

Research Report



The Role of Peer Support for Families affected by someone else's Comorbidity

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Introduction

This report deals with the role of peer support workers for families¹ affected by another person's comorbidity. For the purposes of this paper, comorbidity refers to the co-occurrence of a substance use disorder and a mental health disorder in the same individual.

The peer support worker (PSW) role forms a central part of the expansion of new roles to help transformation of the mental health workforce. This has been set out in Health Education England's report, 'Stepping Forward to 2020/21: The Mental Health Workforce Plan for England which supports the delivery of the Five-Year Forward View For Mental Health² and the NHS Long Term Plan³.

Across academia and service provision most attention on peer support has been focused on the way people with mental health challenges can support others or be supported. We wanted to take a broader approach to understanding how family members who have been affected by someone else's comorbidity can be PSWs for other family members in similar situations. After scanning the literature we have found peer support for families, but this only covers either substance misuse or mental illness, and not comorbidity. Similarly, we have found a long history of PSWs who are recovered substance abusers, but we have not found opportunities for

¹ Throughout this report the term families is used in broad sense to include family members, partners, carers and close friends.

² NHS England, 2016 Five Year Forward View for Mental Health [Available at] <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf> [Accessed 10th April 2020].

³ NHS Long Term Plan, 2019 [Available at] <https://www.gov.uk/government/news/nhs-long-term-plan-launched> [Accessed 9th April 2020].

family members to be a PSW and use their own valuable experience and expertise to help others. Therefore, there is no evidence or practical guidance that relates to the role that can be adopted by family members as PSWs; thus pointing towards a significant gap as their perspective and experience is one which is likely to be both different and relevant.

This thought piece sought to contribute to knowledge in this area by seeking to answer the following questions:

- Can peer support be extended so families affected by someone else's comorbidity provide support to other families in a similar position?
- What are the key and requisite competencies of someone who should be able to support families who have been affected by someone else's comorbidity?

Structure of this report

The following sections of this report start out by covering the literature on comorbidity and its effects on family members. In this section the role of the family is recognised, not only as a facilitator, but more so as people who experience disproportionately worse health outcomes. Thus, the purpose of the section is to highlight where there is an evident need for support in this area. The following section looks at peer support and explains the terminology used in this report. Next, there is an overview of the literature on peer support relevant to comorbidities. Given the paucity of available research, studies covering peer support and substance misuse and mental health are addressed separately, before looking at a small number of reports which place the spotlight more specifically onto peer support and comorbidity. The following sections cover the methods that were employed, involving focus groups and interviews, the findings and recommendations, and the concluding remarks.

Comorbidity and its effect on Families

The direct effect mental health challenges have on an individual's overall wellbeing is well documented. Likewise, the affects of substance misuse on abusers is also well reported. They can each impair mental functioning, damage overall spirit whilst they can deteriorate a person's physical health. There is also growing recognition of the effect of the co-occurrence of mental disorders and intake of harmful substance. The combination of such disorders is associated with a higher risk of delayed diagnosis⁴, more severe psychopathological symptoms⁵, less compliance with treatment⁶, poorer effects of treatment⁷, more impairment of social functioning⁸, increased admissions to emergency departments⁹, higher prevalence of physical comorbidity¹⁰, and suicidal ideation¹¹. People with

⁴ Albanese MJ, Clodfelter RC Jr, Pardo TB, Ghaemi SN: Underdiagnosis of bipolar disorder in men with substance use disorder. *Journal of Psychiatric Practice* 2006, 12:124-127.

⁵ Ringen PA, Melle I, Birkenaes AB, Engh JA, Faerden A, Vaskinn A, Friis S, Opjordsmoen S, Andreassen OA: The level of illicit drug use is related to symptoms and premorbid functioning in severe mental illness. *Acta Psychiatr Scand* 2008, 118:297-304.

⁶ Verheul R, van den BW, Hartgers C: Personality disorders predict relapse in alcoholic patients. *Addict Behav* 1998, 23:869-882.

