Whānau engagement in mental health and addiction services

Key performance indicator literature review, November 2022

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Literature review (November 2022) by Te Pou for the Key Performance Indicator (KPI) Programme, Mental Health and Addiction, Aotearoa New Zealand.
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Executive summary

Whānau engagement can improve people's mental health and addiction service experiences and outcomes (Government Inquiry into Mental Health and Addiction, 2018). Whānau includes people's family, friends, and others in their support network (Manatū Hauora Ministry of Health, 2017). In Aotearoa New Zealand, it is widely understood that whānau are central to individual and collective wellbeing, particularly for tāngata whai ora (people seeking wellness), and for more collectivist cultures such as Māori and Pasifika (Te Rau Matatini, 2014). It is therefore important for services to deliver culturally responsive and whānau-focused support to enhance people's wellbeing (Manatū Hauora Ministry of Health, 2018). *Kia Manawanui Aotearoa*, the long-term pathway to improving mental wellbeing, identifies as a priority the need to integrate whānau-centred models of care, mātauranga Māori (Māori knowledge), and Pasifika models of wellbeing into services (Manatū Hauora Ministry of Health, 2021c).

The Key Performance Indicator Programme (KPI Programme), Mental Health and Addiction Aotearoa New Zealand, has historically included whānau engagement indicators. For adults, this indicator previously measured the percentage of eligible episodes where whānau are present; for children and rangatahi (young people), the indicator measured the duration and percentage of treatment days with whānau present. Currently, the indicator measures the proportion of service activities in which whānau were involved for all groups. Mental health services in Aotearoa New Zealand are expected to record whānau engagement for all activities. Recording whānau engagement is set to be mandatory from 1 July 2023 (Manatū Hauora Ministry of Health, 2022, 2022).

Aims and objectives

This rapid review aims to:

- summarise the rationale for including a whānau engagement indicator in the KPI Programme
- compare Aotearoa New Zealand's approach to measuring whānau engagement to those of other IIMHL countries.

Specific objectives are to summarise in relation to whānau engagement:

- outcomes, barriers, and enablers of whānau engagement in mental health and addiction services
- strategies to increase whānau engagement
- measures used in Aotearoa New Zealand and other International Initiative for Mental Health Leadership (IIMHL) countries.

Findings are primarily drawn from journal publications and grey literature via database searches. The Programme for the Integration of Mental Health Data (PRIMHD) database was a key source of information on whānau engagement.

Key findings

Whānau engagement is associated with positive individual and service level outcomes. Individual outcomes include greater wellbeing and a stronger support system through a person's service journey (Haine-Schlagel & Walsh, 2015; Hogue et al., 2021; Ungar & Theron, 2020). Service level outcomes include a lower likelihood of readmission to services and missing appointments (Aeby et al., 2015; Durbin et al., 2007; Hariman et al., 2020; Vigod et al., 2013).

Various factors can hinder the engagement of whānau with services. For whānau, barriers include not being given enough information or advice by services, lack of support for whānau who are involved in a person's service journey, or not wanting to be involved (Liverpool et al., 2021; Waid & Kelly, 2020). For services, the literature highlights issues including a lack of training, resources, and capacity (Baker-Ericzén et al., 2013; Boland et al., 2019). Services need to be attentive to the complexities of whānau dynamics when facilitating whānau engagement. This includes services recognising when tāngata whai ora may not want whānau to be involved (Bradley & Green, 2018; Waller et al., 2019).

In Aotearoa New Zealand, whānau engagement is primarily captured through mandated data collection in the PRIMHD data set. Between 2017 and 2021, the national average rate of whānau engagement in mental health and addiction services was around 51 percent. Rangatahi aged under 18 have the highest rates of whānau engagement (81 percent) compared to other age groups. Adults aged between 25 and 64 have the lowest rates of whānau engagement (around 35 percent). Whānau engagement rates for Māori and Pasifika track below the national average (48 and 49 percent respectively). Asian peoples have the highest rates of whānau engagement compared to other ethnic groups (56 percent). Rates of whānau engagement across ethnic groups have remained relatively stable over time.

In other IIMHL countries, whānau engagement is measured primarily through service user experience surveys such as the Your Experience of Service survey in Australia and the Community Mental Health Survey in England. Whānau engagement does not appear to be measured as a national KPI in other countries.

The literature highlights some strategies that can improve whānau engagement in mental health and addiction services. These include:

- implementing collaborative service delivery approaches such as shared decision-making (Boland et al., 2019; Bradley & Green, 2018; Coulter & Collins, 2011)
- workforce development such as providing additional training and resources to facilitate whānau engagement. The Supporting Parents, Healthy Children (SPHC) initiative is one

workforce development initiative used to increase the capability of health professionals (Boland et al., 2019; Maybery et al., 2016; Waid & Kelly, 2020)
- improving the information (such as what services and resources are available), options, and advice given to whānau (Foster et al., 2016; Kourgiantakis et al., 2018; Liverpool et al., 2021; Waller et al., 2019)
- providing more support to whānau such as identifying expectations and setting treatment goals; supporting them with psychoeducation, coping strategies, and practical needs such as transport, housing, and employment. Some examples of strategies used in Aotearoa New Zealand to provide more support to whānau include the 5-Step Method and Community Reinforcement and Family Training (CRAFT) (Foster et al., 2016; Ingoldsby, 2010; Waid & Kelly, 2020; Waller et al., 2019).

Conclusion

This review indicates that whānau engagement is a key factor in people's service experience and outcomes. International literature suggests that Aotearoa New Zealand is unique in measuring whānau engagement in national data collections and as a KPI. It is therefore recommended that the KPI Programme use a whānau engagement indicator which reflects the proportion of activities where whānau were involved. It is also recommended that this indicator be used across all communities of interest that the KPI Programme serves.

Sector consultation is recommended to build the indicator further, such as collecting more detailed information about the nature of the engagement and when in the service journey whānau engagement occurs. This information could help create a more comprehensive picture of when and how whānau are engaged in people's service journeys. As Aotearoa New Zealand is unique in measuring whānau engagement as part of national mental health and addiction service KPIs, there is an opportunity to lead the way internationally towards adoption of a more whānau-centred view of mental health and addiction services.

Background

Whānau engagement is a key factor in people's mental health service experiences. In the context of Aotearoa New Zealand, "family/whānau is not limited to blood ties, but may include partners, friends, and others in a person's wider support network" (Manatū Hauora Ministry of Health, 2017). Family and whānau are able to intervene early to prevent mental health challenges from escalating, encourage early intervention particularly for rangatahi, care for people with additional needs, and promote lifestyle changes that lead to greater wellbeing (Government Inquiry into Mental Health and Addiction, 2018). Whānau engagement can be a vital component in addressing people's mental health challenges and problematic substance use (Government Inquiry into Mental Health and Addiction, 2018; Manatū Hauora Ministry of Health, 2017).

In Aotearoa New Zealand, it is widely understood that the interdependence and interconnectedness of whānau are central to individual and collective wellbeing (Te Rau Matatini, 2014). The role of whānau is recognised as an essential aspect of hauora (wellbeing) for Māori (Durie, 2001; Durie et al., 2011). Māori, Pasifika, and Asian cultures in particular have strong collectivist values compared to Western concepts (Faleafa, 2020; Podsiadlowski & Fox, 2011). This means these cultures are more likely to perceive the individual or self as an inseparable part of the family and whānau collective group. Moreover, data shows that Māori are more likely to access mental health services compared to other ethnic groups (Manatū Hauora Ministry of Health, 2021b). Given this cultural context, it is important for mental health services to be culturally responsive and deliver whānau-focused care (Manatū Hauora Ministry of Health, 2018). *Kia Manawanui Aotearoa*, the long-term pathway to improving mental wellbeing, identifies as a priority the need to integrate whānau-centred models of care, mātauranga Māori (Māori knowledge), and Pacific models of wellbeing into services (Manatū Hauora Ministry of Health, 2021c).

He Ara Oranga recommends supporting whānau to be active participants in the support of tāngata whai ora (people seeking wellness) (Government Inquiry into Mental Health and Addiction, 2018). *Kia Manawanui Aotearoa* recognises the need for more interconnected, integrated, people- and whānau-centred services that support the wellbeing of tāngata whai ora and their whānau (Manatū Hauora Ministry of Health, 2021a). This includes ensuring all whānau have access to family peer support and recovery education (Hamer et al., 2014). Te Hiringa Mahara (2022) similarly advocates for improving wellbeing for all by putting both people and whānau at the centre of mental health and addiction services. Acknowledging the role of whānau members in the lives of tāngata whai ora, Te Hiringa Mahara further highlights the need to increase whānau engagement in services (Te Hiringa Mahara, 2022).

Whānau involvement is currently a requirement when people undergo compulsory assessment and treatment under the Mental Health Act (Manatū Hauora Ministry of Health, 2020). The Act states that health practitioners must consult with whānau during the compulsory assessment and treatment process unless it is not reasonably practicable or it is not in the best interest of the person needing mental health support.

Whānau engagement KPI indicator

The KPI Programme is a mental health and addiction sector informed and led initiative. The Programme facilitates continuous service quality improvement across Te Whatu Ora health entities and NGOs through collective data collection, data analysis, benchmarking, learning, and problem solving. Benchmarking mental health and addiction services helps to improve and sustain service provision to tāngata whai ora and whānau (Coombs et al., 2011; Ettorchi-Tardy et al., 2012).

Historically, the KPI Programme has included whānau engagement indicators for the adult, and child and youth communities working in mental health (KPI Programme, 2020). The adult whānau engagement indicator previously focused on whether whānau engagement occurred after the first face-to-face contact, and the child and youth indicator focused on how often whānau engagement occurred and the duration of contacts (KPI Programme, 2020).

The KPI Programme uses data from the Programme for the Integration of Mental Health Data (PRIMHD) database to collect information on whānau engagement in Aotearoa New Zealand. PRIMHD is a Manatū Hauora Ministry of Health mental health and addiction database that collects information on service activity and outcomes. Data is collected from Te Whatu Ora health entities (formerly district health boards [DHBs]) and non-government organisations (NGOs). PRIMHD data is used to look at what services are being provided, who provides the services, and what outcomes are being achieved for tāngata whai ora across Aotearoa New Zealand. Recording this information facilitates service planning and decision-making by mental health and addiction service providers at the local, regional, and national levels.

Aims and objectives

This literature review aims to update our understanding of the rationale for the whānau engagement KPI indicators and to inform the KPI Programme in reviewing these indicators. Key questions are outlined below.

- What is the rationale for including a whānau engagement indicator in the KPI Programme?
- How does Aotearoa New Zealand's approach to measuring whānau engagement compare to those of other International Initiative for Mental Health Leadership (IIMHL) countries?

Specific objectives are to summarise recent evidence regarding:
- outcomes of whānau engagement
- barriers and enablers of whānau engagement for tāngata whai ora, services, and whānau

- effective strategies for improving whānau engagement and whānau experiences in mental health and addiction settings
- whānau engagement measures used in other International Initiative for Mental Health Leadership (IIMHL) countries.

Method

Literature search

This rapid literature review is based on published and grey literature, across a range of systematic reviews and individual studies.[1] This includes an unpublished literature review Te Pou did for the KPI programme in 2017 on the whānau engagement KPI (Te Pou o te Whakaaro Nui, 2017), key documents published by the KPI Programme, and their referenced literature.

Literature searches were conducted using EBSCOHost (Academic Search Complete, CINAHL Complete, MEDLINE Complete, and Psychology and Behavioural Sciences Complete). Additional searches were conducted using Google Scholar and Google. The scope primarily includes articles published since 2018 for areas that were covered in the previous review (such as outcomes of whānau engagement). The scope was extended to 2010 where there were gaps. Literature published until September 2022 were included. Searches used the following key words:

- family/whānau engagement, family involvement, families as co-therapists, open dialogue, family satisfaction studies, support network, kaupapa Māori service models inclusive of whānau engagement, Pasifika service models
- measures of family/whānau engagement/involvement, measures of the quality of family/whānau engagement/involvement, key performance indicator, effective performance indicator, quality measure indicator, outcomes, impacts, improvement, wellbeing
- mental health, psychiatric, mental health services, substance use, addiction, drug, behavioural.

Most research identified in this review were qualitative studies, with quantitative studies found mostly in the literature regarding outcomes of whānau engagement. Where possible, we primarily draw findings from reviews as they provide an indication of the general direction of research. Individual studies were included to supplement evidence provided in reviews. Time and capacity restrictions limited the number of studies identified and appraisal of study quality. The quality and findings from individual studies may vary (due to differences in samples, study methods, and settings) but are included to provide additional information that

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[1] Rapid literature reviews assess what is known about a given topic by using systematic review methods that are simplified to produce information within time and capacity constraints (Tricco et al., 2015).

broader reviews may not otherwise cover. See Table 6 in Appendix A for details of the studies included.

Whānau engagement data in Aotearoa New Zealand was collated from the KPI Programme whānau engagement indicator data dashboard in July 2022.

Language

This report uses person-centred and strengths-based language.

Tāngata whai ora, defined as "people seeking wellness" is used to refer to people accessing services and to people experiencing mental health challenges or substance use issues.

Whānau is used throughout the report to capture support networks including and beyond people's immediate families, such as partners, friends, caregivers, and others in people's support networks.

Family or relatives is used where findings are specifically about people's immediate families, particularly when referencing international research.

Whānau engagement is primarily used throughout the review to align with the language used by the KPI Programme. This centres the agency of whānau in services. Family or whānau "involvement" is used when referencing sources which use this term specifically.

Results

This section presents findings from the literature review in the following subsections:

- individual and service outcomes of whānau engagement
- barriers to whānau engagement for services and whānau
- strategies to improve whānau engagement
- measures of whānau engagement in IIMHL countries and across research.

Each section provides an overall summary of the research followed by more detailed description of the studies underpinning this.

