Foundational Engagement

June 2018

A community action group
MHM2
Mental Health Matters 2

ConnectGroups
helping support groups & individuals

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Acknowledgements

who made this happen

Mental Health Matters 2 acknowledges the Wadjuk people of the Nyoongar Nation on whose land this document was created. We acknowledge the wisdom of Aboriginal Elders and wish to pay our respects to Elders past, present and emerging and to Aboriginal and Torres Strait Islander peoples seeing this message.

This report could not have been produced without the significant contributions of people with lived and living experience whose expertise, insights, skills and knowledge led the planning, writing, supervising and producing of the document.

Thanks to Ann, Bridget, Margaret and Virginia who volunteered their time to support this work while also navigating the travails of living experience. This takes skill, knowledge, energy, stamina and generosity. Thank you.

Acknowledgement is also made to ConnectGroups, the peak body for Self Help and Support Groups in Western Australia, who administered the grant which made this work possible. ConnectGroups continues to put the voice of individuals and families front and centre of their work. Thank you.

This work was made possible by a ConnectGroups' Pay It Forward grant with funding from the Mental Health Commission.

Thank you.

Executive Summary

the short version

> “We are less when we don’t include everyone” [1]
>
> Stuart Milk, LGBTIQ activist

A need to focus on ‘foundational engagement’ has been identified because the involvement of citizens in the decisions which affect them is growing. This report uses the term ‘foundational engagement’ to describe the thinking about, and practice of, intentionally ensuring the participation of people who are traditionally under-represented in decision-making. In this report, the specific focus is on engagement in the mental health and alcohol and other drug sectors. The research sought to identify and examine resources which particularly engage with individuals, families and supporters with experiences of mental distress and alcohol and/or other drug (AOD) use who may also have experiences with homelessness, criminal justice, poverty and discrimination. These are the voices least heard in sector discussions and decision-making, and yet are often the people most affected by those decisions.

Research was undertaken to identify relevant resources in Australia, particularly those which were developed in part or in full by people with lived/living experience of the conditions mentioned above. A limitation of the study was the short timeframe and funding parameters of the project which was scheduled to take place between September 2017 and February 2018.

A number of resources were found and these are examined through the lens of an Evaluation Matrix which was created for this study and which privileges lived experience and Recovery principles. Resources which were not informed, at least in part, by contributions from people with lived/living experience of mental health and AOD, were excluded from the study.

It was heartening to find that although work in this area is still in early development in the relevant sectors, there were a number of interesting and valuable resources being developed at the time of this report with genuine involvement of, or leadership by, people with experiences of mental distress and/or AOD use.

The report identifies that it is important for services to think and plan carefully and intentionally about engaging with people who often continue to live with distress and disruption. Particular attention must be paid to making sure there is no possibility of reactivating their experiences of marginalisation or trauma in the process of engagement. ‘First do no further harm’ is a useful guide. People’s experiences of being left out and discriminated against have, unfortunately, often occurred in the sectors which are now seeking to engage with them.

Learning how to approach this work can be helped by seeking out leaders with lived/living experience and by adopting the principles of deep listening, vulnerability and empathy with a view to seeing people for their strengths and abilities.

Acknowledging that expertise comes in many forms and that expertise gained from lived/living experience is legitimate is also essential to foundational engagement.

Intentionally investing time, energy and resources into building equity into engagement is more likely to result in effective engagement. Paying people for their time and expertise, making sure venues are accessible and that meetings are held at appropriate times, proactively welcoming people into the space, working through lived/living experience leadership and peer networks to identify and encourage under-represented groups are all strategies which were found to be used in successful foundational engagement projects.

The report concludes with a number of recommendations which are offered in an awareness of the context of the tight budgetary situation currently being experienced by the Western Australian State government.

One of those recommendations is the encouragement of the good work already being done by key influencers in these sectors and the call to broaden and strengthen this work into intentional foundational engagement.

Purpose of Study

why we did this report

The key purpose of the study was to produce a report that found and examined similar projects in Australia aimed at engaging well with individuals, families and supporters who are new to service and systemic engagement in the mental health and AOD areas. These are the people and groups whose voices and perspectives are often missing or underrepresented in community discussions and decisions which affect them. The report uses the term 'foundational engagement' to describe this level of engagement and explains this term further in Section 5 - Language and Key Phrases.

The report identifies and comments on resources available in this area. This analysis is offered in the hope that the findings might provide a basis for the future development of a set of strategies specific to Western Australia and aimed at developing foundational skills and knowledge. The research, in surveying available resources, aimed to make it possible to avoid wasting time, energy and resources on creating a product or service where an existing one may already be available and fit-for-purpose.

The intended audience for this report includes anyone with an interest in how we work well and can work better together to include people who may not always be heard. This includes individuals with personal experience of mental distress and/or AOD use; their families, supporters and communities; government and non-government services. Services include, but are not limited to, those that engage people with living experience of mental distress and/or AOD use.

The report aims to provide information to organisations that are in a position to offer resources to build lived/living experience capacity in self-representation and self-determination in the mental health, AOD and forensic (justice) spaces.

Lived experience at the centre (‘Nothing About Us Without Us’)

The emphasis, when looking for and examining resources, was on work informed and guided, if not entirely produced, by people with lived/living experience.

This project was developed and delivered by people with lived and living experience of mental distress and AOD across all areas: planning, research, writing, production and supervision.

Language and Key Phrases

what words are used and why

> “Words are important. The language we use and the stories we tell have great significance to all involved.
>
> They carry a sense of hope and possibility or can be associated with a sense of pessimism and expectations, both of which can influence personal outcomes.[2]”

Language is a powerful tool which shapes how we view and respond to people and their experiences. Using hopeful and respectful language is particularly critical in areas where people are known to experience disadvantage and distress. The mental health area is an area of health where people can still be subject to coercive and traumatising interventions such as hospitalisation against their will, enforced medication and treatment and other restrictive practices, such as seclusion and restraint.[3]

Often the same word or phrase used in engagement may have differing meanings, as in the case of the word 'Recovery'. Lack of clear understanding and agreement around language can lead to confusion and frustration, and can potentially be a barrier to people coming on board. Individuals and families talk about some workers in services who, often unconsciously, use language which is technical, formal and dotted with sector acronyms. This effectively leaves 'non-professionals' out of the discussion and decision-making and renders them reluctant to re-engage. In order to make this report accessible to a wide audience, the commonly used and relevant terms have been discussed and clarified upfront.

The words used to describe people who have experiences of and who may use services in the areas of mental health, alcohol and other drug (hereafter referred to as AOD) and forensic justice were found to be reasonably consistent during this project.

The terms 'service user', 'carer' and other descriptors of individuals are used when directly citing resources that use them. Outside of these contexts, this report uses the following terms and definitions:

CARER

The definition of a carer as derived from The Western Australian Carers Recognition Act 2004 by Carers WA is:

"someone who provides unpaid care and support to family members and friends who have disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue, or who are frail aged". [4]

The term 'carer' is commonly used in the physical health, aged care and disability sectors. It is increasingly used in the mental health sector; however it is not a widely used term in the AOD area. The term is used in relevant legislation such as Western Australia's Carers Recognition Act 2004 and the Mental Health Act 2014 as well as in policies and sector documents. However, the descriptor remains contested in the co-occurring mental health and AOD space. This is because for some people, the term implies disability and dependence which is not congruent with a Recovery approach. The 2013 National Recovery Framework [5] uses the broader term 'family and support people'.

The singular term 'carer' may also narrow focus onto one person and may thus fail to recognise the importance of kinship connections and extended family support in Aboriginal, indigenous and ethnic minority cultures. It is also acknowledged, however that some people may prefer the term 'carer'. This demonstrates the importance of checking with the people who are being engaged with to ensure that language which they choose to describe their roles is used.

CARER REPRESENTATIVE

A Carer Representative is a person who identifies as having a family member or friend who, in this instance, experiences mental distress and/or AOD use and seeks to have the family member/ carer perspective included in discussions and decision-making.

Carers WA describe the role of a Carer Representative as: 'to provide the carer perspective from a community rather than an individual point of view. Carer Representatives engage with the government to give WA carers a voice in the policy, planning and decision-making processes of health and mental health services.

COMMUNITY

While the term 'community' may cause us to think of a geographical area in which we live, work, socialise or study, it may also describe the network of people with whom we find connection – 'a community of choice'. Increasingly, the term also includes online communities where people connect over a particular topic or area of interest. 'Community' also has strong cultural significance for Aboriginal peoples and it is referred to in the Western Australian Aboriginal Health and Wellbeing Framework 2015–2030 as follows: "Community is where we live, support family, maintain our connections to country and culture and go to school and work. These factors are important in developing a strong sense of community. We need to feel safe in our community and know we can find help, including health services close by if we need them. Maintaining and developing the connections between community and services is important in developing healthy communities". [6]

CONSUMER

The terms 'consumer', 'service user' and 'person with lived experience' are commonly used terms in the mental health and AOD sectors ('the sectors'). This report uses the terms 'individual(s)', 'person' and 'people' to represent those who have experiences of mental distress and/or AOD use. They may, or may not, have used services in these sectors. This language is consistent with a recovery approach; preferred terms describe people as individual human beings, rather than in the context of their relationship to services (for example, clients, customers, service users). [7]

It is important to point out that in the AOD space, the terms 'consumer' and 'service user' include families and significant others whereas in the mental health area, they do not.

CONSUMER REPRESENTATIVE

A consumer representative, for the purposes of this report, is someone who identifies as having experiences of mental distress or AOD use (past or current). They are recruited, or volunteer, to voice the consumer perspective to groups and committees convened by stakeholders in the sector. They do this in order to 'ensure consumer rights, needs, views and interests are heard and responded to'.[8] Under this definition, the person might be independent of any agency.

In contrast, a definition by the Consumers Health Forum of Australia says that:

"A consumer representative is a member of a government, professional body, industry or non-governmental organisation committee who voices consumer perspectives and takes part in the decision-making process on behalf of consumers. This person is nominated by, and is accountable to, an organisation of consumers". [9]

For the purposes of this report, a consumer representative will be assumed to be an independent person who is not employed by an agency in a representative role.

CO-DESIGN

"Co-design engages end-users in the design of products or services so they will better serve their intended purpose".10 Co-designing a product or service with people who will ultimately use it can be done as a separate exercise or as part of a co-production process. Co-design can happen without co-production taking place. Co-production cannot happen without co-design.

CO-OCCURRING

The term 'co-occurring' in this context refers to when a person has experiences of both mental distress and AOD use. The words 'co-morbidity' and 'dual diagnosis' are also often used to describe this situation.

CO-PRODUCTION

"Co-production describes a relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities".11

Co-production is underpinned by principles such as those outlined in the 2013 Co-production Report by the new economics foundation, UK:

taking an assets-based approach: building on people's strengths and seeing them as equal partners in designing and delivering services

building on people's existing capabilities: providing opportunities to people so that they strengthen, grow and put these strengths and skills to use

reciprocity and mutuality: recognising that there are different types of expertise and creating the conditions for people to work in equal relationships with shared goals and responsibilities

peer support networks: using a range of peer and personal networks to share knowledge alongside professional networks where knowledge has traditionally been located and shared

blurring distinctions: redesigning services to help remove the classic boundaries between individuals who use services, families and supporters and the professionals who work in services

facilitating rather than delivering: working with agencies to support them to take on the role of helping and supporting individuals and families to design and deliver services, rather than the traditional role of leading and directing the action.

CULTURAL COMPETENCE

Cultural competence is described in 'Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice"[12] as "a commitment to engage respectfully with people from other cultures. It goes on to say that "importantly for individuals, cultural competence requires more than becoming culturally aware or practising tolerance. It can be defined as the ability to identify and challenge one's own cultural assumptions one's values and beliefs. It is about developing empathy and connected knowledge, the ability to see the world through another's eyes, or at the very least to recognise that others may view the world through a different cultural lens".

The WA Department of Health's 2017 Engagement Suite says that "Department staff should:

- be genuinely inclusive of worldviews that are different to their own;
- invest time to recognise others' world views, not simply disagreeing/agreeing with them or dismissing them
- and develop true respect for differing opinions".[13]

It is also important to maintain a broad definition of culture when considering cultural competency. "While many people within professional mental health and suicide prevention organisations may be aware of cultural competency they may not have considered LGBTI people as a distinct cultural group with particular needs and experiences". [14]

DISABILITY

As per the Western Australian Disability Services Act 1993, the word "means a disability —

a) which is attributable to an intellectual, psychiatric, cognitive, neurological, sensory, or physical impairment or a combination of those impairments; and

b) which is permanent or likely to be permanent; and

c) which may or may not be of a chronic or episodic nature; and

d) which results in –
i) a substantially reduced capacity of the person for communication, social interaction, learning or mobility; and

ii)a need for continuing support services".[15]

ENGAGEMENT

The term 'engagement' refers to the wide range of ways in which services can involve individuals, families, carers and supporters in the design, delivery, evaluation and review of health care. For the purposes of this report, the term 'participation' is taken to have the same meaning as 'engagement'. The two terms are used interchangeably.

The Draft Consultation of the Statewide Engagement Framework states that "Involving people in the decisions that impact them is important. Genuine and effective engagement can result in services being developed and delivered in a way that meets the needs of consumers, support persons and the broader community".[16]

EQUITY

Equity is about making sure people get access to the resources they need in order to be able to fully participate. This is particularly important between groups where there are clear power imbalances.

FAMILY AND FAMILY MEMBER

Family members and supporters self-identify in ways which may include formal caring ('carer') or informal caring ('mum, brother, aunty, Opa/ grandfather, close friend…). Consumers also name those who support them in a variety of ways.

The terms 'family', 'family member' and 'families and supporters' are used in this report to represent those 'whose primary relationship with the person concerned is a personal, supportive and caring one'.17 This relationship includes both biological and non-biological connections which gives rise to terms such as 'family-of-choice' or 'family by acceptance'.

FOUNDATIONAL ENGAGEMENT

The term 'foundational' is used here in two ways. Firstly, it refers specifically to engaging with people who are under-represented in formal sector activities such as meetings and forums. Secondly, it denotes some underlying principles which need to be in place to meet with people from under-represented and sometimes marginalised groups in a respectful and effective way. These principles include Safety, Authenticity, Humanity, Diversity and Equity as outlined in the WA Mental Health Commission's Draft Statewide Consumer, Family and Carer Framework.18

Using the metaphor of a ladder, 'foundational' refers to the first two rungs. The third rung of the ladder is a space where people with a lived/living experience actively take part in sector forums or in roles as consumer or carer representatives on committees. Being on the third rung presumes that people already have some support and resources such as access to the Internet, ability to access transport, reasonable English literacy and language skills. The third rung also implies that they are able and confident to engage and contribute in formal settings such as meetings and forums.

HOST ORGANISATION

This is an organisation or group that provides a resource, whether that be face-to-face training, education, written information, voice media, event, or via virtual technology.