⁷ Torrens M, Fonseca F, Mateu G, Farre M: Efficacy of antidepressants in substance use disorders with and without comorbid depression. A systematic review and meta-analysis. *Drug & Alcohol Dependence* 2005, 78:1-22.

⁸ Mazza M, Mandelli L, Di NM, Harnic D, Catalano V, Tedeschi D, Martinotti G, Colombo R, Bria P, Serretti A, Janiri L: Clinical features, response to treatment and functional outcome of bipolar disorder patients with and without co-occurring substance use disorder: 1-year follow-up. *J Affect Disord* 2009, 115:27-35.

⁹ Curran GM, Sullivan G, Williams K, Han X, Collins K, Keys J, Kotrla KJ: Emergency department use of persons with comorbid psychiatric and substance abuse disorders. *Ann Emerg Med* 2003, 41:659-667.

¹⁰ Rosenberg SD, Drake RE, Brunette MF, Wolford GL, Marsh BJ: Hepatitis C virus and HIV co-infection in people with severe mental illness and substance use disorders. *AIDS* 2005, 19(Suppl-33).

comorbidities are also more often unemployed¹², homeless¹³, and involved in violent episodes¹⁴ or criminal behaviour¹⁵. Furthermore it may also be useful to reflect upon the term multiple morbidity, simply defined as the co-existence of two or more chronic or long-term conditions; multiple morbidity, and its impacts, is devoid of research. The research that is emerging highlights people living in the most deprived areas had double the rate of multi-morbidity in middle age than those living in the most affluent areas. Put another way, they developed multi-morbidity 10-15 years before their more affluent peers; and in the less affluent multi-morbidity due to combinations of physical and mental health conditions was common¹⁶. Although these factors are critical to understand, also of significance are the adverse effects they can have upon family and friends, living within these multi-layered contexts, and the support and guidance they need to deal with various situations arising from the interactions between these morbidities.

¹¹ Cottler LB, Campbell W, Krishna VA, Cunningham-Williams RM, Abdallah AB: Predictors of high rates of suicidal ideation among drug users. *Journal of Nervous & Mental Disease* 2005, 193:431-437.

¹² Fergusson DM, Horwood LJ, Lynskey MT: The effects of unemployment on psychiatric illness during young adulthood. *Psychol Med* 1997, 27:371-381.

¹³ Caton CL, Shrout PE, Eagle PF, Opler LA, Felix A, Dominguez B: Risk factors for homelessness among schizophrenic men: a case-control study. *Am J Public Health* 1994, 84:265-270.

¹⁴ Elbogen EB, Johnson SC: The intricate link between violence and mental disorder: results from the National Epidemiologic Survey on Alcohol and Related Conditions. *Arch Gen Psychiatry* 2009, 66:152-161.

¹⁵ Goldstein BI, Levitt AJ: The specific burden of comorbid anxiety disorders and of substance use disorders in bipolar I disorder. *Bipolar Disorders* 2008, 10:67-78.

¹⁶ Barnett KI, Stewart W Mercer, Michael Norbury, Graham Watt, Sally Wyke, Bruce Guthrie: Epidemiology of multimorbidity and implications for healthcare, research, and medical education: a cross-sectional study *Lancet* 2012; 380: 37-43

There are many ways that an individual in contact with someone experiencing comorbidities can be impacted. From Equal Vision's work we have frequently found friends, families, co-habiting partners and co-workers to experience disadvantageous affects on their own physical and mental health, in addition to their own professional and social lives. For instance family members can often assume responsibility for a wide range of tasks which places great pressures upon them. We have heard many stories of children and young people suffering in their homes, as they are trying to make sense of their kin with comorbidities, whilst struggling to cope within their respective learning environments. Even a co-workers response to a colleague of increasing their own workload or helping to hide the reality of a serious situation to aid someone who is struggling with the co-occurrence of substance misuse and mental illness. With the absence of support for these family members they have found creative ways to attend to the issues and dynamics that unfold on a daily basis.