Outcomes of whānau engagement

Whānau engagement in mental health and addiction services is associated with positive individual and service-level outcomes such as facilitating recovery, promoting understanding of mental health challenges and problematic substance use, enhancing access to services, reducing readmissions, and reducing the likelihood of missing appointments (Aeby et al., 2015; Aldersey & Whitley, 2015; Hariman et al., 2020; Haverfield et al., 2019; Hogue et al., 2021; Radez et al., 2022; Ungar & Theron, 2020). Positive outcomes are due to whānau being a key source of social and practical support for people accessing mental health and addiction services. Specifically, whānau and family can support tāngata whai ora by:

- providing general support (such as housing, transport, and support after discharge)
- providing emotional support (such as helping to cope with challenges)
- facilitating communication and information exchange with health professionals
- helping the person experiencing mental health challenges and problematic substance use to seek and access services
- noticing emerging mental health symptoms (Aldersey & Whitley, 2015; Bradley & Green, 2018; Schuster et al., 2021).

These findings are explored in more detail below.

Individual outcomes

The involvement of family and whānau in people's mental health support helps facilitate their wellbeing, recovery, and build resilience (Aldersey & Whitley, 2015; Carswell et al., 2022; Ungar & Theron, 2020). The literature indicates whānau engagement is associated with positive outcomes for people's wellbeing, while conversely, a lack of whānau involvement is associated with poorer outcomes. This is explored further below.

Improved wellbeing

Reviews indicate whānau engagement, particularly in addiction services, is beneficial for both adults and young people (Hogue et al., 2021).

Studies highlight the benefit of engaging families in services for people's mental wellbeing (Ungar & Theron, 2020). A review of studies on parent participation in child and family mental health services found parental engagement was associated with improvements in mental health and general functioning (Haine-Schlagel & Walsh, 2015). Carswell and colleagues' study (2022) highlighted the importance of family and social support in enhancing self-management among people who experience mental health challenges. An individual study by Haverfield and colleagues (2019) found perceived social support was associated with lower levels of depression, post-traumatic stress disorder (PTSD), and substance use. They also found being involved in mutual-help groups, such as peer support, was associated with greater improvements in reducing alcohol use over time.

The literature highlights the benefits of family engagement for people receiving substance use treatment. A meta-analysis found interventions across different age groups that involved family, friends, partners, and caregivers had a small but positive impact on reducing people's substance use and substance-related problems compared to individualised treatments (Ariss & Fairbairn, 2020). Family-based interventions reduced substance use frequency by an average of 5.7 percent. While the effect of interventions was small, they were sustained for 12 to 18 months after treatment, which translated to three fewer weeks of using substances per year. This is significant as even small reductions in substance use can lead to marked improvements in people’s physical and mental wellbeing (Kiluk et al., 2019). Treatment outcomes were similar across different types of interventions, gender groups, type of substance, and level of use at baseline (Ariss & Fairbairn, 2020).

Low levels of social support is associated with poorer outcomes. In a study with people who experienced pharmaceutical opioid dependence, lower levels of social support were associated with unplanned opioid use, greater dependence on prescribed opioids, and negative mental health symptoms (Cooper et al., 2018). Overall, research highlights the supportive role of social connections in recovery from problematic substance use (Best & Lubman, 2012).

Service outcomes

Whānau engagement can positively influence service-related outcomes for tāngata whai ora, such as readmission to services and attendance. These findings are discussed below.

Readmission

Readmission refers to people returning to a service after previously being discharged. Readmission may indicate the person needed additional support before being discharged. During people’s mental health service journeys, whānau can be involved in discharge planning,[2] communicating with the person or the service, attending family therapy sessions, and providing supportive comments (Durbin et al., 2007; Government Inquiry into Mental Health and Addiction, 2018; Haselden et al., 2019; Sfetcu et al., 2017).

Studies show whānau engagement is associated with a lower likelihood of readmission. Hariman and colleagues (2020) found people who were discharged to live with their family were about 39 percent less likely to be readmitted to an acute mental health unit within 28 days, compared to those discharged to live by themselves. People whose whānau are involved with their treatment are also more likely to receive comprehensive discharge planning, which is associated with a lower likelihood of readmission (Durbin et al., 2007; Kripalani et al., 2014; Vigod et al., 2013).

Non-attendance

People miss mental health service appointments for several reasons including forgetting, having conflicting priorities, or difficulty in finding appropriate childcare and transport (Aeby et al., 2015; Agyapong et al., 2011; Mitchell & Selmes, 2007). Evidence suggests family involvement can reduce people’s likelihood of missing appointments by providing a shared responsibility of support such as reminding the person and offering to provide childcare or transport (Kim et al., 2012; McDaniel et al., 2014; Waid & Kelly, 2020). Another study

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[2] A plan to facilitate people’s transition from inpatient to community care by coordinating services, identifying support preferences, planning finances and accommodation, and providing the person with sufficient and relevant information and resources to enhance self-management.

identified an association between family interventions in substance use treatment and greater attendance compared to individual approaches (Al Ghafri et al., 2020). Whānau can also aid in improving services' responsiveness to people by providing important information about the person and identifying potential barriers to attending appointments and other concerns they may have (Bradley & Green, 2018; Ingoldsby, 2010). This is important as facilitating access to support can help address people's mental health needs and improve their wellbeing outcomes.

Barriers and enablers for services to engage with whānau

Some factors are reported by services as hindering engagement and making it more difficult for services to engage with whānau. Key reported barriers in the literature include a lack of available services, training and resources, and limited capacity (Baker-Ericzén et al., 2013; Boland et al., 2019; Eassom et al., 2014; Liverpool et al., 2021). These findings are discussed in more detail below.

Lack of training and resources

A common barrier reported as hindering whānau engagement is a lack of workforce training and resources. Across studies, health professionals acknowledge the importance of involving whānau but may not feel equipped to implement this in their service (Bradley & Green, 2018). A systematic review found healthcare practitioners' skill level could be a barrier to collaborating with people and their whānau, such as knowing when to elicit and incorporate families' values into practice (Boland et al., 2019). Another systematic review identified a lack of access to staff supervision, and skills or confidence around working with families as barriers (Eassom et al., 2014).

In a qualitative study, clinicians reported barriers to including and working with families which included a lack of therapeutic skills, knowledge about treatment options, and awareness of resources for child and adolescent services (Hayes et al., 2019). This may reflect gaps in workforce training and development. Therapists in Baker-Ericzén and colleagues' (2013) qualitative study felt they received limited training and support from service systems, which negatively impacted their ability to provide quality support to families and children.

Capacity

Involving whānau in mental health support can take longer than more traditional individualised approaches and adds to clinicians' workloads (Bradley & Green, 2018). A systematic review identified limited capacity such as heavy workloads, clinic workflow, and poor continuity of care as key environmental barriers to working with whānau (Boland et al., 2019). Another systematic review similarly found factors such as workloads, balancing clinical responsibilities, limited time, and lack of structure and standardised systems as barriers to involving families in mental health treatment (Eassom et al., 2014).

Hayes and colleagues' (2019) study with clinicians found that compared to traditional approaches, involving families requires more time to work at families' pace, move forward only when they are ready, and complete additional administrative tasks. These indicate the additional time and work required to involve whānau must be factored into clinicians' and services' capacity, as evidence shows positive outcomes of whānau involvement compared to traditional approaches. More time is needed to provide support particularly for families of young children, where multiple family members are involved, people with learning disabilities, families with complex needs, and where people who do not come prepared for appointments (Baker-Ericzén et al., 2013; Hayes et al., 2019). In a qualitative study set at a community children's mental health service, clinicians reported rigid protocols and large volumes of paperwork prevented them from providing quality services to children (Baker-Ericzén et al., 2013).

Challenges experienced by whānau

Whānau may experience barriers to supporting tāngata whai ora. Systematic reviews and individual studies commonly report whānau not being given enough information, or advice about alternative treatment options (Boland et al., 2019; Hayes et al., 2019; Liverpool et al., 2021; Schlimm et al., 2021). This can discourage whānau from being involved in people's mental health treatment.

Limited access and information

A key barrier reported to whānau engagement in mental health and addiction services is having limited access to services or being given limited information about the services tāngata whai ora are receiving. This includes being given insufficient information about the treatment being delivered, the person's mental health challenges, and access to alternative options.

In a review by Waid and Kelly (2020), people living in rural areas reported that having limited access to relevant, specialist, or culturally appropriate services was a key barrier for families to engage with services. Studies indicate that being given more treatment options can make whānau feel empowered and thus enables them to engage more with services (Hayes et al., 2019; Liverpool et al., 2021). Further, qualitative findings show being given fewer options or no choice in treatment can result in whānau being less likely to stay involved in treatment (Boland et al., 2019; Liverpool et al., 2021).

Whānau may find it difficult to be involved in treatment. Waid and Kelly's (2020) review found practical issues such as transportation and childcare can hinder whānau involvement. Bradley and Green's (2018) qualitative study found some family members want to be involved in appointments but find it difficult or feel they are not given an opportunity by staff. Another qualitative study found some parents want to support their adolescent while they receive cognitive behavioural therapy (CBT) for depression, but feel they are not given enough information or updates on their child's progress (Schlimm et al., 2021). Conversely, the study found family members who already know about service policies and practices find it easier to be involved. This highlights the importance of staff providing information and actively encouraging whānau engagement.

Tāngata whai ora or whānau not wanting whānau engagement

Some tāngata whai ora may not want whānau involved in their mental health or substance use treatment. Reasons reported in the literature include family conflict, isolation, and their own mental health challenges or problematic substance use. Other reasons may include privacy, preference, or cultural expectations. Whānau may not want to be involved with their whānau member's treatment for reasons such as wanting to respect their privacy or perceiving support-giving as being too difficult.

It is important that staff and services gain permission from tāngata whai ora to involve family members. When facilitating permission for engagement, staff need to be attentive to the cultural needs of whānau. In a study focused on gambling harm, people identified key reasons for not wanting family involved in treatment such as family conflict (including being estranged from families), stigma and misinformation about mental health challenges and problematic substance use, and having limited coping strategies (Kourgiantakis et al., 2018). Additionally, people's relationships with their whānau may decline over time, or tāngata whai ora may have concerns about their information being shared between services and whānau (Waller et al., 2019). As such, it is suggested that services revisit permissions to involve whānau throughout treatment (Bradley & Green, 2018). It is important to fulfil the expressed needs and wants of tāngata whai ora about whether to involve whānau or not where possible, provided it is in their best interests and they are not at immediate risk of danger or threat to themselves or others.

It is important to acknowledge the nuances of people's relationships with their whānau. The Mental Health Foundation conducted qualitative research in Aotearoa New Zealand which explored discrimination towards tāngata whai ora and their whānau (Barnett & Barnes, 2010). Findings indicate that most tāngata whai ora report experiencing discrimination from their whānau such as hiding or denying the presence of mental health challenges, using harmful language, and negative attitudes towards mental health challenges. More recent evidence from Te Hiringa Hauora (Flett et al., 2020) shows that among people who have experienced discrimination because of their mental health challenges, one third reported experiencing discrimination from their whānau. However, despite the presence of stigma and discrimination, tāngata whai ora express wanting whānau to be involved in their lives and to better understand them, particularly at times when their mental health challenges are more difficult (Barnett & Barnes, 2010).

Some tāngata whai ora may simply decide not to involve whānau for privacy reasons, due to preference, or as a result of cultural expectations; not necessarily due to breakdown in relationships. It is therefore important for services to work with tāngata whai ora to identify how to best engage whānau.

Some whānau may decide not to be involved in people's treatment. One scoping review found families' negative attitudes towards mental health professionals and services, and stigma around mental health and help-seeking are key barriers to engagement with child and adolescent mental health services (Waid & Kelly, 2020). In a qualitative study, some parents of young people (aged 11 to 17) who attended CBT decided not to be involved in sessions because they felt their presence would hinder their child's progress, or because they wanted to respect their child's privacy and let them have control over their own progress (Schlimm et al., 2021). In Kourgiantakis and colleagues' (2018) study, family members reported deciding to keep their distance from people who experienced gambling harm when they felt problem-solving or discussing issues became difficult. Another study indicates that some family members may feel too stressed or overwhelmed from supporting relatives with problematic substance use to be involved in their treatment (McCann et al., 2019). It is therefore important for health professionals to consider the reasons why whānau are not involved in treatment; these may reflect underlying reasons that services can address to improve engagement.

Approaches to improving whānau engagement

Strategic documents from Aotearoa New Zealand, services, and research articles suggest various approaches to improving family/whānau engagement in mental health and addiction services. Key approaches include implementing shared decision-making and providing training and resources for health professionals, along with education and resources for family and whānau.

Shared decision-making

Shared decision-making is an evidence-based approach aimed at promoting collaboration between people accessing services, family members, and healthcare providers when making decisions about a person's health (Boland et al., 2019; Hayes et al., 2019; Simmons & Gooding, 2017).[3] Exchanging information about the options, risks, and benefits associated with the treatment and support a person may receive enables healthcare professionals, tāngata whai ora, and their whānau to collaborate to determine the best treatment plan. This should incorporate and be based on the values and preferences of the person accessing treatment and their whānau. Though shared decision-making provides an avenue through which whānau can be engaged in treatment, most research about shared decision-making among adults does not include families, while research among young people does (Simmons & Gooding, 2017).

Successful implementation of shared decision-making has been shown to have several benefits for tāngata whai ora and whānau including increased participation; improved

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[3] Shared decision-making can be done between just the service user and their health professional. For the purposes of this review, only articles that address shared decision-making between service users, their family/whānau, and health professionals are cited.

knowledge, understanding, confidence and coping skills; greater comfort with decisions; and improved experiences with treatment planning meetings and discharge from services (Bradley & Green, 2018; Brooks et al., 2022; Coulter & Collins, 2011). A questionnaire study in adult mental health services found family members valued opportunities to contribute to treatment decisions and being listened to (Bradley & Green, 2018). Additionally, when family members are included and able to make practical decisions, they report feeling less distressed. In another study, benefits of shared decision-making identified by service users, caregivers (including family members), and mental health professionals include improving treatment, opportunities to contribute important information to treatment, and address needs (Schuster et al., 2021).

