



FEATURE ARTICLE

Factors influencing engagement with case managers: Perspectives of young people with a diagnosis of first episode psychosis

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ABSTRACT: *Holistic treatment during a first episode psychosis (FEP) can significantly impact the longevity and chronicity of the illness, as well as reduce the risk of premature death by suicide. However, treatment can only be effective if the young person participates. Given that 19–40% of young people disengage from early intervention services for FEP, this qualitative study aimed to understand how young people experienced engagement with case managers at an early intervention service. Semistructured interviews were conducted with seven young people and themes were identified using interpretive phenomenological analysis. Young people detailed how engagement with a service could be viewed as a process, following different stages between initial referral and discharge. Throughout this process, a number of factors influenced young people's decision to engage with, or disengage from, their case manager. This created a push–pull dynamic with periods of good engagement and poor engagement. Discussion of this dynamic adds nuance to established scholarship about engagement, including shifts over time in the importance of client empowerment and valued features of therapeutic relationships. Awareness and understanding of these concepts may guide changes to early intervention services and address the core issue of engagement.*

KEY WORDS: *early intervention, first episode psychosis, mental health, qualitative research, therapeutic relationship.*

INTRODUCTION

Early intervention services (EIS) for first episode psychosis (FEP) provide assertive and holistic bio-psycho-social treatment to young people in the first 2–5 years following diagnosis (Mihalopoulos *et al.* 2009; Norman *et al.* 2011). Mental health nurses have a vital role in assessing and providing treatment for young people with FEP (Reed 2008). They are often the first point of contact at emergency departments, crisis and assessment teams, or psychiatric inpatient units. The majority of case managers in public mental health services are also mental health

nurses. This role involves providing psycho-education, linking the young person with resources such as housing, educational and financial services, offering individual therapies, delivering both individual and family support, and ultimately providing an effective discharge from EIS (Gleeson & McGorry 2004).

As mental health nurses facilitate treatment at all stages of intervention for FEP, disengagement rates of 19–40% are a core topic of interest (O'Brien *et al.* 2009a). Engagement is a multifaceted issue, encompassing not only attendance at services and compliance with treatment, but also the existence of a therapeutic relationship with a health professional, seeking help and working towards client-centred goals (Conus *et al.* 2010; Wright *et al.* 2011). Disengagement increases the risk of impairment, prolongs recovery, and may increase the duration of untreated psychosis (DUP). This directly correlates

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Accepted February 2015.

with poor clinical, social, and cognitive outcomes (Cuesta *et al.* 2012; Early Psychosis Guidelines Writing Group 2010). Young people who disengage from services also experience higher rates of suicide, violence to others, relapse, involuntary admissions to acute mental health services, problematic substance use, and forensic activity (O'Brien *et al.* 2009a; Stowkowy *et al.* 2012).

The characteristics associated with young people disengaging from EIS have been explored in four studies in Australia, New Zealand, and Canada using retrospective file audits (Conus *et al.* 2010; Stowkowy *et al.* 2012; Turner *et al.* 2007; 2009). Factors associated with poorer engagement include unemployment, higher functioning at baseline, substance use, DUP, poor insight, lack of ongoing symptoms, forensic history, and lack of family support. Different characteristics featured more prominently in each study, and prior studies have found evidence against the influence of insight on engagement, for example Tait *et al.* (2003). Instead, Tait *et al.* argue that a 'sealing over' recovery style is a greater cause of poorer engagement than level of insight. More in-depth research into the experience of engagement as a phenomenon is required to better understand the impact of prognostic factors on levels of engagement.

Similar factors for service disengagement have been found in studies of adult mental health services; however, being under 25 years of age and having a diagnosis of FEP featured strongly as additional prognostic factors (Kreyenbuhl *et al.* 2009; O'Brien *et al.* 2009a). These findings provide a strong rationale for the development of specific, youth-friendly EIS to treat young people with FEP. Reasons given by adults for disengaging from services included a desire to solve one's own problems, practical constraints, dissatisfaction with treatment, feeling one had improved and no longer required the service, independence, fear of the mental health system, lack of a therapeutic alliance, inflexible service models, and lack of family involvement. However, these results are unlikely to be directly transferable to either a specific youth population or specialist EIS.