There is little doubt that the family has a crucial role to play. The branch of psychology that focuses on family relations has been credited with being the catalyst for studies which look at the suffering and conflicts people experience which encompasses the role of the family¹⁷. This can be seen through the emphasis on family therapy systemic models. The idea behind such an approach is that the family can be the basis of personal development, support to its members and a source of socialisation and bonding¹⁸. However, within this movement the conflicts related to comorbidity were viewed as only originating in and being influenced by the family. Substance misuse and mental illness are clearly

¹⁷ Borton CB, Ferigolo, M, Barros, HM: Families that Live with Disorders Related to Substances and Addiction. Journal of Drug Abuse. 2017

¹⁸ Ibid iii

more complex and can only be partially understood by analysing the family context. Nonetheless, what started to be recognised from the family systemic model was the fundamental role the family unit offered in the support and treatment for a person experiencing mental health challenges¹⁹.

Whilst the family unit has been viewed as a contributing factor to the occurrence of a person experiencing comorbidities, and also as a fulcrum of support, the support needs of the family and surrounding network have too often been overlooked, not least by the family members themselves. For instance, there is a developed body of literature which shows the higher risk associated with family members involved in supporting someone who is abusing substances. That this area is often overlooked is concerning as research shows they are more likely to experience stress and emotional and physical strain compared to families that do not undergo this hardship. One study reported work and emotional overload, self-negligence, and medication use associated with high co-dependency among family members who sought the help of a support hotline²⁰. Albeit the concept of co-dependency was developed, and has been used extensively, in the addiction field, however it has done so “without an empirical basis and without consensus on definition”²¹. Co-dependency comprises maladaptive strategies related to non-prioritising attitudes and excessive focus on the substance user that may lead to health and

¹⁹ Ibid v

²⁰ Costa LFA: The Systemic Perspective for the Family Clinic: Theory and Research 2010, 26: 95-104.

²¹ Nordgren, J., Richert, T., Svensson, B., & Johnson, B. (2020). Say No and Close the Door? Codependency Troubles among Parents of Adult Children with Drug Problems in Sweden. *Journal of Family Issues*, 41(5), 567–588. <https://doi.org/10.1177/0192513X19879200>.

emotional harm²². In other words, the concept describes “a range of psychological characteristics among persons who are affected by family members’ or close relatives’ problematic use of alcohol and other drugs”²³. Moreover, within the aforementioned study, this group of families exhibited difficulties in communication, in interaction style and behaviour control, and problem-solving²⁴. Additionally, children of alcoholics are more likely to have problems with alcohol and other drugs, controlling emotions, and suffering. Impaired academic performance and communication were also observed²⁵. Adult sons and daughters, in turn, used depressive and aggressive coping strategies to deal with their parents’ alcohol consumption²⁶. It is worth pointing out that studies have shown that family members of drug users may have difficulties in balancing their own lives and health and, at the same time, help the family member²⁷. It may be useful to consider that the term codependency has served to distract from the potential role of the family member as a positive source of support for those living with addictions/comorbidity, as it biases a view toward enablement, rather than strengths that could be supported to benefit their peers or those in similar circumstances.

²² Dackis C, O’Brien C: Cocaine dependence: a disease of brain reward centers. *Journal of Substance Abuse Treatment* 2001, 21: 111-117.

²³ Nordgren, J., Richert, T., Svensson, B., & Johnson, B. 2020. Say No and Close the Door? Codependency Troubles among Parents of Adult Children with Drug Problems in Sweden. *Journal of Family Issues*, 41(5), 567–588. <https://doi.org/10.1177/0192513X19879200>

²⁴ Dear G, Roberts C: The Holyoake Codependency Index: investigation of the factor structure and psychometric properties. *Psychol Rep* 2000: 87: 999-1002.