Evidence of the efficacy of shared decision-making in addiction treatment settings is more mixed, with some studies showing it is associated with improvements in treatment attendance and reducing problematic substance use symptoms, and others showing inconclusive evidence (Fisher et al., 2021). This may be due to differences in study designs, samples, and types of substances examined across studies. Researchers recommend further work to be conducted to assess how shared decision-making, or facilitating collaboration between tāngata whai ora, whānau, and staff more broadly, can improve outcomes for people accessing mental health and addiction services.

Workforce development

Studies indicate that whānau engagement in mental health and addiction services can be enhanced through training and supervision; organisational support; providing reliable resources for staff and tāngata whai ora; and implementing best-practice approaches that are family-focused. Supporting Parents, Healthy Children (SPHC) is an example of a workforce development initiative in Aotearoa New Zealand that has been found to increase the workforce’s capability to support children of whānau who experience mental health challenges or problematic substance use.

Health professionals indicate that additional training and reliable resources can help facilitate whānau engagement. Boland and colleagues’ (2019) systematic review identified enablers to implementing shared decision-making in paediatric settings as including access to appropriate screening and assessment tools, resources, and training. Another review found ongoing training and workforce development, particularly that focused on increasing clinicians’ range of clinical expertise, was key to improving family engagement (Waid & Kelly, 2020). Eassom and colleagues (2014) similarly identified enablers of family involvement including top-down support from management including the development and implementation of strategic solutions, supervision, ongoing support for staff, and promotion of family involvement. Additional skills identified in this review include workforce development around working with complex needs such as family conflicts; fostering interpersonal qualities such as empathy, and adopting a non-blaming approach to engaging with families; and active collaboration with families. Eassom and colleagues’ review also highlights the importance of services supporting staff by prioritising and promoting family involvement, establishing multidisciplinary support, and creating work cultures which encourage family involvement.

A questionnaire study with mental healthcare workers quantitatively assessed enablers to using family-focused practice (Maybery et al., 2016). Factors supporting use in practice included being able to provide support to children, parents and families, as well as being able to assess the impact of mental health challenges on children, and provide referrals. These factors were influenced by access to workforce development opportunities. For example, provision of family and parenting support was associated with workforce skills and knowledge, co-worker support, and training. Similarly, the provision of support to carers and children was influenced by service availability, and workforce skills, knowledge, and training. Workforce development can therefore support whānau engagement in services.

In Aotearoa New Zealand, Supporting Parents, Healthy Children (SPHC) is a government-funded workforce development initiative aimed at increasing the capability of health professionals to identify and address the needs of children of parents who experience mental health challenges or problematic substance use (Whāraurau, n.d.).[4] This includes developing resources for the sector, whānau, and children; identifying pathways for support; and implementing best-practice approaches. The SPHC guideline for the mental health and addiction sector further outlines the implementation of systems, policies, and practices to achieve systemic change across adults and infant, child, and youth services to better identify and support whānau needs. The 2020 evaluation of the SPHC initiative, which interviewed SPHC champions and project team members, found that the initiative has enhanced the workforce to better serve children of whānau who experience mental health challenges or problematic substance use.[5] Findings indicate various factors have facilitated implementation of SPHC in interviewees' workplaces including training, access to resources for staff and tāngata whai ora, establishing SPHC champions and dedicated project teams, and alignment of values and priorities between workplaces and the SPHC initiative.

Information, resources, and choice for whānau

To improve whānau engagement, the literature indicates services should offer whānau more information about the services provided, resources to help access and understand information about treatment, and offer a greater range of treatment options (Liverpool et al., 2021). This supports tāngata whai ora and whānau to make informed decisions.

Providing information can come in the form of raising awareness or general information about mental health challenges or problematic substance use, helping whānau understand challenges experienced by tāngata whai ora, as well as risk and protective factors (such as

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[4] SPHC is led by Whāraurau in collaboration with other workforce centres in Aotearoa New Zealand, including Te Pou, Le Va, Abacus, and Te Rau Ora.

[5] The full evaluation report can be accessed at https://www.tepou.co.nz/resources/supporting-parents-healthy-children-sphc-evaluation-2020

how psychosocial factors can affect the course of mental health challenges), treatment options, and information on services (Foster et al., 2016). Foster and colleagues' review found that the provision of relevant information was associated with improved family functioning, child wellbeing, communication, coping skills, and family members' understanding of people's mental health challenges. Evidence suggests, however, that families can feel more distressed if they are given information without the appropriate skills training and support to use the information (Krawitz et al., 2016). Services should therefore provide support to whānau to ensure they are well-equipped to be involved in their whānau member's treatment and recovery.

Studies highlight how providing information, resources, and choices for whānau can encourage engagement. Kourgiantakis and colleagues (2018) found that teaching coping strategies and communication skills helped family members to be more involved in people's treatment and support for gambling harm. In another study with parents of children who attended mental health services, parents identified enablers to engagement with services such as receiving easy to understand information so people do not feel overloaded, and receiving information ahead of time through digital resources to make appointments more efficient (Liverpool et al., 2021). Further, Waller and colleagues' (2019) study highlights the benefits of engaging families; people with mental health challenges reported that educating their family members and giving them the skills to understand and communicate was helpful to their recovery.

One specific approach to sharing information with whānau is the Single Session Family Consultation (SSFC). SSFCs are brief consultations with whānau which aim to clarify how whānau will be involved in the support of tāngata whai ora, and to help whānau identify and address their own needs. Tāngata whai ora are given the opportunity to identify which whānau member(s) they want present, what they want to talk about, and what they are not ready to discuss. A study assessing the use of SSFCs found that it is useful for engaging families in mental health treatment for rangatahi (Poon et al., 2017). Further, a study assessing its effectiveness found SSFCs are an effective tool for improving the overall wellbeing of rangatahi who access mental health services (Hopkins et al., 2016).

Additional support for whānau

Whānau may not engage with services for various reasons including their wellbeing, beliefs, expectations, and practical needs (Ingoldsby, 2010; Waid & Kelly, 2020; Waller et al., 2019). When services consider the strengths and needs of whānau and provide additional support it is likely to increase whānau engagement

A review of family-focused practice identified several ways additional support can be provided to families of people accessing mental health services (Foster et al., 2016). Approaches include planning to identify families' short- and long-term goals; potential barriers such as housing and employment; providing practical support (such as transport and childcare); improving social support by broadening service users' and families' social networks; and continuously assessing the changing needs of people and their families, rather than performing a one-off assessment.

A review by Ingoldsby (2010) evaluated methods for increasing family engagement and retention in child mental health programs. Effective approaches included equipping families with coping strategies to manage life stressors (such as job and financial difficulties, relationship conflicts, health problems, and other concerns); and addressing families' motivations, expectations, and needs around attending treatment. The review found that among families receiving outpatient services for children's behavioural challenges, the provision of additional support was associated with increased and maintained engagement, particularly when approaches were implemented continuously during treatment.

The 5-Step Method is an evidence-based, trauma-informed approach that supports whānau members who are affected by someone else's alcohol, drug, or gambling behaviour.[6] The 5-Step Method training equips addiction workers with knowledge and skills to help whānau focus on their wellbeing and their relatives' needs, including children. International research indicates the 5-Step Method is effective in reducing the strain experienced by family members affected by their relatives' substance use (Copello et al., 2010). In Aotearoa New Zealand, 8 In 10 whānau members who worked with the 5-Step Method report improved physical and mental wellbeing, and reduced worry and distress; 6 in 10 show improvements in coping styles; and half experience improvements in social support (Te Pou, 2020).[7]

The Community Reinforcement and Family Training (CRAFT) is an approach for families who have a loved one experiencing problematic substance use who are not interested in making changes or getting help. CRAFT uses supportive, non-confrontational methods to engage people who use substances with treatment. Strategies include positive communication, positive reinforcement, and developing awareness around self-care as a priority for the family (Foote et al., 2013). A review found that compared to traditional problematic substance use programmes (such as Alcoholics/Narcotics Anonymous), CRAFT was associated with a 3.3 times higher likelihood of whānau staying engaged with treatment (Roozen et al., 2010). Overall, this area of research and practice indicates several ways in which services can provide additional support for whānau to facilitate better outcomes for both tāngata whai ora and whānau.

Measures of whānau engagement

This section outlines whānau engagement measures used in Aotearoa New Zealand and in other IIMHL countries. Measuring family and whānau engagement in services is important

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[6] For more information about the 5-Step Method in Aotearoa New Zealand, see https://www.tepou.co.nz/initiatives/5-step-method

[7] Based on data collected from 58 whānau members who worked with the 5-Step Method between 2017 and 2020.

for continuous service quality development, setting goals and benchmarks, monitoring progress towards achieving goals, and for identifying when and where services can improve (Brown & Pirkis, 2009; Coombs et al., 2011; Ettorchi-Tardy et al., 2012). Improving these factors of service quality can facilitate whānau engagement in practice and, in turn, help to improve the experiences and outcomes for tāngata whai ora (Gore-Jones & Dark, 2019; Quality of Care and Outcomes Research in CVD & Stroke Working Groups, 2000).

Aotearoa New Zealand

Program for the Integration of Mental Health Data (PRIMHD)

The national PRIMHD database contains routinely collected information about mental health and addiction service activities, including contact with family or whānau. The main activity measures related to whānau engagement are:

- contact with family/whānau, consumer/tangata whai ora not present (T32)[8]
- contact with family/whānau, consumer/tangata whai ora present (T36)
- support for family/whānau (T47).[9,10]

In 2020, the National Collections Annual Maintenance Project (NCAMP) proposed changes to how PRIMHD collects whānau engagement data (Manatū Hauora Ministry of Health, 2021a). NCAMP claimed that the existing measures provide limited insight into how and when whānau engagement occurs and lack data relating to whānau engagement in community settings. A “family/whānau involvement flag” was therefore added to PRIMHD in July 2021 (Manatū Hauora Ministry of Health, 2021b). This flag indicates whether a whānau member was involved with tāngata whai ora during their mental health service journey. Involvement is interpreted broadly based on each activity—in some instances the whānau member may have just been present in the room, while in others they may have been as involved in the activity with tāngata whai ora.

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[8] T32 includes formal activities such as support plan reviews and goal setting (if the service user is present, record T36); home visits and telephone contacts that identify service user needs and/or support requirements. The contacts recorded need to have a minimum duration of 30 minutes. T01 (mental health crisis attendances) takes priority over any other simultaneous activities, including T36.

[9] T47 activity is used for supportive activity delivered to family whānau members of people with mental health and addiction issues regarding the effects of these issues on the family whānau member (eg provision of information, psychoeducation, facilitation of peer-group support and tools to promote resilience, self-esteem and coping strategies).

[10] Other measures related to providing support for family and whānau include “support for children of parents with mental illness and addictions” (T49) and “support for parents with mental illness and addictions” (T50).

All mental health and addiction services are expected to implement the whānau involvement flag. This will become mandatory for services to collect from 1 July 2023.[11] At the time of writing, nine districts and 107 NGOs collect whānau involvement flag information. Until all services implement the change, whānau engagement data reported using this flag needs to be interpreted with caution. Therefore, results have not been presented here.

KPI Programme

The KPI Programme provides a dashboard for the whānau engagement indicator using PRIMHD (KPI Programme, 2022). The indicator aligns with the proposed Manatū Hauora Ministry of Health family/whānau involvement flag as it also shows whether whānau were involved in a mental health or addiction service activity.

Table 1 presents the average proportion of activities with whānau engagement between 2017 and 2021 by age group. Whānau engagement activities that occurred at any point during the service episode are included.[12] Figure 1 shows quarterly rates over this period. The national average rate of whānau engagement from 2017 to 2021 was 50.7 percent.[13]

Rangatahi aged under 18 years had markedly higher rates of whānau engagement than other age groups, with around 4 in 5 (80.7 percent) having whānau engagement between 2017 and 2021. Half (50.9 percent) of rangatahi aged 18 to 19, and over 3 in 5 (61.8 percent) older people aged 65 and over had whānau engagement. About 2 in 5 (42.1 percent) people aged 20 to 24 had whānau engagement. The lowest rates of whānau engagement were found for people aged 25 to 44 and 45 to 64, with around 1 in 3 having whānau engagement (34.6 and 35.1 percent respectively). Rates of whānau engagement remained largely stable, with no age group showing large changes in whānau engagement during this period.

Table 1. Average yearly rates of whānau engagement by age group from 2017 to 2021 (KPI Programme, 2022)

Year	Age group						
	0 to 17 %	18 to 19 %	20 to 24 %	25 to 44 %	45 to 64 %	65 and over %	Total average %
2021	79.8	49.2	40.6	33.8	33.3	62.4	49.8
2020	79.5	51.7	41.4	34.1	33.6	59.5	50.0
2019	79.9	50.5	42.3	34.1	33.5	62.3	50.4

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[11] The whānau involvement flag was originally set to be mandatory from 1 July 2022 but this has now been delayed to 1 July 2023 due to delays in implementation (Manatū Hauora Ministry of Health, 2022).