INSTITUTION

An institution is defined as an organisation founded for a religious, social purpose.[19] In mental health, the term 'institution' often refers to the large, long-stay psychiatric hospitals in which significant numbers of people were detained, prior to deinstitutionalisation in the 1950's and 1960's when many of these large hospitals were closed and people were returned to the community.

INTERSECTIONALITY

The term 'intersectionality'' is used to describe the increased marginalisation and discrimination that results for people with more than one social identity, which a society has deemed to be 'different' or 'other'. For example, a young gay Aboriginal man in prison is more likely to experience higher stress (which may lead to increased mental health difficulties) than a young, heterosexual white man who lives at home in Perth's western suburbs. It is important to recognise how the multiple factors intersect and overlap to cause a worse experience for the person as compared to someone who may belong to only one marginalised group or to someone who belongs to none.

LIVED/LIVING EXPERIENCE

A person with lived or living experience is defined as a person who identifies as having, or having had, experiences of mental distress and/or AOD use, or a family member or supporter of a person so described. It was felt that the term 'lived experience' might suggest that the experience is one that happened in the past and is now resolved.

The term 'lived experience' has been complemented by 'living experience' to describe current or ongoing experiences.

MULTIPLE UNMET NEEDS

Clinicians, institutions, and service providers use various terms to describe the situation when a person has more than one health issue or disability at the same time. These terms include: 'co-occurring', 'co-morbidity' and 'dual diagnosis'.

People who experience mental distress and AOD use are likely to have other experiences such as: family violence, poverty, homelessness or insecure housing and compromised physical and dental health.[20] Therefore, the term chosen for this report is 'multiple unmet needs'.

The project deliberately avoids using the term 'complex needs' as this is traditionally attached to the individual ('person with complex needs'). This language can contribute to the impression that the individual is likely to have many difficult problems-of-life to solve which sometimes puts him / her in the 'too hard' basket for siloed services. The report proposes that the complexity should be attached to the service delivery and co-ordination, rather than to the person who, like any of us, generally has basic human needs. In the words of Dr Stephen Jurd: 'the duality lies in the system, not the individual'.[21]

NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

The National Disability Insurance Scheme (NDIS) is a new way of providing disability supports in Australia, including for people deemed to have a psychosocial disability as a result of their mental ill-health. People have to apply for the Scheme and be assessed for eligibility. They can be supported to do this. NDIS is managed by the National Disability Support Agency (NDIA).

The NDIS is a social insurance scheme which is different from social welfare. NDIS allocates funding to the person and their family/carer with which they can then plan and buy the 'reasonable and necessary' supports they need to live 'an ordinary life'. This is a significant change, as in the past the funding has gone to services, rather than to the person. It is hoped that this change will mean that more independence and power lies with the individual to get what they need. It is a major change for many services who provide support in community mental health.

By the time the NDIS is fully rolled out across Australia in 2020, it will be providing support to approximately 460,000 Australians under the age of 65 (Source: NDIS).

NON-GOVERNMENT ORGANISATION (NGO)

A Non-Government Organisation is one which operates separately and independently of government (local, state or federal). Often the purpose of an NGO is to support people with a social need in the community. The term 'Community-Managed Organisation' or CMO is often used interchangeably with NGO.

PAID PARTICIPATION

This refers to payments for time and reimbursement of out-of-pocket expenses offered to individuals and family members by host organisations for participation in specific activities.

Increasingly, peak bodies and services in the mental health and AOD sectors are developing and implementing a Paid Participation policy. A local example of such a policy is the WA Mental Health Commission's Consumer, Family, Carer and Community Paid Participation Policy.[22] This policy was developed in consultation with individuals, families, carers and supporters and employees from agencies who represent them. The National Mental Health Commission reviewed their Paid Participation Policy for people with a lived experience of mental health difficulties, their families and support people in 2017.[23]

PARTICIPATION

The terms 'participation' and 'engagement' are deemed for the purposes of this report to have the same meaning. Therefore, they are used interchangeably.

POWER

Power is a word and topic which often invokes discomfort and uncertainty about how to address it – if there is in fact an acknowledgement that a power imbalance is present.

A 2018 resource on Co-production co-produced by Cath Roper, Flick Grey and Emma Cadogan[24] proposes that: "Power is the ability to influence or control. Individuals have power. Groups and organisations have power. Power is exercised in social, political and economic relations, which means it shapes almost everything. When power differentials are unacknowledged and unaddressed, individuals, groups or organisations with the most power will have the greatest influence, regardless of the quality of their ideas or skills. When governments and organisations work with consumers there will be significant and obvious power differentials. There may be some power differentials that are less obvious, but still important to explore and address. Co-production is a way to genuinely shift and distribute power more evenly amongst partners, giving those with less power in the partnership more space to contribute and more influence than they would have in usual circumstances. This can be achieved through affirmative action, for example proactively introducing consumer leadership and decision-making opportunities".

Recognising and acknowledging where power lies or 'pops up' in engagement between services and people who use them is critical to a safe and productive outcome. This is particularly important in regional and rural areas where individuals and families may be continuing to access the same services and sometimes, the same staff, who are engaging with them. The opportunity to change to a different service if things go awry may not be available due to lack of other appropriate services.

PSYCHOSOCIAL DISABILITY

This term is relatively new and is linked to the arrival of the National Disability Insurance Scheme (NDIS). See National Disability Insurance Scheme above for further information.

Under the NDIS, psychosocial disability is described as "a term used to describe a disability that may arise from a mental health issue".[25]

Not everyone who experiences mental ill-health will have a psychosocial disability. It generally relates to those people who have a chronic and severe experience of mental distress and who may need extra supports in recovery.

QUORUM

A quorum is the minimum number of people attending a group or meeting required to be present in order to make the business of that meeting valid. Details of the quorum are found in the Terms of Reference for a meeting or the Rules of Association / Constitution of an incorporated group or body.

One way to ensure that the voices of lived/living experience have a real say in decision-making is to ensure that the quorum has a requirement of a particular number or percentage of people with lived/living experience to be present. A meeting can still proceed without a quorum; however decisions cannot be validated until a future meeting at which the requirements for the quorum are met.

RECOVERY

Recovery is a term that has varying meanings in the physical health, mental health and AOD sectors. The definition used in this report is taken from Consumers of Mental Health WA who define it as 'a personal process of attaining a life that is meaningful, empowered and fulfilling from the person's own perspective, irrespective of diagnosis and/or symptoms'.26

This definition fits well with the definition offered in the Western Australian Alcohol and other Drug Interagency Strategy 2017 – 2021 Consultation Draft: 'the term recover/recovery is considered a process of change where individuals work to improve their own health and wellness to live a satisfying, hopeful and contributing life while striving to achieve their full potential'.27

It is acknowledged that the word 'recovery' is often used in the AOD sector to describe an abstinence-based treatment or support approach but it is not intended to have that meaning in this report.

RESOURCE

This study defines 'resource' as 'a source of help or information'.28 This includes, but is not limited to, people, projects and publications. These may be accessed in a variety of ways including through personal and other networks, social media, podcasts, webinars, websites, leaflets, booklets, academic articles, posters and reports.

SOCIAL CATEGORIES

Everyone identifies and is categorised by institutions, society and self, into social categories such as gender, race, class, sexual orientation, (dis)ability, power, culture, privilege, religion, age, nationality and other sectarian axes of identity. The collective term 'social categories' has been used to describe these identities.

TRAUMA-INFORMED PRACTICE

It is widely accepted that there are strong links between experiences of mental distress, problematic AOD use and trauma. The Australian Psychological Society refers to potentially traumatic events as "powerful and upsetting incidents that intrude into daily life. They are usually experiences which are life threatening or pose a significant threat to a person's physical or psychological wellbeing".29

The APS goes on to state that "an event may have little impact on one person but cause severe distress in another". Trauma-informed practice is a framework which sees people through their strengths and abilities rather than through their deficits and diagnoses. It understands what trauma is and how to respond to it safely. Trauma-informed practice seeks to be thoughtful about what it takes to ensure physical, psychological and emotional safety for everyone. This in turn helps to create spaces for people to regain choice and control.30

Trauma-informed practice is especially important in this area of engagement where individuals, families and supporters may still be experiencing mental and emotional distress or actively using AOD in ways that are unsafe for themselves and others.

COMMONLY USED ACRONYMS

ANPUD	Asian Network of People Who Use Drugs
AOD	Alcohol and Other Drugs
AODAG	Alcohol and Other Drug Advisory Group
AQF	Australian Qualification Framework
ATSI	Aboriginal and Torres Strait Islander
CALD	Culturally and Linguistically Diverse
CMO	Community Managed Organisation (also known as an NGO)
CoMHWA	Consumers of Mental Health WA
DAO	Drug and Alcohol Office (now the Mental Health Commission)
EOI	Expression of Interest
F4FWA	Families 4 Families WA
HCC	Health Consumers Council (WA)
LGBTI	Lesbian, Gay, Bisexual, Trans, Intersex
MHC	Mental Health Commission
MHM2	Mental Health Matters 2
MHiMA	Mental Health in Multicultural Australia
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NGO	Non-Government Organisation
PWLE	Person with lived/living experience. This could be an individual, family member or supporter.
QuIHN	Queensland Injectors Health Network
QuIVAA	Queensland Injectors Voice for Advocacy and Action
RTO	Registered Training Organisation
UN	United Nations
URL	Uniform Resource Locator (webpage address)
WA	Western Australia
WAAMH	WA Association for Mental Health
WACHS	WA Country Health Service
WANADA	WA Network of Alcohol and Other Drug Agencies
WASUA	Western Australian Substance Users' Association

Background to the Study

what's been happening up until now

The requirement to involve people who use services and their families and supporters, and the benefit of doing so, is now well established nationally and internationally.

Examples of international declarations and agreements which support and advocate for people being involved in decisions which affect them include:

- The United Nations (UN) Universal Declaration of Human rights[31]
- The UN Convention on the Rights of Persons with Disabilities[32]
- The Goa Declaration by the Asian Network of People Who Use Drugs[33] (ANPUD)

In Australia, there are also a number of national declarations, policies, standards and frameworks which speak to this important issue. These include, but are not limited to:

- Fifth National Mental Health and Suicide Prevention Plan (2017)[34]
- National Drug Strategy 2017-2026 (2017)[35]
- National Safety and Quality Health Service Standards (2017)[36]
- The Gayaa Dhuwi (Proud Spirit) Declaration (2015)[37]
- Framework for Mental Health in Multicultural Australia (2014)[38]
- Cultural Competency Implementation Framework: Achieving Inclusive Practice with Lesbian, Gay, Bisexual, Trans and Intersex (LGBTI) Communities (2013)[39]
- National Mental Health Standards (2010)[40]
- Carer Recognition Act (2010)[41]

At the time of this report going to print, the National Mental Health Commission released the 'Engage and Participate in Mental Health Summary Report' (June 2018). An excel resource database of policies and frameworks for consumer and carer engagement and participation that were collected as part of the project was also released.

Both resources will be available at http://www.mentalhealthcommission.gov.au/our-work/consumer-and-carer-engagement-project.aspx

People have also been at work in Western Australia. Some laws, policies and frameworks have been in place for some years. These include:

- The Carers Recognition Act 2004[42] (which is being reviewed at the time of writing).
- Standards on Culturally Secure Practice (Alcohol and Other Drug Sector) (2012)[43]

More recent relevant legislation, frameworks and documents which have been released include:

- 'You Matter: A guideline to support engagement with consumers, carers, communities and clinicians in health' (2017). Department of Health[44]
- Consumer, Family, Carer, Community Paid Participation Policy. Mental Health Commission (2016)[45]

- Principles and Best Practice Strategies for Consumer Engagement in the Alcohol and Other Drug Sector in Western Australia (2016). Health Consumers' Council / Alcohol and Other Drug Advisory Group[46]

- 'Involving Children and Young People. Overview and Checklist'. Commissioner for Children and Young People Western Australia (2015)[47]

- Mental Health Act 2014[48]

- There are also a number of relevant 'works-in-progress' in WA. These include:

- The Mental Health Commission's Working Together: Mental Health and Alcohol and Other Drug Engagement Framework 2018-2025 which is due for release around the same time as this report.

The co-designed Engagement Framework explains what engagement is at individual, service, sector and system levels and describes different types of approaches.

Furthermore, the Engagement Framework explains the benefits of meaningful and genuine engagement and what works and what doesn't work, particularly in the mental health and alcohol and other drug sectors. In addition, the Engagement Framework outlines a set of interrelated principles and strategies to enable best practice engagement. (Draft Consultation Engagement Framework).[49]

The Draft Consultation paper is referenced here but will be replaced by the finished document which will be available on the Mental Health Commission's website at www.mhc.wa.gov.au.

The Mental Health Commission, together with an Expert Panel, is currently supporting a number of community consultations to give input to the development of a model for Recovery Colleges in Western Australia.[50]

Recovery Colleges are new to WA but are in place elsewhere in Australia and internationally. There is a range of models but they are all underpinned by similar principles which include recovery, safety, co-design and recognising lived experience expertise. They are unique places for people who use services and those who deliver services to learn together with both sets of expertise being valued.

A transitional Alcohol and Other Drug Advisory Group (AODAG) is overseeing a project, funded by the WA Primary Health Alliance and auspiced by the Health Consumers Council, to progress the creation and incorporation of a peak body for AOD consumers (which includes families and significant others). The AODAG membership comprises government, NGOs and consumers. In order to maintain the legitimacy of the work, the quorum outlined in the Terms of Reference for the group, required 50% of consumer members to be in attendance for a meeting to progress and for decisions of the group to be deemed valid.[51] Once incorporated, the new body will oversee the design and delivery of training for AOD consumer representatives.[52]

An AOD Consumer Peak Think Tank was held in February 2018 to seek feedback and find out what people want from an AOD Consumer peak; what training they would like to receive in the area of consumer representation; and how they would like to be involved in future activities. Consumers included current and potential service users as well as family members and supporters. The application for incorporation of the consumer peak body was lodged in June 2018 and the new organisation's name is the Alcohol and Other Drug Consumer and Community Coalition (AODCCC).

Alcohol and Other Drug Consumer Engagement Forum February 2018

It is exciting and energising that there is so much happening in the 'engagement' space right now. It is also important to ensure that the engagement strategies and resources which have been, and are being developed, are fit-for-purpose at a foundational level to enable a diversity of individuals, families and supporters to be active in engaging in the mental health and alcohol and other drug areas.

The proposal for this research came from Mental Health Matters 2 (MHM2), a systemic action and advocacy volunteer group based in Perth.53 It was borne of emerging concerns that engagement with a wide range of perspectives in the mental health and AOD space was not being well achieved. This was often in spite of best intentions.