Two studies have explored young peoples' experience of engaging with a primary youth mental health service (McCann & Lubman 2012; Muir *et al.* 2012). Headspace is an Australian national service that offers mental health input for young people aged 12–25 years. Muir *et al.* (2012) found that young people described their experience of the headspace service as accessible, acceptable, and appropriate. Specific aspects of the therapeutic relationship that encouraged ongoing attendance included clinicians being youth-friendly, care that aims to facilitate recovery, and clinicians adopting a broad-based approach

to care (McCann & Lubman 2012). This overview of how headspace services are perceived encompasses perceptions of both the service and individual interactions. However, these studies did not focus on specialist services for young people with a diagnosis of FEP, so it is unclear if the findings are relevant to this specific population who require more intensive and sustained treatment. Importantly, young people who attend headspace services do so on a voluntary basis. Young people with an FEP often attend outpatient services after a pathway to care that has involved emergency services or compulsory admission to psychiatric inpatient units. This may impact on the experience of engagement with treating services (Anderson *et al.* 2013).

Using qualitative methodology, this study aimed to explore the engagement of young people with FEP with their case managers at their EIS. Increased understanding of the factors involved in engagement will enable services to reduce disengagement rates and thereby improve service delivery. The study was approved by the institutional human research ethics committee.

METHODS

Design

It was important that the research design would both gather in-depth descriptions of experiences of engagement and value the unique and personal stories of each participant during the analysis phase. Interpretive phenomenological analysis (IPA) was therefore chosen as it encourages specific exploration of a lived experience in order to understand how an individual makes sense of a given phenomenon (Smith *et al.* 2009). The phenomenological aspect of IPA allows the researcher to focus on understanding and making sense of each young person's individual perceptions of a phenomenon. The interpretative aspect of IPA acknowledges that the researchers' preconceived knowledge and experiences are necessary in order to make sense of others' experiences. Nevertheless, IPA expects that the essential qualities of the participants' stories are revealed during the analysis phase by paying full attention to each participant's account.

Participants

Participants were recruited from an EIS in Melbourne, Australia, between August and November 2013. Purposive sampling was used to identify young people who met the inclusion/exclusion criteria, and case managers determined overall capacity to give informed consent. This study aimed for a sample size of seven to 10 participants. This sample size is recommended for a focused IPA study

and is consistent with previous qualitative studies aiming to richly explore a given phenomenon rather than develop generalizable findings from large numbers of participants (Smith *et al.* 2009). Inclusion criteria were: (i) 18–25 years old; (ii) a diagnosis of FEP; (iii) a current client of the EIS; no acute symptoms that would impact on capacity to give consent or participate in recorded interviews; and (iv) low risks to self and others at time of participation. Exclusion criteria were: (i) currently undergoing treatment in acute services; (ii) limited ability to speak in conversational English; and (iii) either a current or prior clinical relationship with the research interviewer who was the principal researcher. Potential participants were identified and invited to participate in the study by their current case manager.

Data collection

When potential participants had been identified, the principal researcher provided an overview of the research and sought consent. All participants were aware that the principal researcher, who was a mental health nurse of the EIS being studied, would conduct the semistructured interviews. All interviews were conducted in private interview rooms and audio recorded. Box 1 contains the questions asked. The median duration of each interview was 30 min.

To ensure that the researchers own preconceived ideas or biases did not impact upon the data, open-ended questions were used during the interviews. The individuals who participated in the study often displayed difficulty

reflecting on their experiences in detail and therefore prompts were included in the interview schedule to allow gentle probing around each question without influencing the direction of the data.

Data analysis

After transcribing and listening to each interview several times, initial and thematic coding was undertaken with the support of analytic software (Dedoose). *In vivo* coding was used to establish emerging themes whilst maintaining the participants' words. Two co-researchers independently reviewed and coded the interview data. This process of analysis enabled a consensus to be reached regarding themes and subthemes. These themes were then grouped to identify connections and subordinate themes.

FINDINGS

Seven young people participated in the study. Two participants were male and five participants were female, all aged between 18 and 22 years at time of participation. Participants had been with the EIS between 5 and 25 months. The overarching concept identified in data analysis was 'the engagement process', recognizing that engagement is a process that changes over time in the EIS. Two further themes regarding phases of engagement were 'the push towards engagement' and 'the pull towards disengagement'. An overview of the results can be seen in Figure 1.