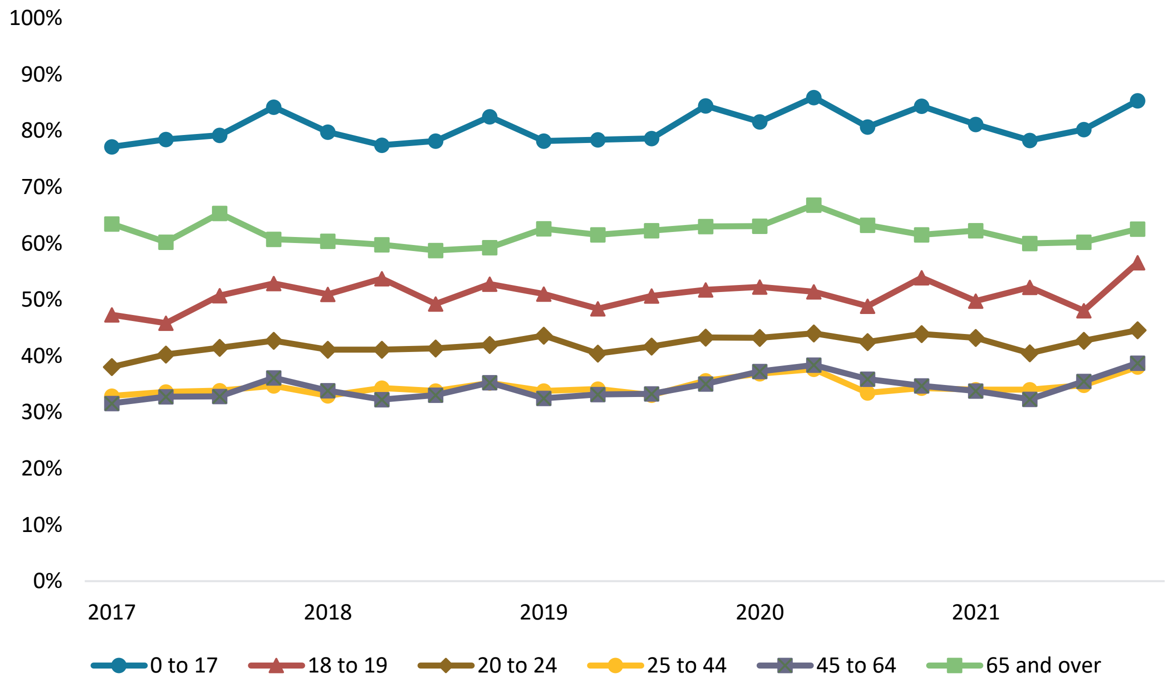
[12] Data includes whānau engagement that occurred within and beyond 28 days after start of service episode.

[13] Due to differences in availability of complete data for age and ethnic groups, the total average presented in Table 2 differs slightly to that shown in Table 1.

2018	83.1	51.6	43.4	35.6	36.6	63.7	52.3
2017	81.3	51.6	42.8	35.2	35.1	61.3	51.2
Total average	80.7	50.9	42.1	34.6	34.4	61.8	50.8

Source*:* Data adapted from KPI Programme whānau engagement data dashboard (accessed July 2022).

Figure 1. Quarterly rates of whānau engagement by age group from 2017 to 2021 (KPI Programme, 2022)



Source*:* KPI Programme whānau engagement data dashboard (accessed July 2022).

Table 2 presents average yearly rates of whānau engagement by ethnic group from 2017 to 2021. Whānau engagement activities that occurred at any point during the service episode are included. Figure 2 shows quarterly rates over this period.

Table 2. Average yearly rates of whānau engagement by ethnic group from 2017 to 2021 (KPI Programme, 2022)

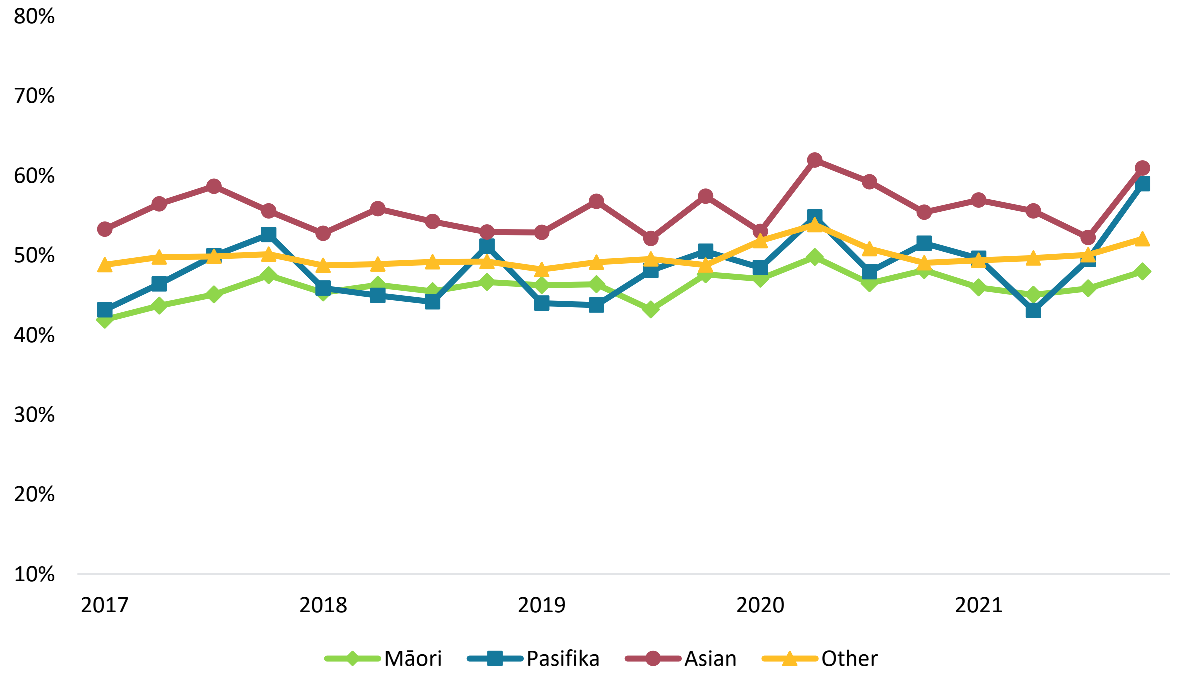
Year	**Ethnicity**				
	Māori %	**Pasifika %**	**Asian %**	**Other %**	**Total average %**
2021	46.2	50.3	56.4	50.3	50.8
2020	47.9	50.7	57.4	51.4	51.8
2019	45.9	46.6	54.8	48.9	49.0
2018	45.9	46.5	53.9	49.0	48.9

2017	44.5	48.0	56.0	49.7	49.6
Total average	46.1	48.4	55.7	49.9	50.0

Source*:* Data adapted from KPI Programme whānau engagement data dashboard (accessed July 2022).

Overall, Māori appear to have slightly lower rates of whānau engagement compared to other ethnic groups, with under half of service episodes involving whānau engagement between 2017 and 2021. Whānau engagement rates for Māori track below the national average. This is closely followed by overall Pasifika rates over the last 5 years, which have improved recently. Around half of service episodes with tāngata whai ora of other ethnicities (including Pākehā, Middle Eastern, Latin American, African, and other ethnicities) involved whānau engagement. Asian peoples had the highest rates of whānau engagement during this period, with over half of service episodes having whānau engagement. Rates of whānau engagement across ethnic groups have remained relatively stable over time, with only rates for Pasifika increasing slightly.

Figure 2. Quarterly rates of whānau engagement by ethnic group from 2017 to 2021 (KPI Programme, 2022)



Source*:* KPI Programme whānau engagement data dashboard (accessed July 2022).

Mārama Real-Time Feedback

Internationally, consumer experience surveys are most often used to collect information on whānau engagement (Te Pou o te Whakaaro Nui, 2018). Mārama Real-Time Feedback (Mārama RTF) is an electronic survey that can be used to routinely collect feedback from people and their whānau about their experiences of mental health and addiction services. The tool can be completed by both tāngata whai ora and whānau. Services receive results in real time which supports the monitoring of progress towards service and sector priorities and allows ongoing and continuous service improvements based on direct feedback from tāngata whai ora and whānau.

The main whānau engagement-related item included in Mārama RTF is: "Family involvement: My family/whānau are given information and encouraged to be involved".[14] The item is rated on a 5-point Likert scale ranging from strongly agree to strongly disagree.[15]

Table 3 presents the annual percentage of whānau involvement reported in Mārama RTF between 2016/17 and 2020/21.[16] The percentage of whānau who agree they feel involved in decision-making in services appears to have decreased slightly over time, from 80 percent in 2016/17 to 76 percent in 2020/21.[17]

Table 3. Percentage of whānau and tāngata whai ora who felt involved in decisions about care as reported in Mārama RTF (2016/17 to 2020/21) (Te Hiringa Mahara, 2022)

Measure	**2016/17**	**2017/18**	**2018/19**	**2019/20**	**2020/21**
Whānau who felt involved in decisions about care	80%	79%	75%	81%	76%

Note. Percentages include 'Strongly agree' and 'Agree' responses. Data source: Mārama Real Time Feedback, analysed by CBG Health Research and Te Pou, November 2021

Figure 3 shows whānau involvement in treatment decisions broken down by tāngata whai ora and whānau responses (Te Pou, 2022). In the period between January 2022 and June 2022, more whānau agreed they were involved in decisions compared to tāngata whai ora. More whānau engagement was reported by tāngata whai ora and whānau accessing Te Whatu Ora district services than NGOs.

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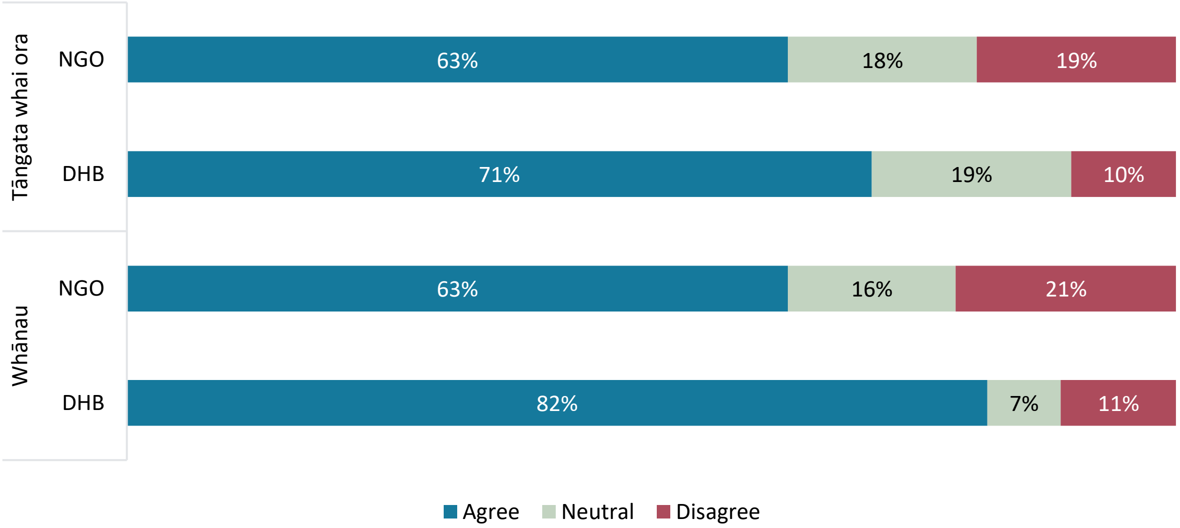
[14] Includes an additional option: "I didn't want them to be involved".

[15] Aggregated response data captured through Mārama RTF is presented through an interactive tool hosted on the Te Pou website, https://www.tepou.co.nz/initiatives/marama-real-time-feedback. This is publicly available and updated daily. National report cards which highlight feedback from tāngata whai ora and whānau are also published on the Te Pou website every 6 months.

[16] It is important to note that Mārama RTF records the number of surveys answered but does not routinely collect non-response rates. Caution must therefore be applied when interpreting results in terms of generalisability across Aotearoa New Zealand.

[17] It is worth noting that the COVID-19 pandemic may have impacted ratings of whānau involvement during 2020/21.

Figure 3. Whānau involvement reported in Mārama RTF for tāngata whai ora and whānau (January 2022 to June 2022) (Te Pou, 2022)



Note. 'Agree %' includes 'agree' and 'strongly agree' responses. 'Disagree %' includes 'disagree' and 'strongly disagree' responses. NGO = non-government organisation; DHB = district health board.

Ngā Poutama

Ngā Poutama was a survey run in 2019 by the Health Quality & Safety Commission as part of the national mental health and addiction quality improvement programme (Health Quality & Safety Commission, 2020). Ngā Poutama surveyed tāngata whai ora who accessed inpatient or community DHB mental health and addiction services, and their whānau. While the survey had a low response rate (3 percent), its whānau-related items are listed below to compare to other whānau engagement measures in Aotearoa New Zealand and internationally.

The three whānau-related items were rated on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree).

- "My family and whānau were included, as much as I wanted them to be, throughout the journey"
- "I was able to have a support person with me during sessions with staff"
- "I was able to access peer-support staff (by "peer-support staff", we mean staff who have also experienced mental distress or addiction)".

In 2022, a second Ngā Poutama survey was undertaken, aimed at the mental health and addiction workforce including family and whānau advisors, support/peer workers, psychiatrists, nurses, and other workers. Findings will be used to design further quality improvement initiatives to make a difference for tāngata whai ora, whānau, and staff. Whānau engagement-related items were rated on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree).

- “We work alongside family/whānau to understand how best to support them and their family member”
- “In this service we involve tāngata whaiora and family/whānau in efforts to improve future practice”

Results of the second survey were not available at the time of writing this report.[18]

Overseas whānau engagement measures

This section outlines family and whānau engagement measures used overseas, with a focus on IIMHL countries. Measures were found from Australia and England.

Australia

In Australia, the involvement of carers in service delivery, planning, and evaluation is a priority area. A carer is defined as “a family member, partner, or friend of someone with a mental illness whose life is also affected by that person’s illness”, and also “provide support and assistance” (NSW Government, 2021). The term “carer” is used in this section as it is the preferred term in the Australian context, and it specifically includes people who are directly affected by a person’s mental health challenges or service journey.

Progress in service delivery, planning, and evaluation of carer support involvement is informed by the Mental Health Establishments National Minimum Data Set, overlooked by the Australian Institute of Health and Welfare (AIHW). This dataset contains a range of information about carer participation, including the use of carer experience surveys. Below is an overview of the service user and carer experience surveys conducted in Australia, including Your Experience of Service, and Carer Experience Service.