The concerns raised with MHM2 by a number of stakeholders included:

- difficulty in accessing sufficiently skilled and available consumer and carer representatives to fill the number of emerging positions in the mental health, alcohol and other drug and health sectors
- poor 'matching' between the person and the role (for example, people on committees who had limited experience of the mental health / AOD area)
- observations that the same pool of individuals and family members was being approached directly by services to be on committees. While this may reflect well on the expertise and contribution of those individuals, there was also concern about 'cherry-picking' individuals who might be reluctant or less confident to give robust feedback
- staff who might not have the skills or resources to work safely with individuals and family members on committees
- representatives being on committees where service providers were not skilled in communication and engagement practices and where consumer and carer representatives felt they were being dismissed, overlooked and at worst, re-traumatised
- places as representatives being taken up but not being thoroughly utilised for a range of reasons including frequent absenteeism, being over-stretched and having no proxy for the position
- peers expressing frustration that the absence or lack of preparedness of other consumer/carer representatives left them feeling under additional pressure to ensure the perspectives were being effectively heard.

While the Mental Health Commission's Paid Participation Policy (2016) has clearly laid out a tiered approach to representation, an investment in capacity building around skill development and knowledge building for individuals and families with lived/living experience needs to underpin this to make it achievable and sustainable.

Staff in government and non-government services also need training, development and support in how to work in what can be radically new ways with individuals and families who, in some services, have traditionally been relegated to the role of passive service recipients.

With representation opportunities generally circulated by institutions, organisations and word-of-mouth, a network becomes essential to the applicant. As applications are generally via Expressions of Interest, those without sufficient skills or confidence to source assistance or create that Expression may not meet the criteria or may not even attempt to apply. If an applicant is not a member of the dominant culture, or is affected by social inequity, social intersectionalities or social disadvantage, the barriers may seem simply too high and impossible to overcome.

Essentially, what is currently the situation in Western Australia is that there tends to be a static pool of individuals at consumer and family member consultations and acting on co-production opportunities within the mental health and AOD sectors. Although this pool of representatives is diverse (it includes people who identify as ATSI, CALD, LGBTIQA, from the dominant culture, etc), it is the same individuals who consistently take up opportunities. It is simply not a big enough pool.

Scope of Study

the limits to our search

The research was particularly focussed on locating resources on foundational engagement in the mental health and AOD sectors which were already available in Western Australia and other parts of Australia.

What was out of scope?

- Resources that were not in some way informed by lived/living experience;
- Resources that did not apply to the mental health or AOD sectors;
- Resources that did not, in some way, engage at a foundational level;

Research Methodology

how we went about our work

DEFINING ‘FOUNDATIONAL ENGAGEMENT’

The first step and most important discussion was to define ‘foundational engagement’. The definition, which is detailed in Section 4 – Language and Key Phrases was shaped from informal, but informed, discussions with individuals, families, supporters and peers, consumer and carer representatives, service providers who were keen to engage effectively and safely, and feedback from people who experience mental distress and AOD use.

Those individuals, families and supporters who were reluctant to engage in sector activities were comfortable to talk about foundational engagement on a one-to-one basis.

DEFINING THE SPACE BEFORE THE ‘THIRD RUNG’

Trying to climb a ladder whose first two rungs are missing can be both unsafe and difficult. Trying to reach a rung (situation or opportunity) which seems unattainable from where you are currently located can be frustrating, disempowering and isolating.

Identifying the barriers to foundational engagement was critical in order to assess whether resources had strategies to address these upfront. Common barriers identified included poverty (I can’t afford the parking and public transport is difficult for me); confidence (what do I have to offer anyway? – I’m just a mental health patient), language barriers (English is my second language or I do speak English and still have no idea what they’re talking about); lack of cultural security (Am I going to be the only African person in the room again?); uncertainty about safety

(‘Will I be emotionally safe in that meeting or will it reactivate previous distressing experiences of being ignored, bullied or undermined?’).

Other barriers may include the need for information to be presented in a variety of formats to facilitate different learning styles, levels of literacy, languages and learning abilities. The effects of factors such as culture, class and (dis)ability were often not thought about in the preparation of resources, including the impact of intersectionalities.

Barriers created by both the marketing of the resource (sent out only by email to people whose details were already known to the service) and resource presentation (large file to download on a phone) can exclude the very people who are so valuable to informing services about how they are really performing on the ground.

To use a metaphor, foundational engagement focuses on replacing the first two missing rungs of a ladder. People on the third rung are actively engaged in sector forums or in roles as consumer or carer representatives. The third rung – where all the action is – can seem to be and often is out of-reach.

Why are two rungs missing? A number of factors influenced the metaphor of the first two missing rungs on the ladder of engagement. Arnstein's 'ladder of citizen participation', although written in 1969, is extensively cited in literature on citizen participation and engagement.[54] The study describes the first two rungs of participation as 'manipulation' and 'therapy' which contributes to non-participation. Arnstein asserts that "these two rungs describe levels of "non-participation" that have been contrived by some to substitute for genuine participation.

Their real objective is not to enable people to participate in planning or conducting programs, but to enable powerholders to "educate" or "cure" the participants".[55] Manipulation disguised as participation can be seen when individuals, families and supporters are engaged with in order to 'tick a compliance box'. The work has already been done; decisions have been made and participation with service users happens late in the process when there is little opportunity to influence the outcome. However, even the late presence of individuals, families and supporters gives the service the opportunity to claim that 'engagement' took place and that the decisions have been endorsed by consumer and carer representatives. An example given by Arnstein as to how 'therapy' is masked as participation is that of public housing tenants being brought together under the guise of participation only to find that the group is actually promoting a 'control-your-child' campaign and there is no opportunity for them to bring up matters which are of importance to them such as evictions or overdue repairs and maintenance.

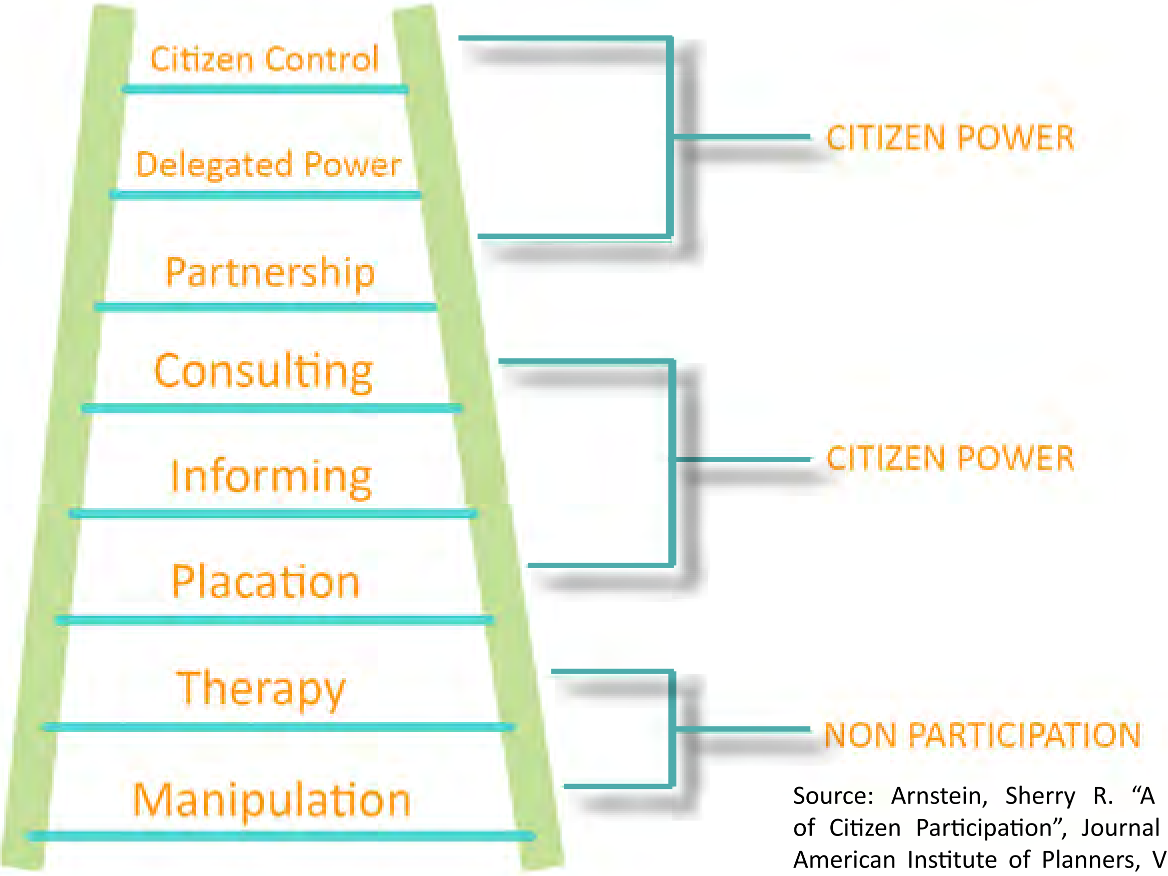
There is no genuine welcoming of or acknowledgement of lived experience expertise at these first two rungs.

This report is using Arnstein's ladder mainly to illustrate the point regarding the missing two bottom rungs in foundational engagement. It is acknowledged that there are a number of much more contemporary models and approaches which reflect more nuanced and dynamic approaches to lived experience participation.[56] A number of these are referenced but not explored here due to the scope and focus of this report.

The sheer size of the gap that a person has to navigate in order to climb directly onto the third rung of a ladder is obviously much greater than if only one rung were missing. This larger gap was seen as much more reflective of the yawning chasms (not just gaps) which exist for individuals, families and supporters who are often managing experiences of mental distress and alcohol and other drug use while also trying to survive poverty, often while in unsafe and unstable accommodation, some of whom may also be trying to comply with criminal court or parenting orders perhaps while managing compromised physical health.

Also, the power of stigma and discrimination which impacts on people's ability and willingness to engage and services' understanding of safe engagement practices cannot be underestimated. This is particularly true for people with multiple occurring issues, including mental distress and active alcohol and other drug use. The two missing rungs may also therefore represent the impact of public stigma which is defined as "the prejudice and discrimination endorsed by the general population that affects a person"[57] and the resulting self-stigma which is defined in the same article as "the harm that occurs when the person internalizes the prejudice".

A similar approach was taken to identifying 'facilitators' to foundational engagement. These are the strategies and actions taken by the service which make it easier and more possible for individuals, families and supporters to engage. The term 'enablers' was not used as 'enabling' has a specific meaning in some areas of the AOD sector. Enabling in that context can be interpreted as actions taken (or not taken), by families, friends and supporters, which shield the individual from the full consequences of their AOD use or behaviour.



Source: Arnstein, Sherry R. "A Ladder of Citizen Participation", Journal of the American Institute of Planners, VOL. 35, No.4, July 1969, pp. 216-224

DEFINING THE THIRD RUNG

So, what is meant by the 'third rung'?
The 'third rung' was seen as a place where fairly healthy and competent individuals were engaged on committees and at targeted sector forums through Expression of Interest (EOI) processes. Often these individuals, families and supporters had good standards of English which enabled them to address the EOIs effectively. They also either had workplace or professional backgrounds in relevant areas and learned quickly how to speak 'sector' language and how to understand the nuances of the particular culture. These increased capacities then helped them get other opportunities, often further up the ladder.

A positive aspect of being on 'the 'third rung' was the opportunity to transfer or renew skills and knowledge from other areas of life and reclaim confidence and competence. It must be remembered that individuals, families and supporters are more than their mental health and AOD experiences. They are often highly skilled and competent workers and professionals in their own right.

However, what was often missing even at the 'third rung' was the opportunity for people there to be properly sustained in what was often difficult work in which they were participating at the same time as managing often chaotic and complex situations in their personal or family lives. Also, there were limited opportunities for newer participants to learn from the experiences of more experienced peers other than through informal and unpaid peer debriefing mentoring and coaching.

THE RESEARCH METHODOLOGY

An initial planning session was undertaken with members of the MHM2 Steering Group to focus the research and guard against 'scope-creep' – the possibility that the researcher could go down 'research rabbit-holes' which, although interesting and relevant to engagement in general, would not focus on foundational engagement.

All the members of the MHM2 Steering Group have lived/living experience and have extensive individual and collective experience, skills and knowledge in the area of engagement and participation. A number of them currently hold, or have held in the past, roles on strategic advisory committees as well as service-level, operational committees. Some have also shared their experiences with mental health and/or AOD at sector forums and in other service settings. All of them are involved in supporting or facilitating the Families 4 Families WA (F4FWA) program.

Families 4 Families WA is a peer led, bi-monthly, recovery-focussed, education and support group for families and supporters which is often also attended by individuals with direct experience of mental distress and AOD use. MHM2 partners with Cyrenian House drug and alcohol agency in the delivery of the F4FWA program which means that additional support and smooth access to service is available for participants. The people who attend F4FWA are often families and supporters who are not active in sector forums, are not well versed in sector language and who have experiences of service which have left them often reluctant to engage. They are individuals, families and supporters who experience the distressing gaps between the mental health, AOD and criminal justice systems, and who are therefore often motivated to make a difference in these area/s but are unsure about how best to go about this given their previous experiences.

The project lead attended a number of F4FWA groups and listened to people describing their attempts to engage with the system at both individual service and systemic levels and the barriers they experienced. Participants also spoke of the people, processes, skills and knowledge which often made the difference in being able to engage and contribute in a way that was meaningful for them.

The project identified and collated resources about consumer and family member engagement which were produced locally, nationally and in some cases, internationally, with a focus on identifying foundational resources. This entailed a search for resources on foundational engagement through the internet, by requesting information from organisations such as NGOs and institutions such as the Mental Health Commission; following leads on resources and approaching individuals, families and supporters through various networks.

THE INTERNET

The Internet provided the majority of resources as well as leads to individuals and organisations and individuals located locally, nationally and internationally. Searches were conducted via the Google Search Engine, including Google Scholar. Google was chosen as it is most-used search engine with a 65.2% share of web search volume worldwide according to internetlivestats.com (2018).58 Other search engines share the remaining 34.8% between them, thus were not used.

Search words/phrases were vast and included terms used by service providers in the sectors as well as plain English words and phrases. Terms and language highly specific to Culturally and Linguistically Diverse communities and Aboriginal or First Nation peoples, or in languages other than English, were not used as this was outside the scope of this project. Publications and resources in languages other than English were excluded.

A total of 1013 words or phrases were searched. It is probable that the results may not have identified niche resources as a result of the limitations, although the lack of mainstream resources may suggest an all-round dearth of information and resources.

A total of 1013 individual searches were conducted and an average of 3 clicks were made on the results provided for each search. What that means is that once a webpage was located, it took a further 3 clicks to access the document or resource.

A further 150 pages were viewed within websites which were found to contain resources sufficiently relevant to warrant evaluation. In total 3188 web pages were accessed in this part of the project.