²⁵ Denning P: Harm reduction therapy with families and friends of people with drug problems. *J Clin Psychol* 2010, 66: 1-11.

²⁶ Carrol K, Onken L: Behavioral therapies for drug abuse. *Am J Psychiatr* 2005, 162: 1452-1460.

²⁷ Prest L, Berson MJ, Protinsky HO: Family of origin and current relationship influences on codependency. *Fam Proc* 1998, 37: 513-528

Impacts on families, and caregivers, including increased rates of mental health and physical conditions and/or increased mortality has also been shown to vary depending on the mental disorder or harmful substance being used. Multidimensional impacts have been observed with serious mental illnesses, including physical health problems (sleeplessness, headache and extreme tiredness), psychological difficulties (depression and other psychological problems) and socioeconomic drift (less likely to marry and higher divorce rate and greater food insecurity)²⁸. And for people who abuse drugs, the impact of each substance has been known to vary. Alcohol addiction may impair conjugal and parental relations, such as the occurrence of domestic violence²⁹. Cocaine or crack consumption causes irritation, aggressiveness, impatience, and suspicion, which impacts the quality of interaction and leads to the loss of family bonds³⁰. Marijuana use may set off a motivational syndrome, which affects the user's participation and integration in the family's daily life and the relation with work³¹.

It can be observed from reviewing the literature that there are significant impacts that family members experience because of their relationship with someone who struggles with comorbidities. Consequently, there is a need to not only recognise this inordinate impact, but to take steps to ensure families are appropriately supported.

²⁸ Fekadu W, Mihiretu A, Craig TKJ: Multidimensional impact of severe mental illness on family members: systematic review *BMJ Open* 2019;9

²⁹ Ibid xiii

³⁰ Ibid xiii

³¹ Ibid xiii

Peer support and Terminology

Peer support involves individuals with personal experience of challenging circumstances using the insight they have gained to provide mutual support and information to a person who is undergoing a similar experience. PSWs are recognised as playing an important role across many mental health and criminal justice services across the UK.

It is important to make some important distinctions between the peer support role and that of other members of the workforce. For instance, in most settings, PSWs will be categorised as being the provider and recipient of non-professional support. In the mental health and substance misuse professions this involves providing non-clinical assistance to people with similar conditions to facilitate their long-term recovery. Therefore, in most situations, peer support work does not aim to remove the need for clinical treatment, clinical guidance or medication, rather their help is delivered concurrently as they offer guidance and moral support which is viewed as beneficial.

A plethora of terms are used interchangeably across the literature to contextualise and define peer support. For instance, recovery champions and peer mentorship are but some. Throughout this report we maintain the language of peer support for consistency. Nevertheless, there are key terms which are relevant to understanding this area which we have illustrated in table 1 (page 13), and which are used in this report.

Table 1 Key terms and definitions of peer support

Terms	Definitions
Peer support	The process of giving and receiving nonprofessional, nonclinical assistance from individuals with similar conditions or circumstances to achieve long-term recovery from psychiatric, alcohol, and/or other drug-related problems
Recovery	A process of change through which individuals improve their health and wellness, live self-directed lives, and strive to reach their full potential
Peer support group	Where people in recovery voluntarily gather together to receive support and provide support by sharing knowledge, experiences, coping strategies, and offering understanding
Peer provider (e.g., (certified) peer specialist, mentor & recovery coach)	A person who uses his or her lived experience of recovery from mental illness and/or addiction, plus skills learned in formal training, to deliver services in behavioural health settings to promote mind-body recovery and resiliency

(Adapted from Tracey and Wallace, 2016³²)

³² Tracy K, Wallace SP. Benefits of peer support groups in the treatment of addiction. *Subst Abuse Rehabil.* 2016, 29:143-154

Peer support and Families affected by Comorbidities

For the purposes of this thought piece, we are interested in exploring the potential for families who have been indirectly affected by someone else's comorbidity using the knowledge they have gained to help others who are undergoing similar experiences. This is an important distinction as we are specific that the families do not need to have lived with a certain medical condition, rather it is that they have experienced a set of challenging circumstances which includes supporting a person recovering from comorbidity. This is important to note, as whilst it is not possible to find peer support for families who are affected, most peer support within the areas of substance misuse or mental health, or the co-occurrence of these disorders, is established by current or past users, which tend to operate out of and be supported by community organisations, community health centres, or alcohol and drug agencies. Therefore, there is no present infrastructure that is geared towards supporting families who are affected by comorbidities.