Your Experience of Service (YES)

The Commonwealth Department of Health’s Your Experience of Service (YES) survey tool has been used since 2015. YES was designed for use in mental health settings and aims to help improve services by allowing service users to have a say about their experiences (Government of Western Australia Mental Health Commission, 2019; Victoria State Government, 2021). The survey’s two questions about family involvement are below.

- “Your opinions about the involvement of family or friends in your care were respected.”
- “You had opportunities for your family and carers to be involved in your treatment and care if you wanted.”

Each item is rated on a 5-point scale ranging from 1 (never) to 5 (always).

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[18] Information about the second Ngā Poutama survey can be found here https://www.hqsc.govt.nz/assets/Our-work/Mental-health-and-addiction/Resources/Nga-Poutama-MHA-staff-culture-survey-poster-May-2022-A4.pdf

The national reporting of YES is done by the AIHW, at both state and local levels. While national data is not currently available, findings at the statewide-level are regularly reported by Victoria (Victoria State Government, 2021), New South Wales (NSW Government, 2021), Western Australia (Government of Western Australia Mental Health Commission, 2019), and Queensland (Queensland Health, 2017).

Table 4 summarises responses to family involvement-related questions across service user experience surveys in Australia. In Western Australia, Victoria, and New South Wales the majority of respondents say they had opportunities for family and carers to be involved if they wanted (Government of Western Australia Mental Health Commission, 2019; NSW Government, 2021; Victoria State Government, 2021). It is critical to note, however, that the state-wide response rate for Western Australia was low (5.4 percent in 2018 and 4.3 percent in 2019). No information on response rates for Victoria and New South Wales was available. The rates reported below must therefore be interpreted with caution.

Table 4. Responses to family involvement-related survey questions across Australia

State	Question	Response type	Responses	
Western Australia	Opportunities for family and carers to be involved	Percentage of respondents (service users) satisfied with item	2018	2019
			Inpatient 85.6% Community 88.0%	Inpatient 78.9% Community 84.9%
Victoria	Opportunities for families and carers to be involved in treatment	Likert frequency scale ranging from Never to Always	2018 to 2019	
			Always 72.3% Usually 17.8%	
New South Wales	You had opportunities for your family and carers to be involved in your treatment and care if you wanted	Likert scales ranging from 1 (lowest rating) to 5 (highest rating)	2019 to 2020	
			Inpatient 4.47	Community 4.51
	Your opinions about the involvement of family or friends in your care were respected		4.33	4.35

Carer Experience of Service (CES)

The Australian Mental Health Outcomes and Classification Network's (AMHOCN) Mental Health Carer Experience Survey (CES) captures the experiences of family members. Carers are offered the survey when they encounter inpatient or community mental health services.

The survey questions below are rated on 5-point Likert frequency or performance scales (ranging from never to always).

- “You were given the opportunity to provide relevant information about your family member, partner or friend.”
- “Your opinion as a carer was respected.”
- “You were involved in decisions affecting your family member, partner or friend.”
- “You were given opportunities to discuss the care, treatment and recovery of your family member, partner or friend (even, if for reasons of confidentiality, you could not be told specific information).”
- “You were involved in planning for the ongoing care, treatment and recovery of your family member, partner or friend.”
- “You had opportunities to communicate confidentially with the treating doctor if you needed (such as by phone, email or in person).”

CES results are available via login on the AMHOCN website but are not publicly reported and thus could not be included in this review.

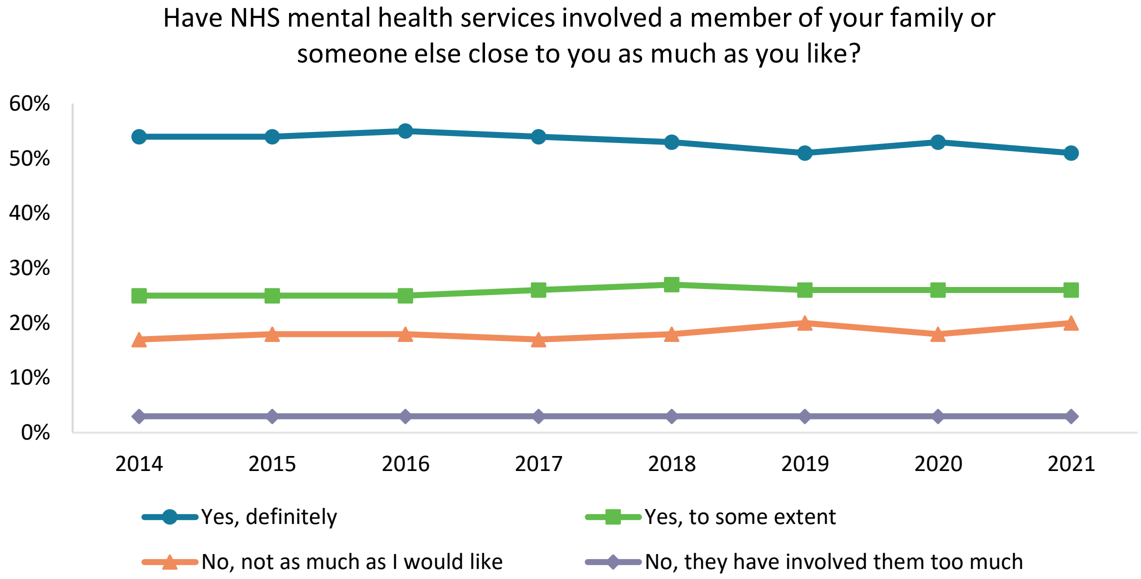
England

Community Mental Health Survey

The National Health Service’s (NHS) Community Mental Health Survey looks at the experiences of people who use community mental health services (Care Quality Commission, n.d.). The survey has been run annually since 2003. It includes one question related to family involvement: “Have NHS mental health services involved a member of your family or someone else close to you as much as you like?”. This question is rated on a 4-point Likert frequency scale with responses ranging from ‘Yes, definitely’ to ‘No, they have involved them too much’).

The 2021 survey included 54 NHS trusts in England, with a total response rate of 26.5 percent. Figure 4 shows that between 2014 and 2021 about 4 in 5 people agreed to at least some extent that their family had been involved. However, the data indicates that the proportion of people who “definitely” felt that their families were involved decreased slightly over this period, while the proportions of people who responded with “No, not as much as I would like” increased slightly.

Figure 4. Responses to the NHS Community Mental Health Survey's family involvement item, 2014 to 2021 (NHS England, 2021)



Note. Data adapted from *2021 Community Mental Health Survey: England results* (NHS England, 2021), retrieved from https://www.cqc.org.uk/sites/default/files/20211201_cmh21_NationalTables_V2.ods

Other whānau engagement measures

A systematic review by Hock and colleagues (2015) identified family engagement measures used across research in substance use and mental health settings for children and adolescents. Table 5 outlines the measures identified and are summarised below.

All the measures identified were designed for the parents or caregivers of children and young people accessing mental health or addiction services. Each measure assessed at least one domain of parent or caregiver involvement: behavioural (such as treatment participation, active support), attitudinal (for example beliefs about treatment), and affective (such as family members' experiences and emotions in relation to their involvement in the child's treatment).

At the time of writing, Hock and colleagues (2015) noted there were no available data or benchmarks against which to compare the results of each measure. This means it may be difficult to determine whether results are clinically significant; health professionals may have to interpret results on an individual person basis.

Table 5. Measures of family engagement in child and adolescent mental health and substance use treatment (Hock et al., 2015)[19]

Scale	Treatment setting	Reporting method	Items	Population	Topics assessed
Credibility Expectancy Questionnaire-Parent Version (CEQ-P)	Outpatient mental health	Parent self-report	6	Children aged 6 to 13 years referred for oppositional, aggressive, and antisocial behaviour	Treatment credibility Treatment expectancies
Therapeutic Alliance Scale for Caregivers and Parents (TASC-P)	Outpatient mental health	Parent/caregiver self-report and observer report	12	Children aged 4 to 13 years	Affective bond Client-therapist collaboration
Multisystemic Therapy-Caregiver Engagement (MST Engagement)	Drug court, community mental health / substance use treatment	Observer report	9	Adolescents aged 12 to 17 referred for psychoactive substance use, on probationary status, not currently involved in other substance use treatment	Caregiver involvement, commitment, and agreement on treatment Goals
The Child and Adolescent Level of Care System / The Child and Adolescent Service Intensity Instrument (CALOCUS / CASII)	Outpatient program, day treatment, public mental health strategies	Clinician report	8	Children and adolescents aged 6 to 18 years	Acceptance and engagement Risk of harm Functional status Comorbidity Recovery environment Resiliency and treatment history
Parent Rating of Parent Involvement	Outpatient mental health	Parent self-report	2	Adolescents aged 12 to 18	None
Family Engagement Questionnaire (FEQ-P)	Child and adolescent inpatient psychiatric treatment	Clinician report	16	Children and adolescents referred for acute psychological and behavioural problems	Parent engagement subscale
Parent Motivation Inventory (PMI)	Outpatient mental health	Parent self-report	25	Children and adolescents aged 2 to 12 years referred for oppositional,	Desire for child change Readiness to change

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[19] Information adapted from (Hock et al., 2015).

				aggressive, and antisocial behaviour	parenting behaviour Perceived ability to change parenting behaviours
Vanderbilt Therapeutic Alliance Scale-Revised (VTAS-R)	Outpatient substance use	Observer report	28	Adolescents aged 12 to 18 referred for substance use	Patient contribution Therapist-patient interaction

Summary

Overall, Aotearoa New Zealand appears to be unique in routinely collecting data on whānau engagement through mental health and addiction service activity records. PRIMHD collects comprehensive whānau engagement-related data through service data collection. The KPI Programme website provides up-to-date data on whānau engagement in mental health and addiction services. Data shows that between 2017 and 2021, rangatahi aged under 18 have the highest rates of whānau engagement, followed by older people aged 65 and over. Whānau engagement for Māori tracked below the national average during this period. In addition, Mārama RTF collects feedback from tāngata whai ora and whānau on whether there were opportunities for whānau engagement and their involvement in decision making. Data indicates that the proportion of people who felt involved in decision-making in services appears to have decreased slightly over time, particularly in 2020 during the onset of COVID-19. This finding is similar to results found by the Community Mental Health survey in England, which indicates that the extent to which people felt their families were involved has decreased slightly over time.

Family involvement measures identified in Australia and England come from service user experience surveys. Mārama RTF differs from these surveys in some ways. First, while results of international surveys are published in standalone reports, Mārama RTF provides results to services in real time and presents summarised data through an online dashboard that is publicly available and updated daily. Second, Mārama RTF asks if whānau are given information and encouraged to be involved, while the overseas surveys just ask about their involvement. Third, Mārama RTF is aimed at both tāngata whai ora and whānau, while the other surveys focus on either group discreetly.

Available information indicates low uptake of YES in Western Australia and a moderate uptake of the Community Mental Health Survey in England. No response rate information was available for YES in New South Wales and Victoria, or for Mārama RTF. Caution must therefore be applied when interpreting results from these service user experience surveys given limited information on their representativeness of people accessing services.

Other whānau engagement measures used across research with children and adolescents vary more widely. Topics assessed include treatment expectations, client-therapist relationships, and readiness to change. These measures used in smaller scale settings enable an understanding of more specific factors associated with whānau engagement that service user feedback surveys do not measure.

Discussion

This review summarises evidence regarding the impacts of whānau engagement in mental health and addiction services, barriers to whānau engagement for services and whānau, approaches to increasing engagement, and whānau engagement measures in Aotearoa New Zealand and in other IIMHL countries.

Research indicates that whānau engagement is associated with positive outcomes including improved wellbeing and a lower likelihood of readmission to services and missing appointments. Positive individual and service outcomes provide further incentive for national strategies in Aotearoa New Zealand to improve whānau involvement in mental health and addiction services and strengthen the rationale for the KPI Programme's inclusion of a whānau engagement indicator. As Aotearoa New Zealand moves towards transforming services to improve mental wellbeing holistically, person and whānau centric service provision is critical (Manatū Hauora Ministry of Health, 2021c; Te Hiringa Mahara, 2022).

Key reported barriers to whānau involvement for services include capacity issues and a lack of workforce training and resources. The literature indicates that while health professionals recognise the importance of engaging with whānau in services, engagement is often reportedly limited by workloads, service flexibility, and workforce knowledge and skills to effectively engage with whānau of tāngata whai ora.

For whānau, a barrier to engaging with services includes not being given enough information, advice, or options about a whānau member's treatment. Being given insufficient information about the treatment process or service journey limits opportunities for whānau to share information with services and to be part of the journey for tāngata whai ora. Another barrier is either tāngata whai ora or whānau not wanting to be involved. Reasons for this can vary - for tāngata whai ora, these can include family conflict or perceived stigma; for whānau, it may reflect wanting to respect the whānau member's privacy or feeling that problem-solving will be too difficult.

Research in this area identifies barriers to whānau engagement reported by tāngata whai ora, whānau and staff. It is also important to consider the broader context of mental health and addiction services that can hinder whānau engagement. One factor to consider is that in Western countries including Aotearoa New Zealand, services are traditionally delivered based on Western, individualistic models of care rather than collectivist, whānau-focused approaches (O'Hagan et al., 2012). Aotearoa New Zealand is shifting towards more holistic, whānau-focused approaches to supporting people experiencing mental health challenges and problematic substance use (Ministry of Health, 2021c; Te Hiringa Mahara, 2022). However, the historical individualism underlying services may factor into why services, staff, whānau, and tāngata whai ora find it difficult to involve whānau in treatment.

The barriers to whānau engagement identified highlight actions services can take. Firstly, services can implement more whānau-centred models of care such as shared decision-making. Such approaches have been shown in the literature to be effective and empowering for whānau. Secondly, to help facilitate the implementation of whānau-centred approaches to treatment and support, workforce development is important to equip health professionals with the skills and tools required to effectively engage with whānau. Thirdly, services can consider what additional support can be provided to reduce barriers to engagement for whānau. Additional support can include providing more psychoeducation, information, or advice to whānau to help them stay engaged. It can also include practical support such as helping with transport, childcare, and facilitating coping strategies. In identifying barriers and actions to address them, this research area contributes to quality development in mental health and addiction services.