THE LIST OF SEARCH TERMS USED:

Google and Google Scholar Search Terms (used alone, and/or in combination, total number of searches collated using a tally system)

User involvement	User representative	User participation	User contribution
User oriented	Community collaboration	Community participation	Community representative
Community engagement	Community input	Community led	Community hub
Community networks	Community involvement	Consumer participation	Consumer involvement
Consumer groups	Consumer network	Consumer driven	Consumer advocacy
Carer participation	Carer involvement	Carer groups	Carer network
Carer driven	Carer advocacy	Carer generated	Carer engagement
Carer representative	Carer hub	Family participation	Family involvement
Family groups	Family network	Family driven	Family advocacy
Family generated	Family engagement	Family representative	Family member hub
Patient involvement	Patient led	Patient participation	Patient Representative
Patient engagement	Citizen participation	Citizen engagement	Citizen representative
Health information networks	Consumer participation	Participation care decisions	Consumer
Mental Health	AOD	Alcohol and Other Drug	Injecting Drug User
Health	Names of various organisations who came up in searches, or were given to be by organisations or individuals or known to the researcher(n=57)	Names of various individuals who came up in searches, were given to me by organisations or known to the researcher(n=24)	Names of papers that came up in searches, were given to me by organisations or individuals, or known to the researcher(n=17)
Consumer and carer participation in Mental Health Services	Mental health Consumer Consultant	Forensic Justice	Barriers

Of interest was the lack of immediate relevant results from online searches. Without possessing a service-provider vocabulary, a novice consumer or family member in Perth, Western Australia, searching for foundational tools and information to form the basis of future participation and engagement, would more than likely find predominantly NGO and Health or Mental Health government websites. Search engine results would identify the term 'consumer' and 'carer' which the individual, family member or supporter may then use to access further and improve results.

Another barrier occurred within the resources and sites themselves in the form of broken or absent links. For example, a website might list or allude to a resource, but either the link would be broken; the website search function would not pick up the resource; or the resource would be stand-alone (not linked to any other page). Without accessing the website's site map, having a guess at the webpage address (URL), or contacting the host organisation, the resource would simply not be accessible. These points will be discussed in further detail under Section 9 (Results).

OTHER ONLINE SEARCH METHODS

* databases of scholarly articles via university libraries;
* when articles were identified by Google Scholar and not open access on the internet
* using search terms

THE LIST OF SEARCH TERMS USED:

Database Search Terms – all combined with 'mental health' and 'health'

barriers consumer participation	**barriers consumer representative**	**barriers consumer engagement**	
community engagement	**community collaboration**	**community participation**	**community representative**
community hub	**consumer and carer participation in mental health services**	**consumer consultant**	**consumer hub**
consumer representative	**consumer engagement**	**consumer participation**	**consumer involvement**
carer participation	**carer involvement**	**carer groups**	**carer hub**
carer engagement	**carer advocacy**	**carer representative**	
family groups	**family network**	**patient involvement**	**family advocacy**
family member hub	**family engagement**	**family representative**	**family participation**
patient engagement	**patient representative**	**patient participation**	
Aboriginal consumer participation	**CaLD consumer participation**	**ATSI consumer participation**	**names of papers that came up in searches, were given to me by organisations or individuals, or known to the researcher which were not open access (n=8)**

THERE’S NOTHING LIKE TAPPING INTO YOUR OWN NETWORK

A benefit of contracting a person with a combination of service provision experience in the human services area coupled with living experience in the health, mental health and/or AOD sectors to undertake this work is their likely access to a personal network in the area being researched. Personal mailing lists, contacts and friends were used to track down resources as well as contact being made with a number of individuals and institutions located locally, interstate and internationally

CONTACTING IDENTIFIED SOURCES

The methods used to contact individuals and organisations were

ONLINE CONTACT

EMAIL

Emails were either sent to organisations via generic email addresses or sent to individuals in organisations. No-one responded to emails sent to them unless personal contact was made with them either before or after the correspondence.

SURVEYS

A four-question survey was created and distributed to institutions, organisations and individuals identified in internet searches as well as through personal networks. The purpose of this was to identify potential resources which could be followed up.

- No-one replied to the initial surveys sent to organisations.
- Of the surveys sent to personal contacts, one personal contact replied to the survey.
- Other personal contacts elected to enquire about the survey and project directly, either in person or via telephone.
- One government department responded by placing the research details in their newsletter with a link to the survey. Two responses were received from that link distribution.

A second survey was produced containing the evaluation matrix. This was not used, as respondents stated they would rather discuss the resource directly or refer to written material than complete a form.

CONTACT FORMS

The two contacts via forms received no replies; however one organisational response was to add the project contact to their newsletter mailing list, as requested, by using the optional subscription tick box on the form.

DIRECT CONTACT

TELEPHONE

A number of institutions, organisations and individuals identified in internet searches as well as through personal networks were contacted.

PERSONAL MEETINGS

Of the institutions, organisations and individuals identified in internet searches as well as through personal networks, all that had knowledge of, or information pointing to, potential foundational resources were approached for more information on the resources found or identified.

OPPORTUNISTIC CONTACT VIA EMAIL, TELEPHONE, PRIVATE MESSAGES and INFORMAL FACE TO FACE MEETINGS

Opportunistic face-to-face contacts occurred within the sector. One contact occurred via telephone because of a private message sent via social media.

Recipients and respondents of online and personal methods of inquiry were chosen using one or more criteria:

- institutions and organisations identified in the internet searches as offering resources that might be partially or entirely foundational;

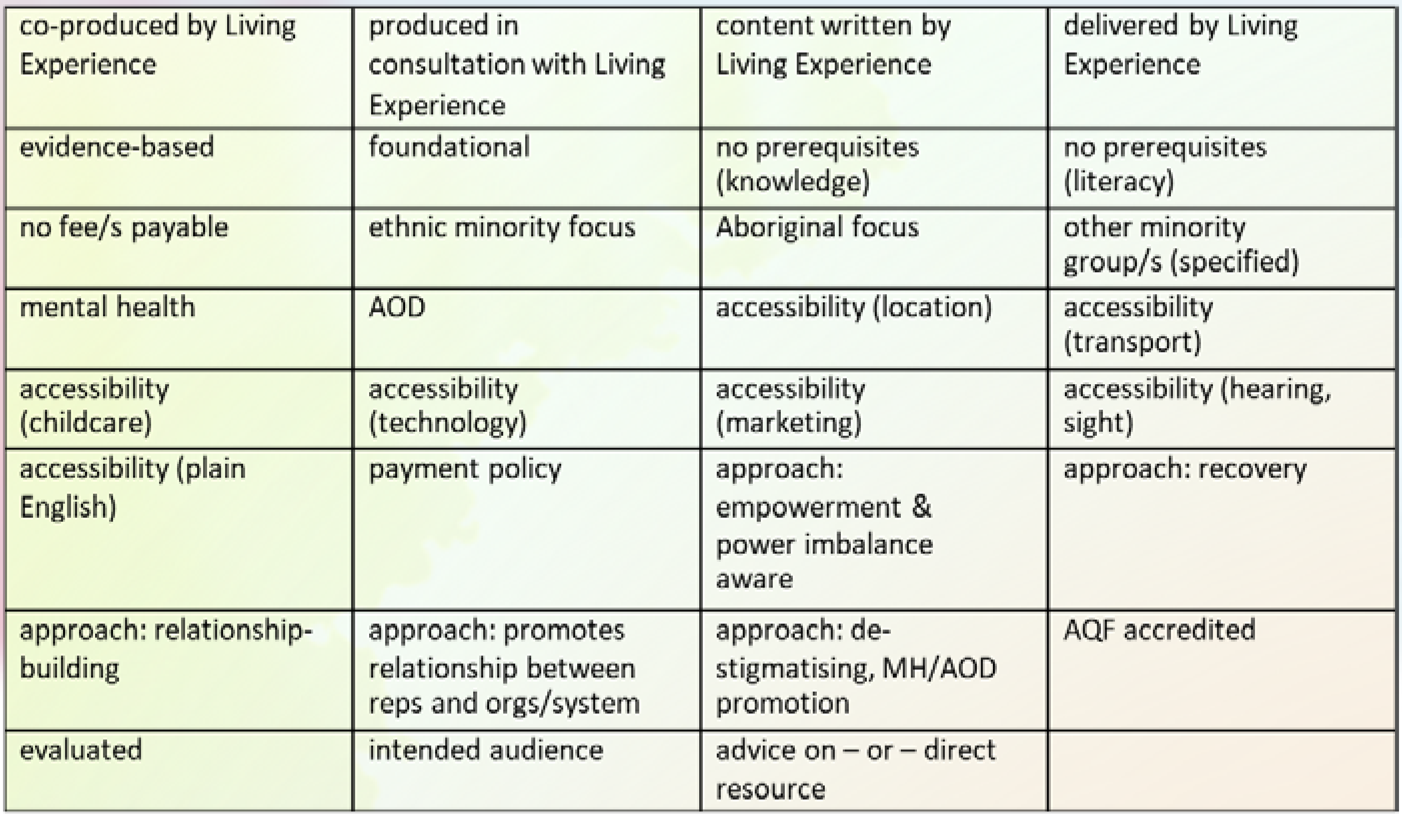
- institutions, organisations and individuals identified by searches, papers, individuals and any other source above that led to resources that might be partially or entirely foundational;

- the personal and social network of the researcher.

Instead of scoring each resource on its content, which would risk creating a hierarchy of resources, each resource was first examined to ascertain whether it would function helpfully at the foundational level.

THE EVALUATION MATRIX

An evaluation matrix was created for this study. Resources were to be assessed according to the presence of the following content:



co-produced by Living Experience	produced in consultation with Living Experience	content written by Living Experience	delivered by Living Experience
evidence-based	foundational	no prerequisites (knowledge)	no prerequisites (literacy)
no fee/s payable	ethnic minority focus	Aboriginal focus	other minority group/s (specified)
mental health	AOD	accessibility (location)	accessibility (transport)
accessibility (childcare)	accessibility (technology)	accessibility (marketing)	accessibility (hearing, sight)
accessibility (plain English)	payment policy	approach: empowerment & power imbalance aware	approach: recovery
approach: relationship-building	approach: promotes relationship between reps and orgs/system	approach: de-stigmatising, MH/AOD promotion	AQF accredited
evaluated	intended audience	advice on – or – direct resource	

The resource was then examined to determine if it either informed foundational resource/s or it was a resource in and of itself.

Other resources of interest were examined and included in this report when the numerous barriers to engagement were recognised and/or addressed in a foundational way.

An evaluation was not able to be done strictly according to this matrix for many reasons:

FINDINGS FROM EXAMINATIONS OF RESOURCES

- Some identified resources lacked the information that would enable evaluation.
- Resources that did address barriers to, and facilitators of, engagement did not identify foundational, pre-engagement and/or post-engagement stages.
- Sometimes foundational barriers and facilitators of engagement were buried in the resource or were sparse or speculative.
- Some resources made it necessary to rely on contents pages and introductions to evaluate relevancy to capacity-building of individuals, families and supporters;
- Some resources were obviously not foundational and pursuing sufficient information to evaluate was deemed unnecessary given the study’s time and funding limitations

ENQUIRIES WITH HOST ORGANISATIONS

Host organisations either could not provide background information on a resource or there was very limited background information available. Reasons given included:

- the resource had been in existence for some time and records pertaining to origins or evolution were no longer available
- the authors and sources from which resources, information and content were drawn, and how this was done, were unknown
- the author/s had left the organisation and no-one knew about the development of the resource.

- a reference was made to a resource in a document or webpage, but the resource could not be located by the host organisation;
- • the resource was no longer used or current, thus access was declined by the host organisation;
- the resource was under review, thus access was declined by the host organisation;
- the host organisation who held the resource no longer existed;
- host organisations were unwilling to participate in a 29-point examination of their resource;
- institutions and organisations were unwilling to have their resource evaluated for fear of appearing on a hierarchal table of rating despite explanation and assurances that the evaluation would not be published or discussed in this report or other medium.

LOGISTICS

Limitation on research time and funding precluded thorough reading of all of the many resources identified as pertaining to consumer participation and engagement. However, all findings with any potential for being or informing foundational resources were examined.

LIMITATIONS OF THE RESEARCH

The following factors limited the extent of this research:

1. Time – the project was time limited.
2. Funding – the project had a (relatively) small budget.
3. Cost – the research grant did not extend to payment for books or membership or subscriptions to journals or academic resources including databases and electronic publications. Although the researcher was able to access some scholarly databases, there were some publications which could not be located or accessed via available sources.

Results

what we discovered

OVERVIEW OF RESULTS

- websites (local, national and international government, organisation, group, individual)
  - some embedded with links including those to:
    - other internal website pages
    - other external websites which meant leaving the site of origin
    - podcasts
    - PDFs
    - events
    - social media
    - surveys
  - archived websites via WaybackMachine (web.archive.org)

- Documents in pdf format (which is ‘a file format for capturing and sending electronic documents in exactly the intended format. A file format for capturing and sending electronic documents in exactly the intended format).59
- ebooks
- databases
- event booking sites (websites from which tickets can be booked)
- social media
- blogs
- scholarly articles
- cartoons and pictures
- videos (audio-visual)
- online courses
- literature produced by organisations but not formally published

FOUNDATIONAL RESOURCES FOUND – WESTERN AUSTRALIA

Resource Name	**Recovery Stories**
Type	Training (held October 2017 – March 2018) 12 x workshops of 3 hours each (plus a 30 minute break)
Access information at	WAAMH webpage https://waamh.org.au/development-and-training/recovery-stories
Provided by	Western Australian Association for Mental Health (WAAMH) Peak body for NGOs in WA
Located at	1 Nash Street, Perth Next to railway station Street parking available
Cost	$66 Valued at $1500 by WAAMH

Recovery Stories was promoted as "a course designed for people with lived experience of mental health recovery, along with carers or family members who would like to share their stories and messages of Recovery with audiences".60

EVALUATION MATRIX ASSESSMENT

Eligibility

ALL participants must:

- Be aged over 16 years on 1 January 2017
- Be a resident of WA
- Have lived experience of mental health
- Recovery as a consumer, carer or family member
- Have a personal Recovery story to share, which has the potential to be inspiring and optimistic
- Be willing to be coached to craft a personal story into a succinct, performance-suited narrative
- Be a fluent speaker of English
- Have basic literacy skills (minimum Year 10 English, C grade or equivalent)
- Be keen to participate in the full workshop process, regardless of subsequent performance opportunities
- Be available and committed to attending ALL the workshops and willing to prioritise attendance. (WAAMH, 2017)

There was a medium to high number of eligibility requirements, although this may have been due to funding requirements.

THIS RESOURCE

- Was written and delivered by a people with lived / living experiences of mental distress
- Promoted recovery
- Was inclusive and welcoming to people from ATSI, CALD, LGBTIQA backgrounds

"We will be looking for a range of speakers who represent a diversity of experiences, perspectives, backgrounds and demographics. We are especially keen to include people who may be from minority or disadvantaged groups including Aboriginal, TSI and CALD communities, young people, LGBTIQA people, people with disabilities and single parents".61

- Included AOD
- Was delivered at a central venue with good access to public transport
- Had not been evaluated at the time of writing.

This document was recently produced and speaks directly to one of the focus areas for this report. The principles for engagement are applicable for foundational engagement.

EVALUATION MATRIX ASSESSMENT

Eligibility

Reasonable literacy and English language reading skills required.