BOX 1: Questions asked during interviews

1. If you were involved in setting up an early intervention service for young people, what would you include?
2. What do you like about (EIS)?
3. Can you tell me about your experience with (EIS)?
4. Who in (EIS) understands you best?
5. What does case management mean for you?
6. How well do you think your case manager understands what your needs are?
7. Are there any good things about seeing your case manager?
8. Are there any negative things about seeing your case manager?
9. Can you tell me about a specific interaction with a case manager that you found helpful?
10. What are the main differences between this interaction and an interaction with a case manager that you found less helpful?
11. Has there been a time when you have chosen not to attend your case management appointments?
12. Has there been a time when you have not been able to attend your case management appointments but would have liked to?
13. Is there anything I haven't asked you about case management that you would like to talk about?

EIS, early intervention services.

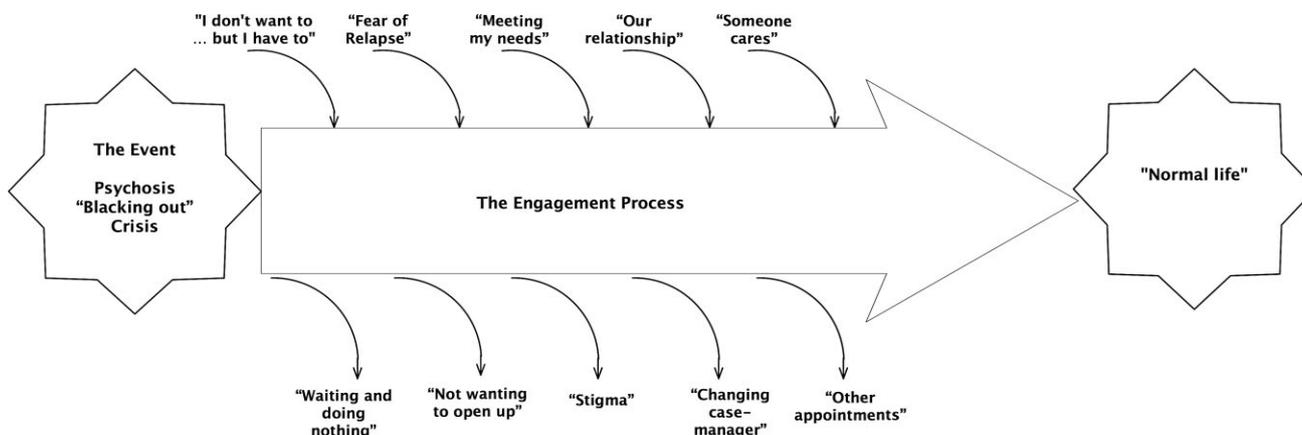


FIG. 1: *The engagement process.*

Engagement process

A significant experience, such as psychotic symptoms or suicidal ideation, was defined as the initial motivator for the young person to attend the service, and thus the initiator of the engagement process. Going forward, a range of factors were relevant for particular young people, as they moved along a trajectory towards what several participants called a ‘normal life’. One participant had achieved what he described as normal life, and was therefore prioritizing appointments outside of the EIS. One participant had re-engaged with his case manager following a period of disengagement, and was therefore in his second cycle of the engagement journey. Ultimately, all participants were striving towards a ‘normal life’, and anticipated that their journey of engagement would end when they had achieved this.

Push towards engagement

A complex mix of compulsion and personal motivation pushed participants towards engaging with their case managers.

I don't want to . . . but I have to

On referral, participants described feeling as if they had to attend the EIS. For some, this was after being told to by a health professional:

My appointments, I had to come in because I had an episode, I was an involuntary patient at the hospital. It was part of my requirements, or whatever, on being let out that I had to come. (Peter)

However, after the acute episode, all participants also described having a strong sense within themselves that they needed to attend:

I felt like I had to do it, absolutely. I had never been offered like the lifeline before and I wasn't gonna miss my opportunity to get some help. (Trisha)

The rationale behind this feeling was varied. For some participants, it was due to their own perceived need to recover from their psychosis and for others it was more to understand their experience.

Fear of relapse

Fear of relapse or of being re-admitted into hospital was not only an initial motivator but also encouraged participants to continue attending the service:

I just knew I had to (see a case manager) otherwise I'd go back to hospital. (Susan)

There was an overwhelming feeling of disempowerment and loss of confidence that came with having a psychotic episode and participants described feeling as though they could not recover independently. These young people therefore looked towards their case manager as an expert who could help them navigate their journey of recovery.