Internationally, Aotearoa New Zealand is unique in having a whānau engagement indicator built into national mental health and addiction service data collections. Rangatahi aged 0 to 17 have the highest rates of whānau engagement, followed by older people aged 65 and over. To improve the service experiences and outcomes for tāngata whai ora, consideration should be given to why adults are less likely to experience whānau engagement than other age groups.

Further examination is recommended to identify how to improve rates of whānau engagement among Māori and Pasifika. Given that Māori and Pasifika are collectivist cultures in which whānau engagement would be expected to be more likely, more research looking at what factors underlie whānau engagement rates is warranted. This could include examining how well mental health and addiction services support Māori and Pasifika communities, perceptions of discrimination, negative past experiences with services, reluctance towards engaging with services, and how poverty and other socioeconomic factors factor into whānau engagement.

Overseas, whānau engagement in services is typically measured through service user experience surveys such as Australia's YES and England's Community Mental Health Survey. User experience surveys generally measure whānau involvement through a small number of individual items rated on Likert-type scales. This, along with low uptake of service user experience surveys, limits the amount and quality of information regarding whānau engagement in services. In rebuilding the whānau KPI indicator, Aotearoa New Zealand sets precedent for other countries to measure whānau engagement more widely on a national level.

Whānau engagement measures used in smaller-scale studies in research capture more specific factors associated with whānau engagement such as treatment expectations, degree of collaboration with therapists, and readiness to change. Though asking in-depth questions is important to understanding processes underlying whānau engagement, they are generally beyond the scope of national data collection and consumer surveys.

Limitations

One limitation of this review is that most studies included, apart from those about whānau measures used in Aotearoa New Zealand and internationally, were qualitative. The lack of quantitative data makes it difficult to gauge to what extent whānau engagement is associated with positive outcomes, how barriers affect whānau engagement, and to what extent strategies increase whānau engagement. This is expected, however, as findings from this review indicate that whānau engagement is not yet an internationally adopted measure and studies to date have tended to be exploratory. Rather, as this review draws on findings from studies conducted in a range of settings (for example, community and inpatient services) and with a range of population groups (such as children, young adults, and older adults), the evidence presented provides a broad indication of the reasons for, effects of, and potentially effective ways to increase whānau engagement in services. More future quantitative analyses can help to assess the specific effects of whānau engagement on people’s service and wellbeing outcomes, and how well different approaches improve whānau engagement. There is also a need for more qualitative research focusing on the experiences of Māori and Pasifika communities.

This review did not report data on the recent whānau engagement flag added to PRIMHD. There is some data available from the PRIMHD database; however, currently, only some Te Whatu Ora districts and NGOs collect this data. This means the currently available data is incomplete with regards to representing services across Aotearoa New Zealand. Additionally, while the available data come from records since 1 July 2021, end dates vary for each service depending on their most recent data submission. These caveats arise from the fact that services may be implementing new systems to implement the whānau contact flag, and services are not currently required to collect this data until 1 July 2023.

It is acknowledged that the KPI Programme whānau engagement indicator itself has some limitations. At this point in time limitations include the inability to report whānau engagement for inpatient and residential support. Currently inpatient and residential support whānau engagement data is not mandated for reporting contacts into PRIMHD, but the ability for whānau engagement to be measured in these settings does exist. For services committed to collecting and reporting this data into PRIMHD, there is opportunity to expand the indicator over time.

Future improvements to the indicator could include the type of engagement (for example phone, in person, and length of time spent engaging). PRIMHD states that involvement is recorded whether the whānau member simply attends or was actively involved in the appointment. Knowing the kind of engagement is useful as it can show how much active support tāngata whai ora and their whānau receive from services. For both these examples, data collection is important for exploring who may be more likely to receive support than others.

Conclusion

Evidence shows whānau engagement is a key factor in positive outcomes for people accessing mental health and addiction services. International literature also indicates Aotearoa New Zealand is unique in measuring whānau engagement as a national KPI. It is therefore recommended that the KPI Programme continue to rebuild and update the whānau indicator for use across all communities of interest the KPI Programme serves.

The indicator should reflect the proportion of activities in which whānau were involved. Mandating the whānau contact flag in mental health and addiction services from 1 July 2023 will add another layer of data to the service story of whānau engagement with services. Using a whānau indicator provides an opportunity to lead an international move beyond measuring whānau engagement through service user experience surveys and smaller measures, towards measuring it as a national KPI. This sets an important precedent to adopt a more whānau-centred approach to mental health and addiction services, and to measure the national approach to holistic wellbeing.

There are opportunities for the whānau engagement indicator to be refined further. For example, recording what type of engagement happens and the length of the engagement. Collecting such data could further illustrate how whānau contribute to the service journey, and where and whether services can encourage whānau engagement. Additionally, it could be insightful to overlay PRIMHD data with Mārama RTF or other consumer experience data to examine the quality of engagement tāngata whai ora and whānau have.

Continued sector partnership and collaboration is recommended to assess the feasibility of further development of the KPI Programme whānau engagement indicator.

Appendix A

Table 6. Details and findings of studies relevant to whānau engagement identified in the literature searches

Title, authors, and country	Study type and aim	Sample	Findings
Therapist, Parent, and Youth Perspectives of Treatment Barriers to Family-Focused Community Outpatient Mental Health Services Baker-Ericzén et al., 2013 USA	Exploratory qualitative study – fundamental qualitative description To describe treatment barriers to receiving family-focused child mental health services for youths with disruptive behaviour problems from multiple perspectives	4 therapist focus groups (n = 26), 3 parent focus groups (n = 14), and 10 young people **Therapists** *Discipline* 50% marital and family therapy, 35% social work, 15% psychology *Primary focus* 46% family systems, 38% cognitive behavioural, 8% psychodynamic, 4% humanistic, 4% other **Parents** *Type* 50% biological, 46% foster/adoptive, 7% relative *Marital status* 64% married, 7% divorced, 14% single (no partner), 14% single (with partner) **Young people** Mean age = 11.4	**Therapists** *Parents' lack of involvement and perceived unwillingness to participate* Therapists felt constrained by parents' lack of engagement; many commented on parents' absence or resistance during sessions. *Inadequately supported in meeting families' needs* Therapists cited a lack of formal service system support as interfering with meeting families' needs and maximising service delivery. This includes having other professionals provide support (eg in-home support, parent education, behaviour management, home restructuring) when they are unable to. Therapists also cited policy issues such as rigid, time-consuming protocols and lack of coordination with services in other agencies. Paperwork was a major barrier in focusing on work. Lack of support in coordinating care includes other agencies not wanting to work with young people with behavioural issues, not wanting to work with co-existing issues (eg substance use *and* depression), and not wanting to work on cases that do not show immediate positive results (which excludes people who need support over a long period of time). **Parents** *Overwhelmed by children's symptoms* Parents reported feeling exhausted by constant struggles with the children's behaviour. They reported being hit by their child, feeling like they're doing something wrong, and feeling afraid of their own child but not being able to do much about it. *Unsupported by formal service system* Parents felt a constant struggle with too much help, not enough help, and nobody to guide them. Parents highlighted system barriers such as the lack of service system coordination and ineffective treatment strategies as contributing to them feeling unsupported. Parents felt not listened to, blamed, and not believed by therapists. Parents' experiences of feeling blamed or ignored made them feel unimportant and disinterested in their child's treatment, fuelling their frustration with service delivery. *Dissatisfaction with mental health services* Some parents did not seem confident in the treatment process. This was partially because therapists would suggest things that parents had already tried but didn't work. Some felt that the system is not capable of addressing more extreme or complex needs. Parents' dissatisfaction was a significant source of their frustration. They felt that travelling to and spending time at community services was a waste of their and their children's time.

			Young people *Openness to discussing parents' problems* Several young people indicated their parents also had problems such as feeling sad, stressed, anger management issues, medical issues, or financial problems. They felt therapists should ask about their parents' problems because they affected their own issues as well. *Openness to parents' active involvement in therapy* Young people spoke positively about their parents' involvement in therapy but reported it did not happen frequently. They felt the lack of family involvement was a concern because it was sometimes more helpful to work through things when parents were present.
Involved, inputting or informing: "Shared" decision making in adult mental health care Bradley & Green, 2018 UK	Qualitative questionnaire study To better understand how family caregivers of people with mental health diagnoses are involved with decision making, particularly about treatment options including prescribed medication	n = 46 family member participants, n = 158 staff	Overall, staff valued the contextual information that families can provide, but families often felt that they were not given enough information and thus were not part of decision making. Both participant groups saw involvement as "opinion-seeking" to shape decisions around treatment options but also to consolidate decisions offered by staff. Family members saw involvement as a way to be listened to/heard and incorporated. When family members adopted coping strategies and could make practical decisions, their levels of distress reduced. **Rules of engagement** *Patient permission* Participants recognised that service users' permission had to be navigated and their wishes prioritised. Staff sometimes felt anxiety about being able to maintain patient confidentiality which could then exclude family members, prevent information exchange, and ultimately deny family the opportunity for involvement. Patient permission is continuously reviewed throughout treatment – permission can be withdrawn at any time, for example, if a service user relationship deteriorates, or due to service user concerns about information exchange between family and staff. *Presence* Staff generally take a passive approach to family engagement wherein they wait for family members to attend appointments rather than actively encourage attendance or negotiating meeting times. Family participants reflected this by highlighting the difficulty of "getting into" appointments or being "given chances" by staff to be involved. Family members that knew about service policy and practices had an easier time being involved in appointments, thus highlighting the importance of staff sharing this information. *Information exchange* Family members and staff both recognised that information is an essential precursor to family involvement; however, staff constraints reduced opportunities for information exchange and thus excludes family from possible involvement. Staff emphasised the important role of family members in providing wider, contextual information about the service user to enhance understanding and inform decision-making, and provide information about service users' response to adherence with prescribed medication.

			For families, information exchange served a dual response – to shape decisions and to support them as carers. The opportunity to provide information to staff, to have a platform to share thoughts and views about care, to be listened to is a key supportive resource for families, and as a means to enhance their mental health literacy and capacity to support at home. Relationships with staff played a key role in family involvement; information exchange is facilitated when staff recognise family members as co-workers or core team members. **Staff "permission" and the carer "agenda"** Some family members felt that staff perceived them negatively and actively excluded them from treatment – in some cases family members were not given enough information or were given the impression their contributions were not welcome. Conversely, some staff felt challenged by family members who held different, and possibly antagonistic, views; and some felt family members did not have the best interest of service users in mind.
Barriers and facilitators of pediatric shared decision-making: a systematic review Boland et al., 2019 Canada	Systematic review To identify and synthesise barriers and facilitators of shared decision-making (SDM) in paediatric practice from the perspectives of healthcare professionals, parents, children, and observers	N = 79 publications	Shared decision-making (SDM) is an evidenced-based approach that promotes collaboration between patients, family members, and healthcare providers (HCP) when making health decisions. By exchanging information about the evidence (options, risks, and benefits) and the patient and family's preferences and values, HCPs, patients, and family members can deliberate to determine the best treatment plan. This approach to decision-making is considered essential for patient-centred care, has garnered increasing international support among policy makers, and is recommended by paediatric regulatory organizations. **Barriers** • Decision level: perceived lack of options, unacceptable alternatives, affordability, lack of research evidence for various options • Innovation level: poor quality information about the child's condition and/or options that were inappropriately tailored to the child and family's health literacy needs hindered SDM. HCPs reported SDM takes up too much time and therefore lacked feasibility for use in paediatric clinical setting • Adopter level: parents' and children's emotional state (eg anxiety, denial, defensiveness), perceptions of poorer health status of the parent or child, preference for traditional services/decision-making, HCPs lacking SDM skills (eg knowing when to elicit and incorporate family values and preferences) • Relational level: power imbalance (ie systematic exclusion of children from decision-making, or children feeling disempowered or intimidated), deliberately biasing certain opinions, (ie when HCPs only provide one option) • Environmental level: insufficient time due to heavy workloads, clinic workflow, poor continuity of care, practice norms (eg expecting HCPs to provide specific recommendations or make decisions) **Facilitators** • Decision level: perceived magnitude of decision being discussed influenced how SDM was encouraged and preferred – lower-stake decisions facilitated SDM. HCPs and parents reported being more willing to include children in SDM when potential outcomes were less risky. Children also preferred to be involved in lower-stake decisions. • Innovation level: high-quality information appropriately tailored to the child's and parents' developmental and literacy needs. High-quality information includes presentation of options, associated risks and benefits, and research evidence.