THIS RESOURCE

- Was developed by a consultant with lived experience on behalf of the AOD Consumer Engagement Advisory Group which has a membership of at least 50% consumers (including families and supporters).
- Is locally produced

Resource Name	**Principles & Best Practice Strategies for Consumer Engagement in the Alcohol and Other Drugs Sector in Western Australia.** **Summary of findings from Consumer and Other Key Stakeholder Consultations in 2016**
Access information at	Health Consumers Council Western Australia https://www.hconc.org.au/resources/engagement-in-the-alcohol-and-other-drugs-sector/engagement-in-the-aod-sector/
Type	Written 44-page document
Provided by	Health Consumers Council Alcohol and Other Drug Consumer Engagement Advisory Group
Cost	Free download

Resource Name	**Lorikeet Centre**
Access information at	MIFWA webpage https://www.mifwa.org.au/our-services/lorikeet-centre/
Type	Member driven community centre Open Tuesday – Thursday 9am – 4.30pm
Provided by	Mental Illness Fellowship of WA (MIFWA)
Activities	Gym Gym instructor 2 x week Computer and internet Weekly gardening program in local community garden Commercial kitchen with outings on Friday nights An annual break to a different destination each year.
Located at	West Leederville, Perth Walking distance to railway station Street parking available
Cost	Free Lunch is $4.60 or members can bring their own

MIFWA's webpage describes the Lorikeet Centre as "a supportive environment in which people experiencing mental health problems can work on acquiring the skills and support they need".

EVALUATION MATRIX ASSESSMENT

Eligibility

- participants must be adults and have experienced / be experiencing mental ill-health.
- has a welcoming approach even via the webpage (which can be an impersonal engagement tool).

THIS RESOURCE

- promotes recovery and its underlying principles such as connectedness and relationships.
- has a low threshold for participation and does not create unnecessary barriers
- is simple to access with good public transport options nearby
- has free access with subsidised lunch and social activities
- has access to computer and internet
- does not require particular levels of literacy or health literacy
- is promoted in a number of ways, including peer networks.
- is of a foundational nature that addresses many barriers at first and second rung levels

Resource Name	**Monthly gatherings**
Access information at	Recovery Rocks https://recoveryrockscommunity.org/our-services/monthly-gatherings/
Type	Social gathering of individuals, families, supporters and mental health workers can spend time together in a relaxed and safe community space. Held on the 4th Sunday of each month 12.30pm – 4.30pm
Provided by	Recovery Rocks Community Inc.
Activities	Socialising, informal peer support Sharing food Art and craft activities
Located at	Ottey Family Centre South Lakes, South Metropolitan Perth Parking available
Cost	Free. Bring a plate of food to share.

The Recovery Rocks Community is "a volunteer-run community of people who have experienced mental health challenges and are choosing to live a life of Recovery and Wellbeing".62

EVALUATION MATRIX ASSESMENT

Eligibility
low threshold – no specific eligibility criteria – other than that the community is one of people who have experienced mental health challenges and are focussing on Recovery.

THIS RESOURCE

- promotes recovery and wellbeing
- has a low threshold for participation and does not create unnecessary barriers
- is located near shops
- is close to Kwinana Freeway for easy access
- is free to attend – bring a plate to share (reciprocity)
- does not require particular levels of literacy or health literacy
- is promoted in a number of ways, including peer networks.
- is of a foundational nature that addresses many barriers at first and second rung levels

The Monthly Gatherings provide a safe and welcoming space for people to come to socialise and get informal connection and support. This is often a critical first step to engagement.

Resource Name	**AOD Consumer Representation Training for Next Step and the Integrated Services (currently being developed) Inaugural session planned August 2018**
Access information at	Mental Health Commission Next Step Drug and Alcohol Service Telephone: (08) 9219 1919
Type	1 x day training consisting of 5 modules
Cost	Free

This one-day training aims to equip Community Alcohol and Drug Service (CADS) consumers, who wish to become consumer representatives on CADS or Integrated Service committees, with the necessary knowledge and skills to do so effectively. The term 'consumer' here includes individuals, families and supporters.

The one-day training is in the final stages of development and is scheduled to be offered in Semester 2, 2018. It will subsequently be offered 3 times a year. The training will be co-facilitated by consumers and service representatives.

EVALUATION MATRIX ASSESSMENT

Eligibility

- have lived/living experience of AOD use as an individual, family member or supporter
- have basic literacy skills in English
- has no knowledge pre-requisites
- is limited to consumers of Next Step and the Integrated Services although the future scope includes broadening eligibility to all consumers of AOD and MH services.

THIS RESOURCE

- is co-designed by people with lived experience (PWLE) of AOD use
- has content which has been written primarily by PWLE of AOD use
- will be co-facilitated by PWLE and service representative
- has a low threshold for participation and does not create unnecessary barriers
- can be delivered at accessible venues
- will be free to attend
- will be promoted in a number of ways, including peer networks.
- is of a foundational nature that addresses many barriers at first and second rung levels
- takes place over one day (9.30am – 3.30pm) includes 5 modules. These modules are:
  - Information on the AOD Sector and Integrated Services*
  - Stigma, Triggers and Self Care
  - Roles and Responsibilities of being a consumer representative. This covers foundational information such as explaining basic meeting terms (Minutes, Terms of Reference) and processes
  - Consumer Engagement – types of engagement and how to participate
  - Future options

*(An Integrated Service is a service where Next Step, the government AOD provider, partners with a Non-Government Organisation delivery AOD services to provide an integrated Community Alcohol and Drug Service (CADS). This Integrated Service provides a broader range of options which includes medical services such as opiate and pharmacotherapy treatment and medical reviews as well as options such as counselling and support groups).

Resource Name	**Families 4 Families WA**
Access information at	Mental Health Matters 2 www.mentalhealthmatters2.com.au Cyrenian House drug and alcohol agency Telephone: (08) 9328 9200
Type	Bi-monthly recovery-focussed, peer led and facilitated education and support group held in Perth, Western Australia for families and supporters of a person with experiences of mental distress and alcohol and other drug use and possibly criminal justice involvement
Located at	182 Lord Street, Perth (Venue kindly supported by Helping Minds and Carers WA)
Provided by	Mental Health Matters 2 which is a volunteer community action and advocacy group. Cyrenian House drug and alcohol agency
Cost	Free

Families 4 Families WA (F4FWA) is a peer support and education group which has been held on the 2nd and 4th Tuesday nights of the month since 2011. The group particularly focuses on families and supporters of people who experience ongoing mental distress, AOD use and possibly, criminal justice involvement.

The group is organised and led by experienced volunteer individual and family peers, most of whom are actively and voluntarily engaged in systemic advocacy and engagement activities. Many of the participants who attend F4FWA are people who are not generally involved in sector discussions.

Unlike a traditional 'support group', F4FWA proactively engages in research and consultation activities.

Families 4 Families WA is run in partnership between Mental Health Matters 2, a volunteer systemic advocacy and action group, and Cyrenian House drug and alcohol agency. A co-occurring mental health and AOD specialist attends from Cyrenian House. This person helps to link individuals, families and supporters into advocacy or support services, if required. This peer-support-plus model provides a good example of a service being 'on tap, not on top' in the partnership with lived/living experience.

EVALUATION MATRIX ASSESSMENT

Eligibility

- have lived/living experience of mental health and/or AOD use as a family member or supporter
- have basic English language skills
- is foundational as defined in this report

THIS RESOURCE

- is co-designed by people with lived/living experience (PWLE) of mental health and/or AOD
- is facilitated by peer family member/supporter
- is free to attend
- is wellbeing and empowerment focussed
- is promoted in a number of ways, including peer networks.
- is of a foundational nature that addresses many barriers at first and second rung levels
- Is held on the 2nd and 4th Tuesday evening of the month.
- is close to public transport and free parking

Resource Name	**Looking Forward**
Access information at	Telethon Kids Institute, Perth www.telethonkids.org.au/our-research/brain-and-behaviour/mental-health-and-youth/aboriginal-mental-health-and-wellbeing/looking-forward-aboriginal-mental-health-project/
Provided by	Looking Forward project team and Nyoongar Elders
Activities	Activities include: Damper and bush medicine-making Storytelling Community days Walks on country.
Located at	Various locations
Cost	Discussed with service

This project does not fall within the direct scope of this research and is therefore not evaluated. However, it has been included because of the foundational engagement work it continues to do successfully with service providers to help them gain understanding of and respect for Nyoongar culture. This shift in understanding results in making mental health and AOD services more accessible for the Nyoongar community, particularly those living in the southeast Perth metropolitan region.

The Looking Forward Project team does this transformative work in conjunction with Nyoongar Elders.

At time of writing, there was no publicly available information available on this resource. For queries, please contact email address given above.

Cariads Compass Self-advocacy training:
2 x 2-hour modules which can be co-delivered by 2 carers who are experienced facilitators over a weekend.

Successfully trialled through WA Country Health Service (WACHS) mental health services in Esperance, Bunbury and Kalgoorlie

EVALUATION MATRIX ASSESSMENT

Eligibility

- participants must be adults
- no pre-requisites

This resource is co-produced by family members with lived experience of caring for loved ones who had experienced, or were experiencing mental ill-health, AOD issues and/or (dis)ability.

- empowering and strengths-based
- has an advocacy focus
- is promoted in a number of ways, including peer networks.
- is of a foundational nature that addresses many barriers at first and second rung levels
- promotes recovery and empowerment
- can be tailored to CALD, LGBTIQA and ATSI carers (to be organised by the host organisation)
- caters for participants with hearing and vision impairment.

Cariads Compass Train the Trainer component:
EVALUATION MATRIX ASSESSMENT

Eligibility

- participants must be adults
- participants must have completed the Cariads Compass Self-Advocacy training

THIS RESOURCE

- is co-produced by family members with lived experience of caring for loved ones who had experienced, or were experiencing mental ill health, AOD issues and/or (dis)ability
- promotes recovery, empowerment and relationship-building
- is a foundational resource that addresses barriers at first and second rung levels.

Resource Name	**Cariads Compass**
Access information at	Email: pmandjj@bigpond.net.au
Type	Self-advocacy training (a resource which teaches self-advocacy to carers) plus Cariads Compass Train-the-trainer resource (a training package for carers who have completed the Cariads Compass self-advocacy training and wish to become trainers).
Provided by	Cariads which is an unfunded, unincorporated group who deliver the resource in rural Western Australia (Funding to travel to other rural centres to deliver and evaluate the product was sourced through ConnectGroups, the peak body for Support Groups in WA)
Cost	Cost is calculated on an individual course basis to cover travel, accommodation and a small charge for the trainer's time. No royalties, development fees or other fees are charged by Cariads.

The little purple book of Community Rep-ing

How to order

To order more copies of
The little purple book of Community Rep-ing
please contact the Publications Officer at
Adelaide Central Community Health Service
Phone: (08) 8342 8600

WHICH ONE IS NOT A COMMUNITY REP ?....

SECTION 7 PAGE [illegible]

The little purple book of Community Rep-ing

Publication of the Not Just A Token Rep Project
North West Suburbs Health & Social Welfare Council

Third Edition Published by
Adelaide Central Community
Health Service

Funded by
Consumers' Health Forum
of Australia

Cartoonist
George Aldridge

Third Edition
2003

Resource Name	**'The Little Purple Book of Community Rep-ing'**
Access information at	Health Consumers Council, NSW http://www.hcnsw.org.au/resources/10/the-little-purple-book-of-community-rep-ing
Type	Book(let) (1994) 19 x A5 pages with cartoons and illustrations. Authors: Marg Tatyzo, Ray Hirst, Charlie Murray, Fiona Verity
Cost	Cost unknown. Can be easily downloaded in full format.

This resource is described by Health Consumers NSW as "a classic resource on community participation developed directly from the experiences of community representatives".63

The book(let) itself is 19 A5 pages long with cartoons and illustrations in which 'consumer rep-ing' (being or becoming a consumer representative) is discussed with insight and humour. Its ease of reading makes this resource accessible and useful for those from Australia's dominant culture.

The booklet describes itself as "… a humorous look at the stumbling blocks [of Rep-ing], with a view to encouraging more people to take steps to become like those other 'thoughtful ones' when engaging community representatives on their committees". The aim of the project was to produce a "… humorous and accessible guide for people wanting to be community or consumer representatives, a guide which was based on the experiences of people who had actually been community or consumer representatives. The project also aimed to bring together people who had been representatives in similar health related areas, and provide them with an opportunity to share ideas, experiences and resources".64

According to the booklet, this resource was written by project staff and members of the Steering Committee at the Health and Social Welfare Council. It is based on stories and experiences of people who had been consumer representatives in health, environment, non-English speaking background issues and disability. Members of (unidentified) Boards of Management, and other community organisations also contributed. The host organisation no longer exists.

EVALUATION MATRIX ASSESSMENT

Eligibility

- requires some level of literacy and English language competence, however the cartoons and illustrations make it accessible for a wide audience.

THIS RESOURCE

- is free to access on the Internet
- is only 19 A5 pages long
- is humorous
- is illustrated by relevant, meaningful, bespoke cartoons
- is based on stories and experiences of people who had been consumer representatives
- is applicable and useful to individuals, groups and organisations
- avoids jargon and uses plain English
- is complementary to a manual called The Community Participation Workshop Kit (see below)

Comments

The resource is 24 years old and as such utilises some terms and colloquialisms that are somewhat dated and might not be meaningful to young consumers or family members today.

It is not available in other formats such as audio, braille, other languages.

The Community Participation Workshop Kit, Parkes Community Health Service, Adelaide is a 40-page manual containing 24 pages of cartoons designed as a training kit to The Little Purple Book of Community Rep-ing. Useful in situations of low literacy levels, it is available through the:

South Australian Community Health Research Unit

C/- Flinders Medical Centre
Bedford Park, SA, 5042
Telephone: (08) 8204 5988
Fax: (08) 8374 0230

Resource Name	**Lived Experience Partnership Checklist plus a complementary 13-minute You Tube media clip**
Type	3-page checklist for Professionals and Organisations This is complemented by a 13-minute You Tube clip on: 'Keeping Families in Mind – Involving Consumers and Carers' which comprises a discussion on the issue by three people with lived experience
Access information via	3-page checklist is free to download at http://www.copmi.net.au/images/pdf/Get-Involved/lived-experience-partnership-checklist.pdf You Tube clip can be viewed at http://www.copmi.net.au/professionals-organisations/how-can-i-help/lived-experience-partnerships
Provided by	Children of Parents with a Mental Illness (COPMI)
Located at	Online
Cost	Free

Lived Experience Partnership project (Children of Parents with a Mental Illness COPMI)
In addition to the resources listed above, there are additional relevant resources available at:

http://www.copmi.net.au/professionals-organisations/how-can-i-help/lived-experience-partnerships.

These include:

- Checklist for lived experience partnerships
- Checklist for participation with children and young people
- Checklist for interviews with people with lived experience
- COPMI lived experience partnership policy
- COPMI staff selection participation policy
- Information on Youth Participation
- Information for people with lived experience of mental illness

EVALUATION MATRIX ASSESSMENT

Eligibility

requires some level of literacy and English language competence, however the YouTube clip make it accessible for a wider audience.