Having needs met

Having needs met, both practically and emotionally, was paramount to maintaining engagement with a case manager. In the earlier stages of engagement, this often took the form of more practical tasks:

After I met (my case manager) a few times in the inpatient unit and got out, and she helped me in an appeal process that I had to go through in school, and that was when I started to be really open with her. (Hannah)

The practical act of helping with a school appeal showed the participant that the case manager was willing

to invest in her as a person, and this encouraged the young person to engage with the case manager.

The opportunity to talk to and seek support from a case manager was another example of needs being met:

Once I realized that like talking about it was really helpful like I was feeling the more I unburdened myself from some of the stuff then I just kept going with it. (Trisha)

The role of the case manager was relational and involved sharing emotions, in order to assist the young person with a variety of needs and goals:

I just talk to her about everything, about how I'm feeling, all the good things, all the bad things, what I did in my week, how my mind is going, is my mind better and how medication is going. (Susan)

Talking with the case manager was therefore seen to be helpful in maintaining recovery and essential for preventing relapse of psychosis.

Physically attending the service also encouraged a sense of purpose and routine. For some participants, attending the service was the only reason they left their house and therefore they valued this:

It gets me out of the house and I get to do something in my day and I get to see somebody and I get to talk to somebody in my day about myself. (Susan)

Several participants reflected that their daily lives at this early stage of recovery were quite restricted, and due to the presence of ongoing symptoms, the stigma associated with their illness or the recent impact that their behaviour had on their social or vocational life, they felt unable to talk to anyone outside of their family about their life-changing experiences.

Case manager–client relationship

Overall, participants described the case manager–client relationship as the key facilitator of engagement. All participants described important aspects of the case manager role including being knowledgeable about psychosis, maintaining confidentiality, and displaying an interest in getting to know the young person. When the case manager was seen as warm, sensitive, and easy going, it was easier for the young person to approach the case manager at times of need:

Well, if there was somebody really – they were all really strict and stubborn and stuff like that, you feel less comfortable asking for help with things. (Peter)

This relaxed attitude was seen as empowering for the young person, and contrasted to authoritative relation-

ships that they previously had with professionals such as teachers or general practitioners.

Feeling cared about

For several participants, the need to feel cared for was demonstrated by the case manager listening to them and believing in them:

She kind of counsels me and, maybe I'm saying the wrong word, maybe not counsels maybe it's just listening, sitting down and listening, listening to what I say and being there to support me. (Susan)

The ability to outreach the client when engagement was tenuous was also viewed as a demonstration of the case manager caring:

She'd end up just coming to my house and saying you alright and stuff like that . . . Just like, at least someone cares you know. (Matt)

This need to feel cared about demonstrates the vulnerability of the participants. Despite the expectations of society and the individual desire to seek independence and move into adulthood, the experience of psychosis was commonly experienced as frightening. There were times when participants wished to retreat from independence and instead wish to be nurtured by adults in their lives.

Pull towards disengagement

As shown in Figure 1, there were also several factors that pulled the young person towards disengaging from their case manager.

Waiting and doing nothing

An uneasy experience of waiting was most prominent when the young person was anticipating allocation of a case manager:

Yeah they were working on it, couldn't get one, a case manager and a doctor for me . . . I just remember waiting and doing nothing. (Elizabeth)

At the EIS, allocation to a case manager may take between 1 and 8 weeks, due to the requirement of a comprehensive assessment, treatment of acute symptoms, and the quantity of referrals that may be processed at any one time. During this time period, the young person continues to be managed by the crisis and assessment team, meeting numerous clinicians. After the acute episode when the young person was feeling most vulnerable, this wait for a case manager led to a sense of recovery being put on hold. The inability to be active in the process of obtaining a case manager accentuated the participants'

sense of disempowerment brought about by their psychosis and the need to seek help.