			• Adopter level: agreement with and desire for SDM (particularly for parents), good health • Relational level: trust and respect between adopters (in the way of positive relationships, respectful communication, appreciating other adopters’ expertise, trusting children’s participation, and trusting that the others will be open and forthcoming), inviting and supporting the child and family • Environmental level: access to SDM tools (eg patient decision aids), resources (eg decision coaches or experts in SDM), and/or training
Perceived stigma and social support in treatment for pharmaceutical opioid dependence Cooper et al., 2018 Australia	Prospective cohort study To examine correlates of social support among people in treatment for PO dependence	N = 108 PO dependent people referred from treatment services	Lower levels of social support were associated with unsanctioned opioid use, mental health conditions, and iatrogenic dependence.
Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors Eassom et al., 2014 UK	Systematic review To synthesise the evidence on implementing family involvement in the treatment of people with psychosis with a focus on barriers, problems, and facilitating factors	N = 43 studies	Themes of barriers and facilitators primarily related to the process of delivering an intervention: context, engagement, and delivery. **Context** Practical needs associated with family work • Barriers o Managing workload, practical burdens, and balancing clinical responsibilities o Poor allowance of time from service o Lack of structure and standardised systems to support family work o Logistics (out of hours and practical requirements not facilitated) • Facilitators o Top-down support and strategic solutions o Logistics (flexibility with appointments) Personal and training needs • Barriers o Problems with access to supervision o Lack of skills or confidence • Facilitators o Supervision and ongoing support Systems-wide approaches and attitudes to family work • Barriers o Organisational culture and paradigms o Unsupportive attitudes of managers o Lacking shared team commitment to family work o Anti-family work attitudes among staff o Difficulties with referrals and finding ‘appropriate’ clients • Facilitators

			○ Organisation prioritisation and shared culture of family work ○ Promotion of family work (among colleagues and within organisation) ○ Collaboration (multidisciplinary support) ○ Personal motivation and enthusiasm **Engagement** Reservations about involving families • Barriers ○ Issues with the nature of family involvement ○ Fear of worsening the situation • Facilitators ○ Supervision and ongoing support Problems with engaging families • Barriers ○ Problems with engaging families to become involved ○ Problems with engagement during treatment • Facilitators ○ Critical period of engagement with services **Delivery** Working with complex needs • Barriers ○ Difficulties working with complex needs (eg family conflict, person’s symptoms) • Facilitators ○ Professional qualities, experience, and skills ○ Professional relinquishing control Working relationships between families and professionals • Barriers ○ Lack of joint working during sessions ○ Professionals not applying systemic thinking effectively ○ Families experiencing approach as negative or critical ○ Lack of staff continuity • Facilitators ○ Equal partnership and active collaboration with families ○ Professional interpersonal qualities (non-blaming approach, empathising) ○ Professional communication ○ Continuity of care Individualisation within the approach • Barriers ○ Approach not considerate of individual needs or cultural differences • Facilitators ○ Having a clear structure, allowing for flexibility

Shared decision-making among people with problematic alcohol/other drug use and co-occurring mental health conditions: A systematic review Fisher et al., 2021 Australia	Systematic review To synthesise evidence around people's attitudes towards, and experience of, SDM in co-occurring AOD and mental health conditions	N = 10 studies	SDM-based interventions led to improvements in reported SDM levels, patient involvement in decision-making and autonomy, patient-centred approaches to care, clinician-patient agreement, attention given to patient concerns and goals in treatment decision-making, therapeutic alliance, and patient knowledge of treatment. Improvements in decision-making processes were reported by both people and clinicians. These improvements were seen across a number of studies comprising a range of designs (RCT and non-RCT, qualitative), outcome measures (validated, non-validated, self-report), patient populations (primary AOD use/mental health disorder vs co-occurring subclinical symptoms), intervention types (clinician-based, decision-support resources), and treatment/service delivery settings (primary care, outpatient, inpatient). Importantly, SDM may work better with people who prefer active or collaborative roles in treatment decision-making, whereas the approach may be more limited with those who prefer more passive roles in treatment. Findings were more mixed with regards to patient-related outcomes such as treatment uptake/adherence, symptomatology, and problematic AOD use. Some research found associations between SDM-based interventions and sustained improvements in mental health and AOD severity and recovery. Other studies showed more mixed findings, with some showing improvements and some showing inconclusive.
A Review of Parent Participation Engagement in Child and Family Mental Health Treatment Haine-Schlagel & Walsh, 2015 USA	Systematic review To review of existing literature on parent participation as an element of treatment engagement	N = 24 articles	**Does PPE overlap consistently with attendance engagement?** Six articles examined links between PPE and attendance. Attendance measures included number of sessions attended and retention in treatment. All six studies found significant positive associations between PPE and attendance. **What factors have been identified as associated with PPE?** *Child factors* – Ethnicity (lower PPE for Spanish-speaking), presence of a medical condition (associated with higher PPE), and previous service use (associated with lower PPE). No associations were found for age, gender, or perceived improvement due to services. *Parent/family factors* – sociodemographics (younger age, female, higher income, higher education level, employed, father presence/both parents attending services linked with higher PPE), referral source (agency referral linked with higher PPE than self-referral), parent functioning (antisocial behaviour and depressed mood linked with lower PPE), parenting (poorer discipline practices, lower PPE), and early poor PPE linked with later poor PPE. • Note: non-significant results also found for education level, referral source, parent functioning, perceived support outside mental health treatment system, history of marital violence, family size, and change in knowledge and efficacy to navigate the child mental health service system. Articles also found higher PPE linked with greater satisfaction, motivation, and perceived barriers (measures of attitudinal engagement). *Provider factors* – One article found the provider's verbal behaviour, specifically using a more directive and confrontational style was associated with poorer PPE.

			Service factors – Phases of treatment (poorer PPE in the middle of treatment, better PPE later), amount of time in treatment (longer time in treatment, poorer PPE), and service location (clinic sessions having poorer PPE than other locations). One non-significant finding showed no relationship between PPE and amount of time in treatment. **Is PPE associated with improved outcomes?** *Symptoms and diagnoses* – Of 7 articles, 3 found significant positive associations between PPE and a measure of symptom improvement. Significant improvement measures ranged across child, parent, and provider reports. Three articles found a significant link between PPE and improved functioning/reduced impairment. **What strategies have been designed to improve PPE and are such strategies associated with positive outcomes?** • Provider reinforcement practices • Assessment of treatment barriers, expectation setting, problem solving, and parent coping • Accessibility promotion and expectation setting • Change talk and assessment of treatment barriers • Psychoeducation and peer pairing to support parents' PPE • Rapport building A large majority of the articles found significant improvements on PPE. Four of the articles that found improvements provided incentives for parents to participate in treatment that are not typically part of service delivery systems, such as weekend session, child care, and payment. Nine of the articles focused on a structured treatment protocol, and one examined usual care. None of the studies reporting PPE improvement used a conceptual framework to guide their design or implementation.
Service user and family member perspectives on services for mental health, substance use/addiction, and violence: a qualitative study of their goals, experiences and recommendations Haskell et al., 2016 Canada	Interviews To understand the perspectives of people most affected by mental health and substance use disorders (and violence; MSD[V]), especially those with co-occurring issues, as well as their family members	N = 73 service users and 41 family members of service users Two broad research questions: • Desired goals and outcomes when seeking help • Ways to improve services/systems	Service users and family members were asked to identify the types of problems they or their relative experienced. Service users' and family members' desired goals/outcomes when seeking help include improving MSD(V) issues, understanding their issues better, feeling/being "normal", addressing practical needs, and improving social relationships. **Ways to improve services/systems** *Types of services/how they are provided* • Being listened to, not judged, and treated with respect • Availability of peer support and help from people with lived experience • Appropriate use of medications and related support • Recreation activities • Assistance with practical needs *Broad systems of care* • Coordinated holistic care and help navigating the system • More accessible publicly funded services • Early intervention

			System issues specifically of concern to family members • A system that supports greater involvement of family members* • Mechanisms for treatment compliance *People felt frustrated by lack of support for family members. Others felt families were not included as part of treatment. Help to service users could be improved if families' insights were used.
Social Support Networks and Symptom Severity Among Patients with Co-occurring Mental Health and Substance Use Disorders Haverfield et al., 2019 USA	Intervention analysis To examine how social support networks relate to symptom severity	N = 406 people in inpatient mental health services with co-existing mental health and substance use diagnoses Intervention: one in-person session followed by monitoring over the telephone (1 per week for 3 months)	Higher family conflict was associated with higher psychiatric severity (including for depression, PTSD, and drug use) across baseline and FUs. Conflict was not associated with alcohol use at initial intake. Families of people with co-existing challenges often experienced heightened levels of conflict, volatility in roles and functions, and poor communication. General social support (the sense of connection and membership towards a group) was associated with lower levels of depression, PTSD, and drug us severity at intake to treatment and FUs.
Barriers and facilitators to shared decision making in child and youth mental health: clinician perspectives using the Theoretical Domains Framework Hayes et al., 2018 UK	Qualitative semi-structured interviews To investigate clinician-perceived barriers and facilitators to SDM in mental health settings	N = 15 clinicians	Analyses identified 21 sub themes across 10 domains of the Theoretical Domains Framework **Capability** *Knowledge* • The majority of clinicians were aware of SDM and what it entailed. Some clinicians preferred other terms for it such as "informed consent", but this is not the same as SDM exactly. • Lack of knowledge about available care and treatment options for patients, particularly around resources for CAMHS. Some were not aware of options within their own service. *Skills* • The overlap needed between core therapeutic skills and skills required for SDM. One clinician highlighted how training helped improve their SDM skills. • Clinicians discussed how SDM in CAMHS incorporates multiple stakeholders' preferences, values, and views, which could lead to disagreements on how to proceed with treatment. Clinicians identified negotiation and containment as key skills. • Clinicians noted the risk of disengagement due to lack of inclusion, eg a young person can disengage and be less likely to participate when not given a choice in their treatment. Conversely, by not including parents, they may not take their child back to the service. • The availability and range of options can affect the young person and family's engagement. **Opportunity** *Limited or lack of psychological interventions for SDM* • There were limited psychological services available – clinicians felt families didn't get enough because options weren't made available. More extreme examples include clinicians feeling there was no option whatsoever – either families accept the treatment offered or none at all.

			• In cases where options were offered, access could be limited by long wait lists, particularly for longer or more specialised therapies. This affected families by driving them to choose shorter therapies or those with short wait lists, and not necessarily ones that would be the best option for them. *Administration and time constraints* Lack of staff members and increased patient demand affected SDM. Clinicians spoke about having to get through administrative tasks and being left with less time for SDM. **Motivation** *Overruling people's wishes* Clinicians spoke of professional boundaries and standards that needed to be upheld while practicing SDM, meaning although people's interests were to be listened to, sometimes they had to be overridden because it wouldn't be in their best interest. *Consequences* Clinicians noted SDM gave young people and families felt empowered by SDM by giving them more power, autonomy, and control *Time* Many felt SDM takes longer than traditional approaches – SDM requires working at the pace of families, and when they are ready to access and take in information. Some cases would take even longer such as younger children, people with learning disabilities, when people did not come prepared to make decisions, or when multiple parties are involved. *Less confidence due to lack of knowledge around options* Some clinicians felt less confidence in discussing particular psychological therapies or medications with young people and families. They needed more information to increase confidence.
A Review of Family Engagement Measures for Adolescent Substance Use Services Hock et al., 2015 USA	Systematic review To review existing measures of family engagement and to assess their conceptual coverage and utility for adolescent substance use providers	N = 58 articles about measures of family treatment engagement in substance use and mental health settings	One aim of this review was to determine whether the measures assessed three domains: • Attitudinal – beliefs about the treatment, the clients' involvement in the treatment, and family members' roles in the treatment process • Affective – family members' experience and expression of emotion in relation to their involvement in treatment • Behavioural – treatment participation and adherence to treatment protocols, efforts to communicate with the treatment provider, and actively supporting the client's involvement in treatment All the measures identified for the parents or caregivers of children. Two measures were administered in a substance use setting, six measures in an outpatient mental health setting, and one was administered in an inpatient mental health setting. Scales identified were: • Credibility Expectancy Questionnaire-Parent Version (CEQ-P) • Therapeutic Alliance Scale for Caregivers and Parents (TASCP) • Multisystemic Therapy-Caregiver Engagement • The Child and Adolescent Level of Care System/The Child and Adolescent Service Intensity Instrument • Parent Rating of Parent InvolvementFamily Engagement Questionnaire (FEQ-P)

			• Parent Motivation Inventory (PMI) • Vanderbilt Therapeutic Alliance Scale-Revised (VTAS-R) All the measures were relatively brief. However, in clinical practice, being able to compare scores to normative data and/or clinical cut-off scores is important for interpretation; this study was unable to identify normative data for any of the measures. The majority of measures identified were administered in mental health settings; administering them in substance use settings may involve adaptations to address different treatment-related and contextual factors. Potential differences include the length and course of treatment, the nature of parental involvement, and family member attitudes towards substance use compared to mental health issues.
Family involvement in treatment and recovery for substance use disorders among transition-age youth: Research bedrocks and opportunities Hogue et al., 2021 USA	Narrative review To summarise youth substance use disorder (SUD) prevalence and service utilisation rates, and present developmental and empirical rationale for increasing family involvement in services	N/A	Literature indicates family-based treatments for SUD are effective across the lifespan. Family-based treatments address family skills (eg communication, coping, problem-solving), family relationships and processes, and family member relations with key extrafamilial persons and systems. Research shows family therapy is a well-established outpatient approach for adolescent SU that has the largest evidence based compared to other approaches
Review of Interventions to Improve Family Engagement and Retention in Parent and Child Mental Health Programs Ingoldsby, 2010 USA	Literature review To evaluate randomised-controlled trials testing methods to improve family engagement and retention in child mental health programs	N = 17 studies	Interventions in which families' motivations, expectations, and needs for treatment were addressed throughout the treatment process were generally successful in increasing engagement. Helping families cope with life stressors and identifying and addressing families' motivations to treatment structure and activities were promising, although these investigations have been limited to families receiving outpatient services for children's behaviour problems. **Pre- and early treatment strategies to improve engagement and retention** *Brief interventions to address interpersonal or practical barriers* One study found training providers to support families' steps to initiate therapy and to address families' expectations about treatment, financial concerns, scheduling, and transport issues during the first session led to higher enrolment and early engagement than controls. A follow-up study compared whether a 30-minute phone interview that addressed family concerns and barriers to treatment or a combined approach involving a provider engagement-oriented first session affected engagement during the first 18 weeks of therapy. Families who received the combined approach completed more visits than those who only received the phone interview. Overall, helping families overcome practical barriers may result in greater initial engagement, but long-term engagement was not measured. *Family systems engagement approaches*