THIS RESOURCE

- is free to access on the Internet
- has been developed by people with lived experience
- has complementary resources in different formats
- allows the voice of lived experience to be heard directly on the media clip
- destigmatises mental illness
- is foundational in its focus.
- also has links to resources for engaging with young people

Resource Name	**Capacity building project for consumers in the AOD sector to increase participation and engagement as consumer representatives / peer roles**
Type	Training and development
Access information via	Queensland Injectors Health Network (QuIHN) Phone: 07 3620 8111 or 1800 172 076 (Freecall) Email: quihn@quihn.org
Provided by	Queensland Injectors Voice for Advocacy and Action (QuIVAA) and funded by QuIHN
Located at	Brisbane, Bowen Hills
Cost	Free-Consumer participants remunerated according to QuIHN's Reimbursement and Remuneration Statement developed by project.

Queensland Injectors Voice for Advocacy and Action (QuIVAA) Project (Consumer Engagement and Participation Project CEPP)

This capacity-building project to improve consumer engagement and ultimately peer involvement in AOD services is due for completion in mid-2018.

The information gained was from a conversation between the writer and the Project Lead, who is a person with lived experience of problematic AOD use (as described by the person in question).

Intended aims of the project are to:
- work with individual, family and supporters who have lived / living experience of AOD use with a view to become engaged initially in representation and later as peer workers
- provide a meaningful and informed expert by experience perspective to the AOD sector
- develop a training package for consumer representatives
- develop a change management training package for workers
- provide information sessions and training to institutions and organisations to increase their capacity to work with consumer representatives and peer workers

It is not possible to evaluate the resource at this stage as it is not yet completed. However, it appears to be already emerging as a valuable resource at the foundational engagement level and is being informed and developed by a skilled and knowledgeable lived experience leader who has extensive experience in the multiple-occurring mental health and AOD sectors.

Watch this space!

Resource Name	**Straight to the Source produced in 2010**
Type	148-page manual
Produced by	The Association of Participating Service Users A service area of the Self Help Addiction Resource Centre Victoria
Access information via	The resource can be accessed at http://www.sharc.org.au/wp-content/uploads/2014/04/APSU-Straight-From-the-Source-Manual.pdf
Cost	Free download

The Association of Participating Service Users (APSU) is a Victorian advocacy service of the Self Help Addiction Resource Centre (SHARC). It is staffed by consumers and was set up to ensure that the perspectives of people who use AOD services contributes to the delivery of services as well as policy and professional development and research. A number of additional, relevant resources are also available on the SHARC webpage.

EVALUATION MATRIX ASSESSMENT

Eligibility

- requires good level of literacy and English language competence
- destigmatises AOD use

THIS RESOURCE

- is free to access on the Internet
- is produced in collaboration with AOD consumers

This resource was launched in February 2018 and is intended to support consumer-led initiatives in Victoria. While there are a number of resources available about Co-production generally, this resource focusses focuses on co-production in the area of mental health. This resource was evaluated as the practical advice it provides for those wishing to embark on co-production activities is highly applicable to foundational engagement.

EVALUATION MATRIX ASSESMENT

Eligibility

requires some level of literacy and English language competence, however the graphic design and illustrations make it accessible for a wide audience.

THIS RESOURCE

- is free to access on the Internet
- is only 26 pages long
- has effective graphic design which helps to make it accessible
- highlights 5 case studies which involve people with lived/living experience
- is produced by people with lived experience.
- addresses the issue of power and how to work with it.

Resource Name	**Co-production** **Putting principles into practice in mental health contexts** **2018. Cath Roper, Flick Grey & Emma Cadogan**
Type	Written 26-page resource plus 5 Appendices Open access resource
Access information via	Email: Cath Roper at croper@unimelb.edu.au The resource can be accessed at https://recoverylibrary.unimelb.edu.au/__data/assets/pdf_file/0010/2659969/Coproduction_putting-principles-into-practice.pdf
Cost	The work is licensed under a Creative commons Attribution 3.0 licence. It is a condition of this license that the authors are credited if content is adapted or replicated.

Resource Name	**MadQuarry Dictionary A consumers guide to the language of mental health (2013)**
Type	32-page written resource
Produced by	Our Consumer PlaceEmail: service@ourconsumerplace.com.au http://www.ourconsumerplace.com.au Melbourne, Victoria
Access information Via	The resource can be accessed at http://www.ourcommunity.com.au/files/OCP/MadQuarryDictionary.pdf
Cost	Free download

Our Consumer Place is a resource centre run by people diagnosed with “mental illness” and auspiced by Our Community.   It has been developed by consumers for consumers and recognises that lived experience provides valuable and crucial insights and must be respected.

The MadQuarry Dictionary was created from a national competition inviting consumers to contribute their entries. Entries were judged by Janet Meagher AM, a distinguished consumer elder in Australia.

Example: Abscond (from hospital) verb 1. Needing some time-out to work out future strategies. 2. Searching for community. 3. Searching for inclusion. 4. Self-determination. 5. Lift watching The act of developing an escape plan

EVALUATION MATRIX ASSESSMENT

Eligibility

requires some level of literacy and English language competence, however the graphic design and illustrations make it accessible for a wide audience.

THIS RESOURCE

- is free to access on the Internet
- brings an amusing and invaluable lived experience perspective to language in the mental health sector

Given the lack of foundational resources located in the time period available, a limited search was made on third-rung resources for themes that were relevant to foundational engagement and would be useful in producing foundational materials.

THIRD RUNG RESOURCES: ELEMENTS AND IDEAS RELATING TO FOUNDATIONAL ENGAGEMENT. THESE ARE NOT RESOURCES FOR FOUNDATIONAL ENGAGEMENT.

This research project identified many models, frameworks and engagement resources written by consultants, organisations, government departments, individuals and, occasionally, a consumer group, that were aimed at the stage defined in this report as third rung.

Although the project scope did not include evaluation of such 'third rung' resources, many of these resources discussed skills and experience required of consumers to engage which offered some insights that might usefully be applied in developing foundational engagement materials.

'Third rung' resources were found that discussed outcome areas and key outcomes of consumer engagement and participation. However, these were framed in terms of benefits to the organisation rather than focussing on benefits to consumers.

The majority of the resources discussed how organisations could support consumer and/or carer representatives in their role, and how organisations could get the most out of engagement. There were recommendations around building the capacity of staff and clinicians to value, empower and solicit the lived/living experience voice. There were recommendations on course content for pre-engagement training which covered formal aspects of representation such as meetings, EOIs, payment policy, representation and responsibilities. There were rationales for engagement and discussions 'proving' how empirically valuable consumer participation was to service delivery. The focus, however, tended to be on what would happen after the individuals, family members or supporters were engaged.

Within these discussions were some less explored ideas. There was a suggestion in some resources that services actively support people with lived / living experience to use participation as a learning experience.

Supports included mentoring, debriefing, and seminars for engaged individuals, families and supporters in which opportunities to network, compare experiences and learn both formally and informally were facilitated. These were floated as suggestions and ideas however. There was no information found about any actual support resources and how they were delivered or developed nor were there evaluations of any such resources.

There was no resource found in this area (third rung engagement) that discussed pre-engagement capacity-building at a foundational level or provision of basic skills, social services and knowledge.

An example of a third-rung resource which may be of use in developing foundational materials is the Health Consumers Alliance of South Australia (HCASA) consumer training. HCASA offers a six-hour course in the Adelaide Central Business District, SA, for "… members of the public who are interested in becoming a consumer advocate in SA Health and Local Health Network consumer advisory structures"65. Participation payment offered includes; "travel costs e.g. fuel, parking, public transport if needed and … some funding available to support travel costs for country consumers."

Additional relevant training and development resources are outlined below.

COURSES WITH FORMAL QUALIFICATIONS

Resources marketed as consumer training and courses varied from formal Australian Qualification Framework (AQF) accredited units offered by Registered Training Organisations (RTOs) to less formal training, courses and workshops offered by NGOs. The former articulated into formal qualifications and the latter were advertised as preparatory steps to consumers being present at the engagement table.

Australia has a national policy for regulated qualifications which are delivered by Registered Training Organisations (RTOs) called the Australian Qualification Framework (AQF). All AQF qualifications go through a government accreditation process and are quality assured. Providers are formally registered and authorised under law to issue the AQF qualifications for which they are approved. From the AQF website.[66]

> **“The AQF is the national policy for regulated qualifications in Australian education and training. It incorporates the qualifications from each education and training sector into a single comprehensive national qualifications framework. The AQF was first introduced in 1995 to underpin the national system of qualifications in Australia encompassing higher education, vocational education and training and schools.”**

VICTORIA

Qualification	**Provider**	**Cost**
Course in Consumer Leadership AQF Code 10163 NAT	Health Issues Centre and The Benchmarque Group Pty Ltd	$1 089.00 (GST inclusive)

The course requires three days of contact hours plus an additional eighteen hours of self-directed learning for successful completion.[67]

Advanced Qualifications:

One university was identified that offered a Professional Qualification for consumer representatives and health professionals.

SOUTH AUSTRALIA

Qualification	**Provider**	**Cost(2015)**
Professional Certificate in Health Consumer Engagement	UniSA International Centre for Health Development	$1 000.00 for first course and $1 200.00 for second course (GST inclusive)

The course brochure states that the course has been co-designed by the University of South Australia and the Health Consumers Alliance of South Australia.

This resource is currently being reviewed for wider applicability and scope by UniSA's Consumer Engagement Research Team therefore has not been assessed. Although the resource is not foundational. as defined in this report, due to the involvement of lived experience representatives in the resource's development, it is included here.

The Consumer Engagement Research Team
can be contacted via Angela Berndt: Angela.berndt@unisa.edu.au or telephone 8302 2806.

FORMAL CONSUMER PARTICIPATION TRAINING

'Third rung' resources often state the importance of appropriate consumer representative training. In response to this need, some training and education in how to 'do' consumer representation is offered by Australian NGOs. 'Third rung' training course content identified in this study included:

- skills
- effective participation
- self-care
- risk assessment
- roles within groups
- communication skills
- networking and consultation with fellow consumers
- active listening
- assertiveness
- negotiation and conflict resolution
- effective advocacy
- contextual Knowledge
- how the consumer voice has shaped mental health system change
- types of committees on which consumer representatives serve
- understanding the responsibilities of consumer representatives
- meeting procedures
- committee dynamics
- conflict of interest
- confidentiality
- national standards
- personal beliefs, values and networks

These skills and contextual understandings might be useful to institutions and organisations as elements in the creation of foundational resources.

BARRIERS AND FACILITATORS TO FOUNDATIONAL ENGAGEMENT

More general themes were drawn from a number of resources. These resources identified that:

- some individuals, families and supporters feel that they lack credibility in the eyes of mental health professionals
- some individuals, families and supporters may have limited knowledge and understanding of health issues.
- their communities may also have limited knowledge and understanding of health issues. conversely, some individuals, families and supporters believed they had better skills and knowledge of navigating across multiple sectors than some practitioners who tended to be focussed in one area. Their experience of having this expertise overlooked or dismissed often led them to disengage.
- some individuals, families and supporters believed that participation would be ineffective, unrewarding or tokenistic given their previous experiences of services.
- there was often a lack of understanding of safe engagement practices by service providers.

Papers and frameworks made occasional references to barriers and facilitators at foundational entry level. One such example is the study by Gee at al in which individual and systemic barriers from foundational to actual engagement levels are named but not necessarily discussed in any depth.

Research directly involving consumers and family members generally began at the level of actual engagement by services, and was written to inform service providers on consumer engagement strategies, benefits and practice.

In a study by Gee, McGarty & Banfield (2016).[68] consumers and carers cited individual barriers to participation which included "… fatigue and stressful workloads among representatives, high level of commitment and skills required to manage the workload, changes in life circumstances of representatives which requires attention, committees not providing material in advance of meetings, and uncertainty at times about purpose and direction". These types of findings were reflected in other studies and papers researched during this project.

Consumer engagement frameworks and papers for engaging with members of Culturally and Linguistically Diverse communities regularly discussed barriers and facilitators. These documents are very useful in identifying CALD-specific barriers and are transferable when considering some aspects of foundational resources. For example, it is important for foundational resources to be culturally competent and to recognise that using literacy levels of the dominant culture is inappropriate when providing foundational resources.

> **One of the major barriers to consumer participation identified was the effects of consumers' history of disempowerment and lack of choice.**
>
> (Gee, McGarty & Banfield, 2016)

> **… for some consumers, a lack of confidence, motivation, energy, cognitive skills, a clear sense of direction, assertiveness or communication skills (particularly the ability to articulate ideas in group settings) created a barrier to participation.**
>
> (Honey,1999)

LITERACIES RELEVANT TO ENGAGEMENT

In 2006 the Australian Bureau of Statistics' Adult Literacy and Life Skills Survey (ALLS) measured the literacy level of Australians.[69] The ALLS provided information on knowledge and skills in four domains:

Prose literacy: the ability to understand and use information from various kinds of narrative texts, including texts from newspapers, magazines and brochures.

Document literacy: the knowledge and skills required to locate and use information contained in various formats including job applications, payroll forms, transportation schedules, maps, tables and charts.

Numeracy: the knowledge and skills required to effectively manage and respond to the mathematical demands of diverse situations.

Problem-solving: goal-directed thinking and action in situations for which no routine solution is available.

As a by-product of these domains, a fifth domain measuring health literacy was produced.

Health literacy: "… the knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy".70 (ABS, 2008).

Results of the above survey were grouped into 4 skill levels with Level 1 being the lowest measured level of literacy. To assist with interpreting the results, Level 3 was regarded by the survey developers as the "minimum required for individuals to meet the complex demands of everyday life and work in the emerging knowledge-based economy" (ABS, 2008).

The ALLS revealed approximately 46% of Australians aged 15 to 74 years had scores at Level 1 or 2 on the prose and document literacy scales. On the numeracy scale approximately 53% of Australians were assessed at Level 1 or 2. On the problem-solving scale approximately 70% of Australians were assessed at Level 1 or 2.

On the health scale, approximately 60% of Australians attained scores at Level 1 or 2. For the health literacy and problem-solving scales, the unemployed and those not in the labour force had the highest proportion assessed at Level 1 or 2 (75% and 84% respectively).

Those with lower literacy scores (Level 1 and 2) were less likely to have used the Internet. The ALLS was conducted in English. Literacy skills of people whose first language was not English scored lower than the population whose first or only language was English. Seven countries took part in the survey with Australia ranked in the middle of each scale.

HEALTH LITERACY

Health literacy is described as the degree to which individuals can obtain and understand basic health information to make appropriate decisions regarding their health. While this was named as a barrier in some resources, there was little discussion about how this could be addressed.

Individuals, families and supporters who attend sector forums and meetings have often discussed the exclusionary language that is used, often unwittingly, by health service providers. Phrases such as 'primary health care' or 'iatrogenic effects' may seem commonplace in a service, however, these are not terms easily understood in the general community. They do not pass the pub test! This speaks to the need to have clearly understand language which is available in a range of formats to best suit people's learning and communication.