Not wanting to open up

Reluctance to self-disclose was another significant factor that impeded some participants from engaging with their case manager:

Really it's up to the client to open up to the case manager. If the client doesn't open up then the case manager won't know about that person so it's, it can be hard and it's not because of the case manager, it could be that the client doesn't want to open up. (Susan)

Participants described initially feeling reluctant to open up to their case manager due to the stresses of retelling the story or because talking was not perceived as helpful. The amount of information that participants chose to disclose also ultimately affected the level of engagement that the young person and case manager could reach. Disclosure was dependent on elements such as stage of engagement, presence of symptoms, sensitivity of information, and the quality of the therapeutic relationship.

Stigma

Stigma was felt to impact the level of engagement some young people had with the case manager. Many clients had encountered stigmatizing comments prior to initial referral:

I had a doctor ask me 'do you go crazy?'. (Naomi)

Prior experiences of stigma were clearly remembered by the participants and not only influenced their willingness to engage with a mental health service, but also their perceptions of themselves.

Change in case manager

Disruptions to continuity of care, such as a change in case manager, impacted participants' level of engagement with their case manager and the overall service. One participant described being guarded when meeting her second case manager, as she was not sure how long they would be working together:

I was pretty reluctant in talking to her, like I didn't know whether there was another change or not. So I was pretty much like reserving things to myself. So I was pretty much afraid that the next thing they're going to tell me that I have to change your case manager again, and I have to repeat myself all over again. (Hannah)

Several participants felt that if their case manager changed, they would struggle to come into the service and open up to another person.

Other appointments

At times, other aspects of life impacted on ability to attend appointments. The priority the young person placed on attending was therefore subject to changing needs:

Just having appointments with like job-seeking agencies on the same day and stuff like that. (Matt)

Towards discharge from the EIS, other appointments gained precedence in the participants' lives, which can be seen as a positive progression as the young person moves towards 'normal life'.

DISCUSSION

The key findings of this study were that engagement should be viewed as a dynamic process rather than a static phenomenon. Throughout this process, different factors influenced young people's decision to engage or disengage with the EIS. Two core issues that largely influenced engagement with the EIS were disempowerment and the therapeutic relationship.

Engagement as a process

This study suggests that engagement is best understood as a process incorporating different stages. This idea is supported by existing published work; however, research that describes engagement over time has been largely theoretical and not based on client self-report (Wright *et al.* 2011). Engagement continues to be viewed in clinical practice as a target to be met, rather than a process that may fluctuate over the course of treatment (O'Brien *et al.* 2009b). Engagement is therefore presented as a status that is required before case management or therapy can begin. This does not acknowledge the effort that the case manager must direct at keeping the young person engaged throughout their time in the service, whilst the young person struggles with the push-pull dynamics of engaging with them. Understanding the push-pull dynamic throughout interactions may allow clinicians to empathize with the client along this journey and match the approach to the process experienced by the young persons.

Role of disempowerment in engagement

A significant issue that influenced engagement was found to be disempowerment. It is interesting to note that a sense of disempowerment initially pushed young people towards engaging with their case manager ('fear of relapse' and 'can't do it myself'). The onset of psychosis caused the young person to lose their sense of control, and this was associated with strong emotions of fear and

hopelessness. The service and the case manager were viewed as a resource to help the young person understand their experience.

However, if aspects of the service were seen to disempower the young person, such as the process of waiting to be allocated a case manager, the process of losing a case manager, or feeling forced to talk about sensitive issues, the young person experienced a strong desire to disengage. As the young person moved towards recovery, the amount of disempowerment that they were willing to tolerate also decreased. This fluctuated according to wellness, as those participants who were continuing to experience symptoms were more likely to tolerate a greater sense of being disempowered by the service. This is supported by the prognostic studies which identified that lack of ongoing symptoms was a characteristic of those who were more at risk of disengaging from EIS (Stowkowy *et al.* 2012; Turner *et al.* 2007)

Throughout the existing published work, a sense of control within the engagement journey has been seen as integral in maintaining engagement (Priebe *et al.* 2005). It is most prominent in studies conducted in adult mental health services, which specifically identify that the individual's desire to be an independent and able person, desire to solve one's own problems, feeling one had improved and no longer requires the service, independence, and lack of control over treatment goals were important in the engagement process (Kreyenbuhl *et al.* 2009; O'Brien *et al.* 2009a). This is somewhat predictable as adults expect to be living independent lives, accomplishing their selected career path and having relationships.

