Moira Somerville
1996	Leonie Manns elected co-chair of World Federation of Psychiatric Users  The first Victorian carer strategy released; Victoria's Carer Initiatives  Strengthening the Partnership
1997	Lemon Looning game developed. This is a consumer perspective training tool for mental health staff
1998	2nd National Mental Health Plan COPMI Vic program starts at Outer East Area Mental Health Service (later known as FaPMI)
1999	COPES (Carers Offering Peers Early Support) Initiative developed by Cate Bourke. First COPES Workers employed (Liz Ward and Carol Kimpton).  St Vincent's Hospital Melbourne establishes a Family and Carer Participation Committee





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Late 1990s - 2000s	<ul> <li>Key consumer and carer groups established, including:</li> <li>Australian Mental Health Consumer Network (AMHCN)</li> <li>National Community Advisory Group in mental health or NCAG</li> <li>National Centre for Consumer Participation in Health (NCCPH) established but short-lived</li> <li>Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) nationally funds a new group of consumer workers through Personal Helpers and Mentors Scheme (PHaMS)</li> </ul>
2000	First Carer Consultants employed in Victoria - Jeanette Murphy (St Vincent's), Kali Paxinos (North West Area Mental Health Service) First Consumer Academic employed at University of Melbourne (Cath Roper)
2001	First Carer Consultants Network (CCN) committee meeting for mutual support and networking. Later changed to CCNV (now Carer Lived Experience Workforce or CLEW)  First Consumer Advisor employed at North Western Mental Health (Wanda Bennetts)
2002	National Consumer and Carer Forum (NCCF) was developed by peak consumer and carer groups and the Australian Health Ministers' Advisory Council Mental Health Standing Committee (AHMAC MHSC). In 2005 NCCF changed its name to the National Mental Health Consumer and Carer Forum (NMHCCF)
2005	DHHS released Chief Psychiatrist's Guideline, Working Together with Families and Carers  First Carer Academic employed at the Bouverie Centre (Peter McKenzie)  First consumer employed full-time in mental health executive (Vrinda Edan)  First Carer Conference held in Melbourne with 400 attendees
2006	National Action Plan on Mental Health (2006–2011)  'Experiences of Care' - Partnership between VMIAC and the Mental Health Carers Network of Victoria to design and deliver the consumer and carer experiences of care survey funded by DHS. In 2011 this came to be known as MHECO
2007	Australia become one of the first signatories to the UN Convention on the Rights of Persons with Disabilities (CRPD)  The National Register of Mental Health Consumers and Carers (NRMHCC) formed. This pool of 60 mental health consumer and carer representatives from across Australia work to provide a strong national consumer and carer voice
2008	DHS employs the first Consumer and Carer Participation Policy Officer with declared lived experience (Keir Saltmarsh)





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2009	ARAFEMI Vic employed the first Carer Advocate (Michelle Swann)  Carer Consultants receive recurrent funding for the first time and for the first time were employed in child and aged mental health services. Prior to this they were only employed in adult mental health services and funded through the Carer Support Fund
2010	Australia passes the Carer Recognition Act.  The National Standards for Mental Health Services released. This document contains standards relating to consumers (Standard 6) and carers (Standard 7)
2011	National Carer Strategy released  The Centre of Excellence in Peer Support (CEPS) founded to provide a centralised online resource centre for mental health peer support
2012	Establishment of the National Mental Health Commission on 1 January Victorian Carers Recognition Act passed Monash Health employed the first consumer and carer peer support workers in clinical bed-based services Jackie Crowe appointed as National Mental Health Commissioner First Carer Participation and Involvement Strategy completed for a mental health community support service (Prahan Mission) Carer Consultants officially included in HACSU award DHHS established consultation meetings called Consumer and Carer Partnership Dialogues to ensure consumer and carer workers had an ongoing opportunity to inform the implementation of mental health initiatives. The Dialogues ceased in 2016
2013	ARAFEMI merged with Mind Australia  National Mental Health Commission funded development of training resources for the nationally recognised Certificate IV in Mental Health Peer Work  First PeerZone facilitator training delivered in Melbourne and subsequently PeerZone workshops began to be provided for consumers in Victoria
2014	The Victorian Mental Health Carers Network was re-launched as Tandem – the peak body for Mental Health Carers in Victoria  Revised Mental Health Act (Vic) released. The Act promotes supported decision-making and encourages strong communication between health practitioners, consumers, their families and carers  The Victorian Mental Health Complaints Commissioner (MHCC) opened. It was created by the Mental Health Act 2014 to be a specialist independent mental health complaints body  VicServ (now known as Mental Health Vic) commenced training Certificate IV in Mental Health Peer Work





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2015 _ 2016	Victoria's 10-year mental health plan released, including a commitment to grow the peer workforce.
	Post Discharge Support Initiative piloted at St Vincent's and Goulburn Health. In 2016 the program was rolled out to all adult mental health services, and Orygen youth mental health service. This was the first statewide program to employ peer support workers in clinical mental health services
	DHHS funded Intentional Peer Support (IPS) 5-day core skills training for peer support workers employed in the Post Discharge Support Program, and 2-day Introduction to IPS for colleagues and managers
	DHHS funded Families where a Parent has a Mental Illness (FaPMI) coordinators in every area mental health service
	Consumer Coproduction Workforce Group (later called the Consumer Workforce Development Group) and Carer Workforce Development Group established to identify and facilitate work on consumer and carer workforce development priorities
	First statewide Consumer and Carer Workforce Development Officers employed (Vrinda Edan and Lorna Downes)
	Tandem employed Carer Advocate to support families and carers individual advocacy needs
2017	First Caring With, introduction to carer peer work courses delivered
	Senior Carer Policy Officer employed by the Office of the Chief Psychiatrist (Frances Sanders)
2018	Expanded Post Discharge Initiative Forum held in March. The forum bought together consumer and family carer workers, their coordinators and managers to facilitate shared learning
	Recognising and supporting Victoria's carers, the Victorian Carer Strategy (2018-1022) released. Priority 1 includes a commitment that "Victorian carers will have better access to carer peer, professionally-led and community-led support and grassroots community support programs"
	Working together with families and carers Chief Psychiatrist's guideline updated and released
	Research - Developing a model for peer support in emergency departments to identify the optimal role for peer workers in emergency departments
	National Mental Health Commission held a roundtable of peer leaders from across Australia for an initial discussion around development of National Peer Workforce Development Guidelines
	DHHS fund 6 Prevention and Recovery Centres (PARCS) to employ peer support workers
2019	The Statewide Consumer and Family Carer Workforce Development Coordinators incorporated into the Centre for Mental Health Learning, Victoria (CMHL)
	The Self Help Addiction Resource Centre (SHARC) appointed to establish and host the Australian Hub of Intentional Peer Support (IPS)





## **Contributors and acknowledgements**

We welcome your ideas about what's helpful and how we can improve this resource. Please contact us:







We acknowledge Vrinda Edan's considerable input into this tipsheet.