FINANCIAL

Participation Payment Government departments, peak bodies and NGOs in the mental health and AOD sectors are increasingly developing and implementing new or updated Paid Participation policies. As well as providing much needed financial reimbursement for time, costs and expertise, the presence of a Paid Participation policy indicates a thoughtfulness about the needs of individuals, families and supporters which augurs well for the next steps of engagement.

FUNDING

For lived / living participation to be sustainable and meaningful, it requires a line item to be clearly identified in the budget. Without this, there will continue to be inadequate Participation payments and support resources. For example, printing or photocopying hard copies of reports or meeting documents are the sorts of hidden expenses which people often do not have money to cover.

While people who work in services have access to general administration supports such as internet access, paid telephone, photocopier, printer, a computer that works and can be fixed or replaced easily if there's a problem, this is not the case for individuals, family members and supporters, particularly in the early days of engagement or pre-engagement.

Having to pay for parking and other costs upfront while waiting for up to four weeks for reimbursement from a government department can make a significant difference to a person on a tight budget and their capacity particularly if they are reliant on income from Centrelink payments or casual work. This difference in access to resources is a fundamental inequity which must be resolved prior to engagement.

> **“There can be economic as well as well as social and ethical reasons why a health care facility or organisation may believe that the provision of financial assistance to pay consumers to attend training and/ or to meet any costs associated with the training or education is in its best interests as well.**
> (Commonwealth Department of Health and Aged Care, 2000) 71 ”

ACCESSIBILITY

Communication; mediums and methods in Australia:

The Internet was the medium through which most institutions, organisations and groups were found to formally communicate resource offerings. Some used the Australia Postal service, often specifically when asked by individuals, families and supporters who did not have internet access. Informal communication was via word of mouth and networking.

Written texts were the main methods of communication found. Seven podcasts were located via the Health Consumers Council of WA website (see example 2 below), two of which were related to consumer engagement and participation.

INTERNET PRESENCE

All finalised foundational and third rung resources identified during this project had an internet presence.

The number of host organisations who offered ‘third rung’ resources, and the types of those resources, fall outside the scope of this research and, therefore, were not recorded. The methods offered, however, are of interest to inform future resource accessibility. Some Western Australian examples are presented below:

EXAMPLE 1:

CoMHWA's e-newsletters available online through links or to subscribers.

- subscription available to the public and secured by contacting the organisation via email or telephone and;
- newsletters accessible by clicking on a link
- membership; 614 individuals and 64 organisations and groups (as at 4 March 2018)
- [http://www.comhwa.org.au/news/newsletters/]

EXAMPLE 2:

Health Consumers Council of WA podcasts.

- podcast streaming on ‘How You Can Become Involved In Improving The Health System’ and ‘Why it's important to have consumer perspectives & engagement’.
- 3 followers, 7 tracks (as at 4 March 2018) [https://soundcloud.com/user-992850294]

EXAMPLE 3:

Health Consumers Council of WA Facebook page.

- links, opportunities, training, events and networking opportunities
- created 2 years ago, 22 members and 4 posts in the last 30 days (as at 4 March 2018)

Excerpt: Description
This group is for people who are either upcoming, experienced and/or active Health Consumers' Council (WA) Inc Consumer Representatives. This the community for you to connect, learn from one another and to share information and resources. Source will provide you with:

- Links to relevant resources about consumer representation and the health care sector to build your knowledge
- Consumer Representative position opportunities
- Training and education notifications
- Events so you can save the date
- A place to network

Please check out Source regularly so you can Connect, Learn and Share.

FORUMS AND EVENTS (EVENTS)

Host organisations sometimes offer events to build consumer and family capacity to engage in planning, delivery and evaluation of health care. Events identified in this research have been described by hosts in many ways; common amongst them being; consultation, 'think-tanks', courses, information sessions, and training.

As anecdotally reported by consumers and family members, events can be useful to formally or informally facilitate the sharing of skills, connect people with resources, and/or provide networking opportunities at different levels. Attendees have reported utilising events to exchange information, ideas, contact details and resources that host organisations do not necessarily include. These exchanges can certainly include foundational aspects of engagement, but this research project did not find events that were foundational in and of themselves.

CULTURAL SECURITY

Aboriginal and Torres Strait Islander (ATSI) peoples Searches revealed no foundational ATSI-specific resources on consumer engagement and participation for ATSI consumers and family members.

The Australian Human Rights Commission (2012) publication 'Aboriginal and Torres Strait Islander Peoples Engagement Toolkit'[72] provides general engagement recommendations and principles. This is an informative and useful document for institutions, organisations and individuals who offer foundational and non-foundational engagement resources but is not health, mental health or AOD specific.

FACILITATORS OF ENGAGEMENT WITH ATSI COMMUNITIES

widespread community involvement an explicit focus on the Indigenous population as a whole and high-risk individuals in particular the use of Indigenous health workers regular contact with participants was identified as contributing positively to the engagement process (Huffman and Galloway, 2010)[73].

> “Mr Atem highlighted the need to build the capacity of refugees, not only by providing resources, but through leadership training and the development of practical skills.”
>
> (Refugee Council of Australia, 2017[74])

ETHNIC MINORITIES /CALD COMMUNITIES

According to the 2016 census, almost a third of Western Australia's population (32 per cent) reported they were born overseas (ABS, 2016). The 2007 census identified about two-thirds of those born overseas were born in non-English speaking countries (ABS, 2007).

No foundational resources for ethnic minority communities were found during this research project. There were, however, publications identified that could be useful in informing future foundational resources.

One such publication is Consumer Participation and Culturally and Linguistically Diverse Communities: A Discussion Paper. Section 2 of the Discussion Paper speaks to CALD consumer participation;

> “***… there is a scarcity of literature documenting CALD consumer participation practice. The Centre for Ethnicity, Culture and Health (CEH) argues that, compared with the growing developments in consumer participation in general, there is little documented work on consumer participation models, methods and strategies for CALD communities (CEH, 2005:6-7). In general, lack of research and evidence based on CALD communities' health is also reported by the NHMRC, arguing that "mainstream research frequently excludes consideration of people from CALD backgrounds due to perceived methodological difficulties and costs" (2005:22), and that: "programs are unlikely to succeed unless they are based on mutual respect and understanding, and are adopted as shared responsibility by the community.***”
>
> Mansourian, McBride & Romios, 2007, p 7.)75

> “**Reports on the experience of CALD consumers in mental health care have highlighted consumer experiences of cultural insensitivity, institutional racism and culturally inappropriate care**”
>
> (MHiMA Framework for Mental Health in Multicultural)76

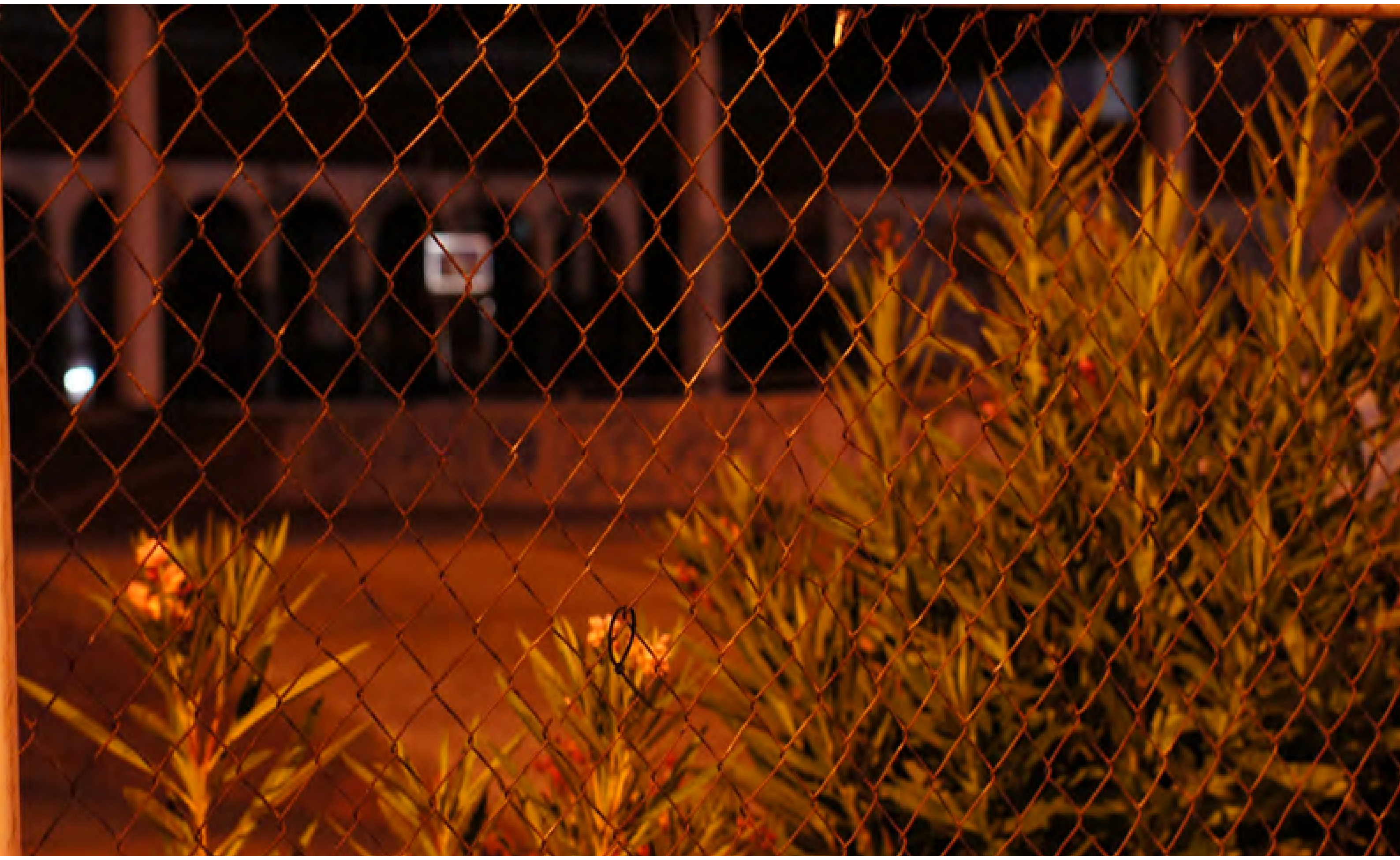
A list of relevant barriers, enablers and potential strategies identified and discussed in publications found on CALD engagement is detailed below. These are taken from resources aimed at informing service providers about engagement. Although not written as a foundational resource, they are useful to institutions, organisations and groups that may want to create those type of resources. The lists below are not exhaustive. Sources are given at the end of the lists.

BARRIERS

- Low levels of mental health literacy
- Insensitivity to the socio-cultural needs of CALD consumers and communities
- Lack of understanding of socio-cultural factors
- Lack of effective communication
- Systemic and organisational barriers
- Ongoing issues for CALD participation
- English language proficiency
- Insensitivity to the needs of CALD background communities
- Family responsibilities
- Social isolation
- Access to transport
- Cost

FACILITATORS

- Culturally appropriate venues
- Cultural competency
- Comparative analysis between demographic and service utilisation data: knowing who is out there and who is and isn't using the services
- Accessible and appropriate language services
- Developing equal partnerships with multicultural and ethno-specific agencies, organisations and multiple community groups
- Availability of accessible health information
- Workforce diversity in institutions and organisations
- Whole-of-community approach
- Organisational commitment with adequate resourcing
- building trust with communities through community development
- dedicated strategies and partnerships
- targeting community engagement and improving mental health literacy



Of relevance to this project are some of the strategies suggested in the Discussion Paper by Mansourian et al 2007. Some of these have been taken directly from the Discussion Paper and others have been re-phrased for the purpose of articulation into the development of future foundational engagement resources.

POTENTIAL STRATEGIES TO FACILITATE FOUNDATIONAL ENGAGEMENT

- The use of (local) ethnic media such as radio and newspapers.
- The implementation of CALD-specific consultation and participation initiatives.
- The full integration and inclusion of CALD consumers as part of their participation experience with the aims of supporting participation, conveying facts, and educating and learning from them.
- The provision of information in a variety of translated formats (CDs, videos, diagrams, pictures, brochures, websites).
- The provision of language and interpreter services.
- The development of cultural competency among service staff and management.
- The development of resources in collaboration with or, indeed, in co-production with CALD communities.
- The development of resources that acknowledge cultural practices and beliefs.
- The acknowledgment of barriers that exist for CALD communities' access to resources.
- The acknowledgement of the stages of adjustment and response to stressors experienced by individuals and communities.
- The use of informal networks as well as working through community leaders to encourage participation of all community members.
- The development and maintenance of reciprocal relationships.
- The enhancement of health literacy among CALD communities.
- The building of trust between communities and services.
- The active engagement by services with the community, rather than requiring community members or representatives to engage with the service.

The paper, 'Cultural competency in health: A guide for policy, partnerships and participation' (National Health and Medical Research Council, 2005)[77], speaks to engaging consumers and communities in terms of reciprocal relationships and suggests "approaches that combine community development, capacity building and peer education help establish reciprocal relationships and strengthen a community's capacity to support its members and liaise with the health sector."

Sources for the above lists were the National Mental Health Consumer and Carer Forum (2010)[78], Mansourian et al (2007), MHiMA Framework for Mental Health in Multicultural Australia Key Concept 4 Consumer and carer participation (2014), and Experts by Experience: Strengthening the mental health consumer voice in Tasmania (2009)[79].

> **“Service providers need to “understand the concept of culture and its impact on human behaviour, and recognise how specific problems are experienced, expressed and defined by consumers and carers of diverse cultural backgrounds”**
>
> (Procter cited in NHMRC, 2005, p24) 80

CO-OCCURRING FOCUS

Specific and special consideration towards multiple occurrences such as mental health diagnoses and AOD use coupled with cognitive impairment and/or physical conditions including disability, was not detected in resources found.

LIVED EXPERIENCE AUTHORSHIP

Resources identified in this research project ranged from standard course content written by unidentified persons and institutions (one example being the Course in Consumer Leadership, AQF Code 10163 NAT) to current and emerging foundational resources which are being written and co-produced by people with lived experience.

There is an opportunity for training organisations and universities to provide skills and knowledge building to lived experience groups and work alongside them in order that the views, understanding and expertise of lived experience is more effectively heard in future foundational engagement resources.

ADVANCED KNOWLEDGE

The concept of ‘advanced knowledge’ was introduced in Honey (1999). Advanced knowledge was deemed to be advantageous to consumers already engaged in mental health sector participation as it provided “… the opportunity to think about and find out more about the topic and to work out any questions [consumer participants] want to ask.” (p265).

Discussion

bringing it all together

The purpose of this study was to produce a report that finds and examines resources in Australia which are aimed at supporting foundational engagement with individuals, families and supporters in the mental health and alcohol and other drug (AOD) sectors. The particular focus was to highlight those resources developed in full or part, with or by people with lived/living experience in the relevant areas.