Role of the therapeutic relationship in engagement

The participants of this study described the client–case manager relationship as a vital reason for choosing to engage on an ongoing basis with their case manager. They principally valued assistance with understanding their own psychosis and making sense of their experience. This concept not only included being given knowledge, but also having their experience understood by the case manager. This mutual understanding was built over the time spent together. These themes are mirrored in the study conducted by (Wright *et al.* 2011) who identified contact, dialogue, transformation and shared understanding as integral aspects of building and maintaining engagement with a mental health service.

Initially, the case manager was seen to be the decision maker within the relationship, by giving information, and promoting engagement. As the participant moved through the stage 'something to do, someone to talk to', it

was expected that the ratio of control within the relationship would shift from the clinician to the young person. The relationship would therefore move from a caring, protective relationship to a more flexible partnership. However, there is potential to shift back towards the case manager being caring and protective if relapse or crises occur. Towards the end of the journey of engagement, the power within the therapeutic relationship should sit with the young person, as their understanding of their psychosis and themselves is achieved, and the role of the case manager is no longer required.

Due to this shifting dynamic, the therapeutic relationship for this population may need to be more flexible and less formal than those within services for adults or within standardized psychological therapies. This notion is corroborated by previous research that suggests the relationships between the case manager and young person in youth services are less formal than traditional case manager–client relationships (McCann & Lubman 2012). Earlier experiences of health professionals being paternalistic, such as during involuntary treatment or when the young person was initially told to attend the EIS, contrast with the more flexible partnership that young people experience with their case managers in the later stages of the therapeutic relationship.

It is clear that the role of the therapeutic relationship is vital in building and maintaining engagement with the case manager. As the Australian Clinical Guidelines state, 'the role of the therapeutic alliance is a moderate-to-strong predictor of outcome, regardless of therapeutic approach, including with young people' (Early Psychosis Guidelines Writing Group 2010; p. 67). This study found that young people themselves also value the therapeutic relationship and it is a crucial element in their decision to engage.

Limitations of the study

The major limitation of the current study is the potential selection bias. Participants were selected by case managers, who may have chosen young people whom they felt were well engaged and it was difficult for the principal researcher to approach those clients who were currently disengaged. The intended population posed some dilemmas in conducting in-depth qualitative research. Levels of rapport between the researcher and the participant fluctuated throughout each interview. This might have been due to the developmental stage of the population, reflect the stage of recovery they were in, or the relative inexperience of the research interviewer. All participants requested the interviews be conducted at the service in which they were treated. Whilst this enabled attendance,

it might have constrained the young person's frankness about the service. The fact that the principal researcher was also a clinician of the wider EIS service might also have impacted the honesty and frankness of data collected, despite careful consideration of confidentiality and no dual relationship at time of consenting or participation.

Implications

The study findings have implications for mental health nurses and all staff and leaders in EIS. The importance of the therapeutic relationship between case manager and client should not be underestimated. Having knowledgeable, friendly, and approachable clinicians is vital to promoting and maintaining engagement. Encouraging young people to attend the service can be seen as vital to their recovery; however, if engagement is modest, or if disengagement has occurred, then outreaching should be encouraged to build rapport and trust. While outreaching is a common feature of community mental health nursing practice, it may be less so for colleagues with practice orientation to formal therapy. The reasons why outreach is occurring should be reviewed by the multidisciplinary team and supported by management.

The findings highlight the importance of service structures and processes and how these influence the engagement of the young person with their case manager. For example, young people would benefit from meeting their case manager as a priority on referral and having access to substantial time with their case manager to foster engagement and build a therapeutic relationship. The measures that are in place to protect the clinician's time with their clients should therefore be valued in policies and procedures. When possible, potential changes in case managers should be flagged as early as possible, so that replacement case managers begin to build rapport. Demonstrating a smooth transition and collaboration between case managers may not only maintain engagement with the service, but facilitate a good enough end to a relationship, which young people may not have experienced prior to their client–case manager relationship.

More research is needed to advance knowledge on this complex topic. A longitudinal study, following participants through their journey of engagement at different time intervals, would allow for the stages of engagement to be more thoroughly investigated. Such research could further explore whether the factors that promote or dissuade from engaging with a case manager are phase-specific. This would also allow data to be collected from those young people who do disengage from EIS. To further enrich the data, interviewing case managers with a

range of disciplinary backgrounds would allow for different perspectives of engagement to be explored.

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