What is evident from scanning the extant literature is that there is minimal attention to the use of peer support for families affected by comorbidities. Therefore, to provide some context, literature which borders on this area will be covered. One area of relevance is the role of peer support for people who abuse substances. It is acknowledged that the outcomes of such peer support initiatives will be different to that for families, as, for instance, it is not the immediate requirement for families to stay involved in addiction treatment systems, which is often part of the role of a peer support worker to help someone who abuses substances.

What the literature shows is that, historically, peer support has often been a key component of addiction treatment and recovery services,

including in 12-step programmes³³, therapeutic communities³⁴ and community reinforcement approaches³⁵. Similarly, it has been employed in mental health. The Wellness Recovery Action Plan (WRAP) is one example. WRAP is a self-administered template that provides a structure for people to monitor their distress and wellness, and to plan ways of reducing or eliminating relapses. Peer support initiatives and some mainstream mental health services train people to do their own WRAP, in a number of countries including New Zealand³⁶.

However, it would be fair to say the evidence base for various forms of peer support in mental health and addiction is incomplete. A recent review looking at peer support in relation to substance misuse, in particular, states that this area of study is hindered by a lack of rigorous evaluated outcomes³⁷. They did identify studies showing higher rates of abstinence and improved treatment engagement. Similar findings have been recorded in relation to the area of mental health³⁸. Further, a study assessing the benefit of adding peer support within recovery to the care of adults with co-occurring psychosis and substance use, involving 137

³³ Allen J, Anton RF, Babor TF, Carbonari J. Project MATCH secondary a priori hypotheses. *Addiction*. 1997, 92: 1671–1698

³⁴ Guida F, De Leon G, Monahan K. *Measuring Peer Interaction in the Therapeutic Community*. Chicago, IL: American Psychological Association Convention; 2002

³⁵ Higgins ST, Wong CJ, Badger GJ, Ogden DE, Dantona RL. Contingent reinforcement increases cocaine abstinence during outpatient treatment and 1 year of follow-up. *J Consult Clin Psychol*. 2000, 68: 64–72

³⁶ O'Hagan M. *Peer Support in Mental Health and Addictions. A Background Paper*. Wellington: Kites Trust; 2011

Ibid³⁷

³⁸ Gillard, S: Peer support in mental health services: where is the research taking us, and do we want to go there?, *Journal of Mental Health* 2019, 28: 341-344.

adults with both disorders with at least one prior admission in the past year documented positive findings³⁹. This was a randomised trial comparing standard care against skills training with and without peer support focused on social engagement. The results showed that adding peer support can increase engagement in care over the short term and reduce substance use over the longer-term for adults with co-occurring disorders. Positive findings have also been documented in relation to satisfaction rates. Evidence in both mental health and addiction shows reduced symptoms of mental illness and or substance use, reduced dependency of health services, improve practical outcomes in housing, employment and finances, improved coping strategies, better social support and access to network and reduced mortality and suicide rates⁴⁰. Although these findings are promising they only relate to the outcomes and experiences of those who experience medical conditions, not those of families who have been affected by someone else's disorders.