			One intervention was the Strategic Structural-Systems Engagement (SSSE) which involved contacting family members prior to the first session to assess sources of resistance keeping family members from engaging in treatment, then employing methods designed to reduce the type of resistance each family member experienced. Methods include “joining” with family members to identify concerns, values, and interests; encouraging them to keep the initial appointment; establishing a leadership role to facilitate trust in the provider’s abilities to address family problems; and negotiating and reframing problems to instill hope. One study found retention rates of 58 to 75% versus 25% in control conditions. Overall, pre- and early treatment interventions appear to be effective at increasing engagement at early stages of treatment and there is less evidence for long-term retention. More intensive interventions, and those that addressed practical barriers, were among the most effective. The majority of these studies were at community mental health services, limiting generalisability to other settings such as inpatient services. **Continuous and integrated strategies** These studies include structural changes in how treatment was delivered (eg group vs individual treatment, offering additional services or incentives, comparing providers with different training and experience), and clinical methods that were integrated into the treatment program (eg engagement-focused sessions). *Adjunctive family support* Interventions in which providers integrated or offered adjunctive treatment sessions aimed at helping parents address life stressors (including job and financial concerns, relationship conflicts, health problems, worries, and issues relating to receiving social services). In one study that aimed to address concerns not directly related to treatment and to help families resolve problems, families that received additional support had only a 5% increase to appointment times but had greater retention than those with no additional support (71% vs 53%). Another study indicated that identifying families’ beliefs, expectations, and needs early in treatment and matching those during treatment is an effective approach to increasing engagement. *Motivational interviewing (MI)* An approach based on transtheoretical and self-efficacy models. Involves clinical approaches designed to address ambivalence that people may have about treatment. MI providers communicate empathy, avoid confrontation and arguments, highlight discrepancies between current behaviour and desired outcomes, use self-motivational statements, and collaborate on behaviour change plans – all of which are hypothesised to reduce resistance and strengthen commitment to treatment. One study found families that received MI had higher rates of engagement than controls (56% vs 35%) and retention (56% vs 35%). These suggest that adapting MI techniques to focus on family engagement in on-going therapy has promise.
Facilitators and Barriers to Family Involvement in Problem Gambling Treatment Kourgiantakis et al., 2017	Qualitative study To examine facilitators and barriers to family involvement in problem gambling (PG)	N = 11 pairs of people experiencing PG (PGIs) and family members (FMs)	Both PGIs and FMs identified six themes of facilitators and barriers to family involvement in PG treatment. **Facilitators** *Communication* – more frequent and better quality communication with FMs. This included listening, remaining calm, and focusing on positive changes. Helped them identify problems. Honest communication elicited greater support.

Canada	treatment with a sample of people experiencing PG and family members		*Support* – Participants described the role of non-judgemental support encouraged goal attainment and treatment attendance. PGIs highlighted professional support that taught them skills to regulate emotions and communication skills to respond more appropriately helped them better understand the impact of PG on their families. FMs also discussed how professional support (including emotional support, information about PG, developing better communication strategies, coping skills to deal with situations and stressors) helped them outside of treatment. *Coping skills* – Participants described the benefits of coping skills on family involvement and new ways of coping with negative thoughts or emotions. Both PGIs and FMs referred to self-care coping strategies as ways to help them feel calmer, less irritable, feel healthier, have better communication, less conflict with one another, and helps cope with managing emotions and changing negative thoughts. **Barriers** *Conflict* – Some people no longer wanted to attend professional services or did not want their family involved due to conflict. Those who reported this described feeling high stress and negativity. As a result, FMs explained they would keep their distance from PGIs and problem solving or discussing issues became difficult. *Isolation* – Some PGIs were estranged from their families and from other support networks, including friends and professionals. For some PGIs, isolation was due to feeling shame from PG. Some FMs discussed needing to talk to someone but feeling their own shame about their family member's PG. *Mental health/substance use* – For some people the presence of MH/SU challenges created additional barriers such as stigma, misinformation about mental health, limited coping strategies, lack of professional treatment, lack of support, and the consequences of misunderstood or mistreated MH/SU issues; all of which contributed to FMs not wanting to be involved. Some FMs kept their distance because they did not understand the PGI's MH state or because they did not want the pressure of feeling they have to make changes. There were some FMs who were facing their own MH/SU challenges.
A scoping review and assessment of essential elements of shared decision-making of parent-involved interventions in child and adolescent mental health Liverpool et al., 2019 UK	Scoping review To identify and examine the existing support interventions available to parents for promoting and implementing SDM in CAMHS settings	N = 23 interventions available for use with parents targeted towards ASD, ADHD, and emotional and behavioural problems including depression, self-harm, or general mental health care	The majority of interventions were rated as low-SDM, 5 were medium-SDM, 8 were high-SDM. Interventions that helped parents prepare for appointments were seen as helpful. Factors including time, accessibility, and appropriateness of the intervention were cited as barriers and facilitators to implementing SDM interventions. **Facilitators** *Parents* • Clear, easy to understand, gives opportunities to ask questions • Web interventions can save time, increase efficiency of the process, and give parents information prior to sessions • Information presented in visualised form • Having resources that provide reliable information and outlined available treatments – made them feel empowered • No increase to duration of appointments

			Clinicians • Minimal training requirements to provide intervention • No increase to duration of appointments • Having information that is credible and reliable, and having resources that did not increase time burden **Barriers** • Paperwork loads for clinicians • Power struggles when involving youth in SDM • Not giving parents alternative choices • Not having availability of services or the capacity to coordinate services among providers • Information overload for parents
Experiences of family members supporting a relative with substance use problems: a qualitative study McCann et al., 2019 Australia	Interviews To explore the experiences of affected family members (AFMs) who support a relative with substance (alcohol or other drugs; AOD) misuse	N = 31 AFMs recruited through AOD helplines and their associated social media accounts in Victoria, Australia	One overarching theme with six subthemes were abstracted from the data: **Feeling overwhelmed by and struggling with the experience.** Overall, supporting someone with substance use issues can be overwhelming and isolating, with the relatives' AOD issues having negative effects on their wellbeing. Participants cited feeling stressed, distressed, frustrated, and exhausted with having to face challenges daily. Most felt resentful about being in a situation they have little control over, making them feel powerless. Stress was exacerbated by lack of stability or predictability in their lives and the financial impact of their relative's AOD use. • Emotionally draining and exhausting • Maintaining constant vigilance, curbing social activities • Grappling with financial impact • Struggled to cope with harmful family dynamics • Avoiding and containing aggression • Fearfulness and hopelessness about the future
'It's always difficult when it's family… whereas when you're talking to a therapist…': Parents' views of cognitive-behaviour therapy for depressed adolescents Schlimm et al., 2021 UK	Qualitative study (thematic analysis) To explore parents' experiences of their adolescent child's cognitive behaviour therapy for depression	N = 16 parents of adolescent children who were randomly allocated to CBT in a large multisite RCT for adolescent depression Children were aged 11 to 17 who met diagnostic criteria for moderate to severe depression CBT was carried out over 28 weeks and comprised of up to 20 sessions	**Parents' perceptions of the adolescent's journey through therapy** *Respecting the adolescent's privacy and offering control* Most parents tended not to ask their children about therapy to respect their privacy and give them a sense of control over treatment. They did not want to appear intrusive. Parents perceived control as crucial for facilitating positive outcomes. **Parents' perceptions of the therapeutic setting and process** *The importance of positive patient-therapist relationship* All parents saw the role of the therapist as key to adolescents opening up. Many highlighted the importance of adolescents being treated as equals and using a collaborative approach. Most parents who reported that CBT resulted in little to no improvement attributed this to the lack of connection they felt between their child and the therapist. *Lack of communication with parents*

		Parents varied in involvement in sessions – some didn’t attend at all, some were present for the first half or last 10 minutes of sessions, some attended joint sessions	Some parents felt they wanted to be updated on their child’s progress; one felt they were given insufficient information from the clinic. One said they would’ve appreciated advice about how to support their child at home and during recovery. *Perceived advantages and disadvantages of parental involvement* Most seemed to feel their presence would make it more difficult for the adolescent to open up to the therapist, so they chose not to join their child in CBT sessions. However, some parents viewed their involvement as helpful for both themselves and their children. Family sessions seemed to provide opportunities for children and parents to confront issues together. Joint sessions were seen as helpful particularly when the therapist had good mediating skills. One parent saw involvement in goal-setting as key to ensuring that all three people were on the same page.
‘Triadic’ shared decision making in mental health: Experiences and expectations of service users, caregivers and clinicians in Germany Schuster et al., 2021 Germany	Cross-sectional study To achieve better insight into the current SDM patterns of triads of service users, caregivers, and clinicians in inpatient mental health care, and their expectations towards the prospect of triadic SDM	N = 94 triads of inpatient service users, caregivers, and clinicians Sample from a psychiatric inpatient hospital in Germany	**What is/could be the benefits of involving caregivers?** All three parties most often stated that caregiver involvement is important and improves therapy (40.4% service users, 53.2% caregivers, 36.2% clinicians). Caregivers see contact with clinicians as opportunities to contribute important information for the treatment (40.4%). Clinicians thought caregiver involvement as a chance to clarify organisational and social issues (27.7%), closely followed by acquiring information (26.6%). Other cited benefits include diagnostic classification/information to the psychiatrist, psychoeducation/information for the caregiver, therapy improvement, and support and wellbeing for the caregiver. Only 17.7% of service users and 27.7% of clinicians thought caregiver involvement is not beneficial. **What role do caregivers play for service users?** Support – cited by 98.4% of service users, 92.5% of caregivers, and 66.7% of clinicians. This was further subdivided into emotional support, support in everyday life, and support in coping with the illness. Some clinicians reported caregivers (36%) as having a negative influence on the service user **What role do caregivers play during service user-caregiver-clinician contact?** Service users see caregivers as experts in their mental health condition (25%) and in seeking information (25%). Caregivers themselves wanted to seek more information (46.4%) and as experts in the mental health condition (42.9%). Clinicians see the caregivers’ role as giving service users a feeling of security and offering support (30%), followed by them providing important information (25%). Clinicians described inappropriate behaviour in 17.5% of caregivers **What should involvement of the caregiver ideally look like?**

			Most participants (67% service users, 73.4% caregivers, 58.8% clinicians) agreed caregiver involvement should be initiated by the clinician/service, but that service users should be the one to decide whether there is any caregiver-clinician interaction.
Supporting family engagement with child and adolescent mental health services: A scoping review Waid & Kelly, 2020 USA	Scoping review To undertake a scoping review of empirical literature aimed at identifying key factors in the social ecology of families which influence family engagement with child and adolescent mental health services To identify and describe models of intervention designed to help facilitate access to care	N = 40 studies published between 2000 and 2019	Key factors associated with CAMHS family engagement: **Client factors** • Individual and family attitudes towards help-seeking behaviour ○ Stigma and shame related to mental illness and help-seeking, reliance on informal support, lack of awareness of available services, poor motivation for treatment, negative attitudes towards mental health professionals/services, inability to recognise symptoms, fear of being shamed. ○ Social support and caregiver-initiated referrals appeared to bolster engagement with mental healthcare • Concerns regarding logistics of scheduling and attending appointments ○ Not having time due to work schedules, family obligations, difficulty finding childcare, transportation issues (long commutes, limited public transport options) particularly in rural and suburban areas • Confidence in service providers' ability to effectively meet their needs **Service factors** • Scheduling and referral processes ○ Long delays between initial referral and first appointment, • Flexibility and availability of relevant services ○ Inflexible meeting times and locations, lack of after-hour services, • Provider competency and specialist availability ○ Discrepancy between client and services' view of the nature and severity of the issue, limited range of clinical expertise, inadequate diagnostic services, Suggestions to improve include workforce development, ongoing training, technology-supported referrals/utilisation in service delivery, flexible screening and assessment tools, implementing personalised care strategies that can be tailored to clients' needs, improve cultural competence, designing offices to be youth-friendly, enhance respect towards adolescents, **Community factors** • Availability of relevant services within clients' local area • Community attitudes and stigma surrounding mental health treatment ○ Particularly in rural communities where people don't feel a sense of anonymity **Health system factors** • Costs associated with mental health treatment • Complex insurance authorisation procedures • Inadequate funding to compensate specialists • Insufficient consultation and referral options

			○ Lack of coordination between professionals/clincians (eg primary and specialty care providers), shortages of qualified mental health professionals • Lack of culturally appropriate services Suggestions for improvement include embedding specialty care services in primary care settings, increasing funding, and establishing trust between the community and health system via education, sustained community engagement, and advocacy **Interventions** *Family outreach* • A collection of interpersonal approaches designed to build rapport, educate, share information, and facilitate connections to needed services. These focus on educating families about mental health(care), and are generally effective. • One review found family outreach strategies were effective in helping parents increase their awareness about substance use issues among adolescents, which supported adolescents’ help-seeking and subsequent access and engagement with mental health services. Another study found acknowledging families’ attitudes towards mental health services and external barriers improved short-term engagement. • Successful components include motivational interviewing, use of family systems theory in treatment planning, focusing on increasing family coping strategies, empowering self-efficacy, enhancing the therapeutic alliance over the course of treatment, ensuring the client has choice during treatment, managing expectations related to progress and perceptions of therapy, utilising complementary services, and positioning families as co-therapists

Family-focused recovery: Perspectives from individuals with a mental illness
 	
Waller et al., 2019
 	
Australia
	Qualitative study
	
	To investigate how people with mental health challenges define ‘family’ and the role (if any) family plays in their recovery journey
		N = 12 people diagnosed with a serious mental health disorder	Overarching themes
			• **Understanding of recovery** - Participants saw recovery as relational, and about acceptance, empowerment, regaining control, and a ‘lifelong journey’. One person was resigned about recovery. Participants included children, grandparents, nieces/nephews, partners, and clinicians as family
			• **Family contributions to recovery**
			  • Sense of purpose
			  • Monitoring their recovery
			  • Practical assistance, eg financial, transport, housing
			• **Good’ and ‘bad’ family involvement** - Some noted families can be a source of stress, eg because of crossing boundaries, guilt tripping
			• **Involving families in recovery -** Participants noted no one approach can meet the needs of all individuals and their families. Common strategies services can use include education, helping the person understand and communicate with their own family, identifying the family’s needs to support them in being involved, or simply asking the person if they would like family members to come with them to appointments.

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