The metaphor used in the report is that of a ladder of engagement used by government, service providers and others wishing to engage with individuals, families and supporters on which the first two rungs – the foundational level - are often missing. This makes it difficult, if not impossible, for people from a diversity of backgrounds and communities who have lived/living experiences of mental health and AOD use to participate easily in a range of sector activities and discussions. These activities include but are not limited to: committee membership on service level or strategic committees; training and development; policy development and review; consultations; forums or other activities.

It is particularly important to ensure a diverse voice in activities claiming to use co-design and/or co-production approaches which, by their very nature, are power-shifting and power-sharing approaches. The Western Australian Association for Mental Health, in its submission to the 'Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015-2025' advocated that "vulnerable and marginalised groups, who may not engage with services, need particular consideration in service design and engagement strategies'.[81]

Third rung engagement was defined as participation which presumed that individuals, families and supporters already had a level of confidence, competence and resources. These opportunities were often made available through an Expression of Interest process followed by a selection interview. These processes alone assume a reasonable level of literacy and English language use and can be anxiety-provoking. Even when selected, it was often assumed by services that the individual, family member or supporter had sufficient cash to pay upfront for expenses such as travel, parking, coffees, printing and internet access. This could be challenging to manage on tight budgets. Having to raise issues around payment and resourcing is potentially shameful for individuals, families and consumers, especially those from some ethnic minority communities.

The need to intentionally create a safe space for people with lived/living experience to enter and contribute comfortably, the understanding of why this was important and tools and strategies to make this happen, were rarely mentioned in the materials located by the research. This is despite safety being commonly mentioned in consultations around engagement such as those which took place for the development of the Western Australian Mental Health Commission's Engagement Framework, which is due for publication around the time of this report. The draft consultation document for the Engagement Framework included Safety as one of five underlying principles and describes it as "developing cultural, physical, moral and emotional safety for everyone involved'.[82] Ensuring safety is particularly crucial when working alongside people who often have backgrounds and/or ongoing experiences of distress and disruption. The term 'lived/living experience' was used to denote that many individuals, families and supporters continue to manage those difficult experiences while engaging at service, system and strategic levels.

While this may also be true for some people who work in services, they at least have the support of a stable income, paid leave - including carer and sick leave, workers' compensation cover, an Employee Assistance scheme which offers them and family members access to free counselling and hopefully the support of colleagues and a mental-health aware employer.

LANGUAGE

Language is an important tool with which engagement is crafted. Using the language of 'educating' or 'informing' ('doing to')[83] will invoke a different response by individuals, families and supporters to engagement than language which seeks to recognise lived experience expertise (learning from experts by experience).

The difference in the labels given to describe people and adopted by them is note-worthy. There was consistency across the mental health sector with the words 'consumer', 'carer', 'family' and (less frequently) 'lived experience' common in resources found.

The AOD sector tends to use the term 'consumer' fairly consistently and 'users' to a lesser extent. As stated in the Language and Key Phrases section of this report, the ways in which people identify in the mental health, AOD and other allied areas, for example, justice and child protection, are contested.

WHO'S THE EXPERT?

The willingness and commitment to embrace the perspective of lived/living experience is underpinned by an assumption that this perspective has value. While Recovery is now embedded in international, national and state frameworks, policies and standards relating to mental health, it is important to acknowledge that some mental health services continue to be dominated by a reductionist bio-medical model[84].

In this model, individuals are more likely to be viewed through the lens of their diagnosis and deficits (schizophrenics and addicts), rather than through a strengths-based model (people with a diagnosis of schizophrenia who have unique strengths and abilities).

Families and supporters may also be excluded from engagement as a result of similar discriminatory views[85]. Within a narrow medical model, the expert view is that of the psychiatrist or senior clinician, certainly not that of the individual, family or supporter.

> **“These systems of meaning, which dominate mental health service delivery, presuppose and privilege psychiatric understandings of madness and distress as involving 'illness' and 'disorder', which must be cured, fixed, and managed. The Special Rapporteur on the Right to Health has recently made recommendations aimed at addressing 'the imbalance of the biomedical approach in mental health service.”**
>
> (Human Rights Council 2017, p. 20)

Genuinely acknowledging the value of lived expertise and implementing strategies to embrace it is a paradigm shift which requires courageous leadership committed to culture change and a willingness to resource this area. Making this shift for individuals, families and supporters who experience mental ill-health and alcohol and other drug use is particularly momentous given what is known about the high levels of stigma and discrimination they face.[86]

Tritter and McCallum (2015) in their paper on ‘The snakes and ladders of user involvement: Moving beyond Arnstein’ suggest that: “the key contribution users make arises from their distinct personal experience and non-medical or technical frame of reference; it is asking questions that health professionals have not considered. One aim of user involvement may be to break down boundaries, share experience, and buld understanding. This suggests not a hierarchy of knowledge – relevant professional versus irrelevant lay – but rather a complementarity between forms of knowing, set within a willingness to acknowledge differences”.[87]

Achieving meaningful engagement means acknowledging different types of expertise as equally valuable and building equity strategies (for example, a Paid Participation policy) into engagement to ensure that people with lived experience, including those who may also be living in poverty[88] can attend and inform discussions and decision-making.

A resource developed by Roper, Grey and Cadogan (2018) entitled ‘Co-production – Putting principles into practice in mental health contexts’[89] was found to be the only resource that explicitly dealt with the issue of power within a co-production approach in a mental health setting and provided strategies to address it. This resource would be valuable for anyone wishing to become more familiar with the inherent issues involved in engaging in an area where there is such a structural imbalance of power. It is important to remember that mental health is the only health area where people can still be involuntarily detained and forcibly medicated against their will.

These restrictive practices may have been experienced by the people with whom a service is attempting to engage and while they may have been historical experiences, the trauma caused by them may still be unresolved.

Honey (1999)[90] examines empowerment in consumer participation. The context in which it is discussed relates to individual and institution experiences, situations and aims. Honey speaks to both participation and engagement; considerations for getting the consumer to the table and what institutions need to do once the consumer is there with a focus on empowerment. “Disempowering experiences, structures and attitudes were found to be central barriers to consumer participation. Provision of empowering experiences, skills and environments was at the core of strategies suggested to increase participation. Empowerment and consumer participation can be seen to interact in an upward spiral, with empowerment leading to increased participation and participation contributing to increased empowerment.” (p 265).

The Special Rapporteur on the Right to Health[91] states that

> ***"It is important to facilitate the empowerment of individuals, especially those with particular mental health needs, through the support of self-advocacy initiatives, peer support networks, trialogues and other user-led advocacy initiatives, as well as new working methods, such as co-production, which ensure representative and meaningful participation in health-service development and provision. In that regard, creating space for civil society and supporting the activities of non-governmental organizations is crucial to restoring trust between care providers and rights holders using services."***

LIMITATIONS

There were a number of limitations to this study.

The research did not explore foundational engagement at an individual level where people and practitioners work together as partners in care for the person's individual health needs.

The majority of the research was required to be carried over the Australian peak holiday period in order to bring the report to completion within the required timeline as per grant requirements. Surveys were distributed and telephone contacts were made between November – January. This made it more difficult to speak directly to the appropriate person in a service who might be the most familiar with the particular resource being sought. It also may have contributed to the low number of responses to the survey.

Due to limitations of funding and time, it was not possible to explore foundational engagement in relation to specific groups within the mental health and alcohol and other drug sectors such as children and young people; older adults; people living in rural, regional and remote communities; refugee communities nor to delve into sub-groups within a larger group, for example, in the LGBTIQ community. The groups mentioned are among those who are known to be under-represented in engagement and decision-making.

The scope of this research was to locate and examine foundational engagement resources in Australia. It did not therefore examine international resources which may be focused on foundational engagement or have relevant elements. The following resources may be of interest in this area: the Team Recovery Implementation Plan (TRIP)[92]; Open Dialogue[93]; Comprehensive Continuous Integrated Systems of Care (CCISC)[94] and Implementing Recovery through Organisational Change (ImROC)[95].

'FINDING NEMO[96] ON THE 'NET'

'Finding Nemo' is a movie which tells the story of a clownfish who searches for his son (Nemo), experiencing many adventures, blocks and frustrations and meeting unexpected allies who help him succeed. The challenge of finding up-to-date and relevant information via the Internet could be seen as a similar journey. This situation is contributed to by webpages that are not kept up-to-date and links which were found to have expired. There was also little information available online about projects in development. These were generally tracked down through personal, peer and professional networks. This therefore, requires that the person carrying out the research has active, well-developed networks in the relevant areas.

The difficulties experienced in finding useful, relevant resources for this report was reflective of the difficulties often experienced by individuals, families and supporters in accessing information in order to effectively engage with services.

People who experience mental ill-health or problems with AOD use and their families and supporters have a range of skills, experience and knowledge of accessing the internet. These variances are in addition to the issue of physical access to the internet, the quality of the physical device being used (an old phone versus an up-to-date laptop) and the quality of the connection (copper wire landline versus NBN). The latter is particularly relevant for those living in regional, rural and remote areas of Western Australia. Trying to locate a resource that is not easily found can be frustrating. This can be influenced by the person's current level of health, time available to them to undertake searches, level of interest and cognitive (dis)ability. These factors can intersect and change quickly.

Sites and resources are best accessed when easily found and navigated, when clearly labelled, when the language and terms used are consistent and when allocated a stable, permanent place within an active website.

BARRIERS TO EFFECTIVE ENGAGEMENT

The barriers to effective foundational engagement were identified and discussed. Barriers to general engagement are also detailed in a number of recent reports including the Western Australian Mental Health Commission's Draft Consultation Engagement Framework[97] and are relevant to foundational engagement. They include:

- tight timelines which make meaningful engagement difficult
- minimal or zero budget for participation payments or reimbursement of expenses
- lack of understanding of the benefits of engagement
- lack of knowledge and skills around engaging with individuals, families and supporters who have lived/living experience of mental health and AOD use
- unacknowledged and unaddressed issues of power and control
- stigma, discrimination and prejudice
- lack of clarity around engagement processes
- unwillingness to stay with the process which can sometimes be uncomfortable and challenging
- poverty and insufficient resourcing to engage
- inappropriate language or literacy level used
- lack of culturally competent engagement understandings and strategies
- lack of understanding or support from senior decision-makers.

FACILITATORS FOR EFFECTIVE ENGAGEMENT

A number of factors contribute to effective foundational engagement. These include:

- providing training and resources for individuals, families and consumers
- developing resources which are graphic-based, rather than those with large blocks of text. Examples include presenting information in infographics which are easy to understand or via podcasts which can be downloaded to a free app.
- building and promoting a culture within an agency that values lived experience expertise
- Support and encourage frontline workers, including peer workers to share information about foundational engagement opportunities with their clients
- co-designing safe spaces and processes for engagement
- creating easily accessible and understood policies and processes which support engagement. These might include a Paid Participation policy, clear complaints processes, opportunities to give feedback on the process and experience of engagement
- having a commitment to building respectful relationships between staff and individuals, families and supporters
- addressing stigma, bias and discriminatory actions or practices
- recognising that individuals, families and supporters engaging at a foundational level may also be managing allied issues such as poverty, poor housing, lack of reliable transport and having flexible practices to acknowledge these very real problems-of-life

> **“ I would not have considered applying for the consumer rep role if my support worker hadn't encouraged me to. ”**

COMMUNICATING THE BENEFITS

Host organisations often describe the benefits for individuals, families and supporters of engagement, in their marketing of resources. These may include:

- being paid an honorarium
- ensuring consumer rights, needs, views and interests are represented
- being a partner in the planning, delivery and evaluation of health care services
- expanding knowledge and skills
- building confidence
- learning how to research information and resources.

The benefits of increasing engagement with individuals, families and supporters in the broader health care system are well evidenced in national and international literature[98] According to the Australian Capital Territory's Consumer and Carer Participation Framework (2011), these include:

- improved health outcomes for consumers
- increased openness, trust and respect
- improved safety and quality of health services provided
- improved safety and quality of health services provided
- improved responsiveness based on meeting consumer needs and community priorities
- increased openness, trust and respect for consumers, carers and community
- improved efficiency and cost effectiveness in how health services are provided
- increased accountability to consumers and carers
- increased consumer focus to drive quality improvement processes
- inclusion of valuable insights from consumers and carers which may not otherwise be apparent, or may be significantly different to those held by health professionals
- improved access to a diverse range of skills, experiences and knowledge
- increased capacity to meet accreditation standards
- improved job satisfaction, staff retention and morale
- reduced conflicts, complaints, litigation; and absenteeism
- increased social capital towards a more inclusive community

Given these benefits, it is particularly important that decision-makers ensure that foundational engagement strategies and practices become embedded as part of general engagement and participation initiatives to ensure that a diversity of lived/living experience expertise informs future policies and practices.

Conclusion

what we've made of it all

There can be no doubt that effective engagement at a foundational level is crucial to ensuring a diversity of perspectives from individuals, families and supporters with experiences of mental health and AOD use. It is particularly important in the areas of mental health and AOD given the stigma and discrimination that continues to affect individuals, families and supporters with experiences of these conditions and who are often managing multiple-occurring problems of life.

Developing initiatives and strategies that not only encourage engagement at a third rung level, but also at a foundational level, will be crucial moving forward, particularly as the language and practice of co-design and co-production becomes more common in the mental health and AOD sectors.

Initiatives must address equity issues to support individuals, families and supporters effectively taking part in a range of engagement activities. Strategies must also address out-dated organisational cultures which may not view people with diagnoses of mental illness or those with histories or current AOD use as having something of significant value to offer to service/system design, development and leadership.

However, given the plethora of standards, policies, laws and frameworks around engagement of people who use services in the design, delivery and review of those services, it is important to now to take positive action to ensure these are transformed into best practice[99] at a foundational level rather than to create even more of the same.

It is also important to build on the empowering work currently being done in fairly disconnected ways in the area of foundational engagement. Many of the resources available and coming online soon will help to create a body of knowledge and skill-building to enhance foundational engagement. It would be useful to evaluate these resources with a view to establishing how effective they become in practice.

Recommendations

what we recommend should happen from here

This report was produced in the context of the tight budgetary situation currently prevailing for the Western Australia State government. With that in mind, the following recommendations are made.

- Build on existing foundational engagement resources such as those outlined in this report, rather than wasting resources in duplicating work already done.
- Evaluate existing engagement resources to establish which are the most effective and provide the best value for different population groups.
- Encourage and support services to produce or adopt a contemporary Paid Participation policy.
- Pay particular attention in evaluation of agencies to the existence and/or development of nuanced policies and practices which support foundational engagement.
- Ensure that foundational engagement policies and practices are part of contractual requirements.
- Co-produce and resource training and development opportunities for individuals, families and supporters from under-represented groups.
- Provide leadership opportunities to people with lived/living experience to lead engagement initiatives and to share their expertise in the sectors generally.
- Create spaces and free events within the sectors where engagement can take place in informal ways in community venues.
- Highlight and promote initiatives and agencies who implement effective foundational engagement.
- Support frontline workers, including peer workers, to proactively share information with their clients about upcoming foundational engagement opportunities.
- Encourage partnerships with training institutions and universities to facilitate the involvement of and future leadership by people with lived experience in course design and research opportunities.

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