One project that did provide support to families was delivered by Adfam⁴¹, offering a whole family recovery approach. It entailed offering training, resources and support to families to understand the impact of drugs and alcohol on their lives, and to build sustainable relationships and positive futures. The support families received was delivered by peers who had recovered from substance misuse. Whilst this project bears similarities to the focus of this thought piece, there is no reference to mental illness,

³⁹ O'Connell, M., Flanagan, E., Delphin-Rittmon, M, Davidson, L: Enhancing outcomes for persons with co-occurring disorders through skills training and peer recovery support. *Journal of Mental Health* 2017, 29: 6-11

⁴⁰ O'Hagan M. Peer Support in Mental Health and Addictions. A Background Paper. Wellington: Kites Trust; 2011

⁴¹ Adfam. Changing Lives Using peer support to promote access to services for family members affected by someone else's drug or alcohol use [Available at https://adfam.org.uk/files/docs/Changing_Lives_2018.pdf Accessed 18th March 2020]

meanwhile our focus is on families who have been affected being the peer support workers. Nevertheless, the findings from the project are worth noting. The project found that PSWs engaged family members through an informal approach that services could not and which families found affirming. Families reported that PSWs understood issues from their perspective, and they were able to offer a flexible service. Also, the presence of PSWs helped families to access services they may otherwise shun. There were however some barriers, as families did not attend the offices of the drug service, and it was assumed this was due to stigma.

From this brief review of the literature it is evident that peer support can provide a number of benefits. Generally, most evidence points to promising findings for those who are directly affected as a result of their own comorbidity. Whilst there are no empirical studies addressing any improvements for family members, one small scale study showed benefits for families. Therefore, when considering the impact of comorbidities on families, peer support offers an opportunity to a section of society who is too often overlooked. This report helps to shine light on this area.

Methods

This report focused on exploring the potential of peer support for, and by, family members who have been affected by someone else's comorbidity. To add to the knowledge base we sought to answer the following questions:

- Can peer support be extended so families affected by someone else's comorbidity provide support to other families in a similar position?
- What are the key and requisite competencies of someone who should be able to support families who have been affected by someone else's comorbidity?

To answer these questions we carried out data collection using mixed methods qualitative research. Six focus groups and six interviews were carried out with family members, friends and carers who had been affected by comorbidity.

Whilst data collection was focused predominantly on answering the above questions, a range of other contextual information was drawn out to better understand more about the experiences of participants.



This included exploring the participant’s experiences of services they had previously accessed (where applicable), discussing with participants their knowledge of the co-occurrence of drug and substance misuse and their interpretations of this. The focus group sessions also offered an opportunity to examine with participants the behaviours of people with comorbidities and to share the challenges family members had encountered.

All data collection was carried out in Merseyside with the participants also residing in the county. In total, 64 people contributed their time to the research. Participants from different age groups and ethnic backgrounds were represented across the six focus groups and interviews.



Table 2 Participant breakdown

Age		Gender		Ethnicity	
16-25	18	Female	38	White British	32
25-65	34	Male	26	White other	4
65+	12			Black	2
				Dual heritage	26

Findings and Recommendations

From the data collection phase of this project a number of findings emerged and recommendations developed. This section initially presents several case studies to draw attention to some of the challenges that were presented. Following this, the next three sections document the key findings across three sub-sections which look at: Existing service provision, the Potential of Peer and Peer Support Worker Competencies.

Presentation of Case Studies

Dealing with financial challenges

David abused substances and had underlying psychological trauma. His comorbidity, and in particular his cocaine addiction, had resulted in two spells of imprisonment. Although he was married, he stayed at his parents' house for periods of time and all of his post was registered there. David had managed to get into debt and was unable to cover the payments. Consequently, bailiffs continuously knocked and harangued David's parents and threatened to remove property that belonged to them. His parents were unaware of their legal status in this scenario which all contributed to immense pressure and fear being placed upon them, without any support.. After tolerating these circumstances for over four months they eventually paid to see a solicitor and the problem was partially resolved. Families affected by somebody else's co-morbidity could benefit from peer support in these circumstances for guidance.

Help when feeling alone

Lianne had lost two of her brothers due to heroin addiction. She had become the brunt of my jokes throughout her life: from school, social to work environments, because of her brother's drugs misuse. Although she had attended a service in Liverpool for families of drug abusers she had not managed to find a safe space to be able to talk about her specific experience, where there was also an understanding of her own mental ill health, and her own wellbeing. She had a feeling that peer support groups with people her own age who had encountered similar experiences would help her to not feel alone.

Support to understand one's own trauma and handling conflictual situations

Dean and his sister turned up at their mother's house to find that she had died and was lying on the floor. At this time, it was Dean's brother who had the responsibility to care for their mother. However, he had been abusing substances and had not been at his mother's abode for several days. This created a huge conflict between Dean and his brother, which built upon other situations when there was a feeling that the brother had shirked his responsibilities or placed undue burden on the family. In describing this case, Dean unearthed how he had never taken the time to understand his own trauma and felt that peer support could help to identify such matters. Similarly, it was felt that peer support could play a role in helping those who are affected to talk with others about managing conflict arising from similar complex circumstances, to share ideas about coping strategies and learn how to handle difficult situations.

Peer support in situations involving safeguarding

Danielle had three children and her partner Brian had mental health challenges for which he had unmet needs, and he also had a cocaine addiction. Brian would not seek support for his mental health issues and the organisation providing the substance misuse interventions were not suitable. Brian's addiction had been going on for 14 years but sometimes it spiralled into drastic circumstances. For different reasons this raised a concern for social care who commenced a process about the children's welfare. Although Danielle was confident the children would not be hurt, during this whole situation she did not receive any guidance, she did not have information about her rights and she felt alone throughout. Danielle believed peer support could have played a fundamental role to reduce her isolation and assist her to access relevant support she was either not aware of or felt she could not access for herself or her family, particularly her children.

Balancing competing priorities and looking after one's own welfare

Having a young daughter in a relationship with comorbidities created strains on Peter's ability to cope with living in the same house. Yet, at the same time ensure that he could maintain good care for this daughter including getting her to attend school regularly. Peter has had no one to talk to throughout his ongoing experience and in opening up for the first time was able to perceive the level of stress he was under and how it was impacting on him emotionally, physically and mentally. He was certain that peer support, which would walk alongside him throughout these complexities, would have eased the burden he often felt.

Existing Service Provision

Participant's experiences varied; many had not tried to access support because they could not find it or did not think it was available. Others had accessed support but reported a negative experience.

Table 3 Existing Service Provision Findings

Findings	Recommendations
Families often found it difficult to disentangle their own health and wellbeing needs — and to think about themselves — rather than focusing on the person with comorbidity.	More appropriate and targeted care is needed to raise awareness about the indirect effects of comorbidity.
Many families were unaware of support that is available to them. Many participants expressed how this was the first time they had not felt alone with their problems.	Existing services need to be more pro-active in engaging families who are impacted.
A limited number of people had accessed family-based support but found it inappropriate as it only dealt with either mental illness or substance misuse. They also found the activities were not stimulating, run at inconvenient times and were not focused on different age generations.	Existing services need to ensure they have the right expertise to support families dealing with co-occurring disorders, to review their activities and to reflect on their service user profile to ensure people with different, and intersecting, protected characteristics feel welcome.

The Potential of Peer Support

Participants were largely optimistic about the opportunities that could be offered by different peer support models. The benefits were largely perceived to be because of the informal nature of mutual support. However, for those who had accessed peer support previously they felt that such groups in Merseyside need to be clearer about their purpose and do more to allow peer groups to be peer led. They also felt that existing peer support structures were unwelcoming and they had an embedded culture which was not affirming.

Table 4 The Potential of Peer Support Findings

Findings	Recommendations
Families felt PSWs could play a critical role and would often be their first port of call	Tailored groups for families affected by people with comorbidities should be piloted and be peer led.
Families can feel helpless and with a feeling no-one shares their problems	Peer opportunities and safe spaces should be explored for those affected.
Support organisations do not offer effective support and families have insight into this	There needs to be a conduit to hold services to account for their performance
Participants described how having family members with comorbidities can be shameful, but they felt the focus group provided a space with like-minded people which gave a strong sense of common-ground they had never experienced previously.	Further opportunities for bespoke community-based opportunities where affected families can come together to create a sense of positivity and solidarity.

Peer Support Worker Competencies

This section draws on the findings relating to the skills, experience and knowledge that participants felt peer support workers should possess to be able to provide effective support to families.

Table 5 Peer Support Worker Competencies Findings

Findings	Recommendations
Families sometimes struggle to know what actions to take when supporting loved ones.	Peer work should be able to help families understand how to self-care including setting and maintaining boundaries (including family approaches and guidance on how to not be an enabler)
Families are often unsure how to handle debts, specifically those owed by the person with comorbidities and the family's debt which has arisen from their response to the circumstances.	Peer work could help to guide families to understand their rights in relation to debts owed.
Families can blame themselves and feel guilty.	Peer work could provide emotional support guidance (e.g. explaining they have done nothing wrong)
PSW should have strong interpersonal skills and specific knowledge	Genuine, non-bias, good communicators, relatability, non-hierarchical, listening skills, confidentiality, broader SM awareness, aware of own prejudice

Families can struggle in how they manage their own anger	Peer work could help families to explore how to manage confrontational situations.
Families experience their own trauma and feelings which too often remain hidden and suppressed.	Peer work should be able to direct or facilitate opportunities to affected families to manage their own emotions, behaviours and physical health
There is a need for those affected to have common ground with the PSW	PSWs characteristics should provide some choice to families (a variety of demographic options - e.g. age and gender - of those affected)
Families can often feel judged by professionals and practitioners and feel intimidated by the terminology used by them.	Peer workers could share knowledge on how to engage with different services.
Families can feel helpless and with a feeling no-one shares their problems	PSW could help families to jointly develop coping strategies.
Some families are unaware when their loved ones are abusing substances or experiencing mental illness	PSWs should be skilled to help families identify signs of substance misuse, different behaviours and self harm, including the signs of relapse.
Some families don't understand services and their limitations (incl confidentiality).	PSWs should be skilled to offer guidance about how services operate and the advantages of engagement or treatment integration.

Conclusion

This piece work set out to understand the potential for peer support to help families who have been affected by someone else's comorbidity. In particular, the aim was to understand whether there is a role for families who have been affected by someone else's comorbidity to be able to help other family members who are also affected. The second aim of the thought piece was to explore what would be the key competencies of someone carrying out this role.

This thought piece involved 64 people who had been directly affected by someone else's comorbidity. In a number of situations people had had to deal with the death of somebody they loved. Taking account of this, and the many of dilemmas that were presented, one of the key findings to emerge from this thought piece was the overwhelming feeling that there was an absence of any appropriate support for them. Participants had accessed peer groups but felt their needs were far from being met which compounded their deep sense of shame. This sense of shame was also a barrier to any possible support being accessed.

What was challenging in the discussions was for the participants to understand their own visibility and the necessity of support for their own needs, and not that only of the person with comorbidity. This was particularly concerning as the impact of comorbidity seemed to catalyse a domino effect of comorbidity in family members, which they minimized. This illustrated one of the barriers to service access and the failure of existing services to reach out and highlight this. Nonetheless, there was a sense that peer support that is appropriately set up and with effective models of engagement would hold potential. Participants felt that peers with a similar experience could help to engage with them in a way they

could not communicate with clinical professionals. Also, they felt that peer support groups could evolve to be more effective in holding services to account so their voices are listened.

A range of key competencies were discussed that participants felt peer support workers could and should possess to be effective in their role. This involved support with confrontational situations, knowledge on access to therapeutic support to guidance on how to deal with (in)formal debt linked to an abusing loved one. All of these findings are key to understand as they epitomise the need for policy attention in an area which, for too long, has been overlooked, and for families who have suffered, and will continue to suffer, significantly.