Engagement in specialized early intervention services for psychosis as an interplay between personal agency and critical structures: A qualitative study

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Abstract:

Background. Specialized early intervention programs for individuals experiencing a first episode of psychosis prioritize service engagement, generally operationalized as attendance, treatment completion, therapeutic alliance, and treatment adherence. However, there are critical theoretical and methodological gaps in understanding how service users experience and define their engagement with the service.

Objectives. This study aimed to explore how current and former service users define their engagement with a specialized early intervention program.

Design. A qualitative descriptive approach was used to explore service users’ decisions to use, remain involved with, and/or leave early intervention services.

Setting. This study took place in an early intervention service for psychosis in Montreal, Canada.

Participants. Twenty-four participants who had experienced a first episode of psychosis and had been engaged in the service to varying degrees (fully engaged, partially engaged, disengaged) took part in in-depth interviews.

Methods. In-depth interviews were employed to collect rich insights into participants’ experiences and perceptions. The interviews were transcribed and analysed using thematic analysis, beginning with an inductive approach and completing the analysis using a theoretical approach. During the analysis, our original notions of engagement and disengagement were challenged by theorizing engagement in terms of agency and structure. Researchers engaged in reflexive practices to maintain and promote research rigor and trustworthiness.
Results. Participants’ narratives were thematically analyzed and organized into three themes: fluidity and temporality of engagement and disengagement; engagement as an ongoing negotiation; and critical structures and agency. Participants described engagement in a variety of ways, some of which were broader than service use and focused on self-care and commitment to recovery. These conceptions were subject to change as the individuals’ perceptions of their needs changed. As needs changed, individuals also negotiated and renegotiated their care needs with themselves and with their treatment team. These exercises of agency were constrained by key structures: the treatment team, family and friends, and societal conceptions of mental health.

Conclusions. Our study findings argue for an expanded definition of engagement which prioritizes individuals’ experience and acknowledges the steps towards recovery that they may make outside of the purview of the service. It also underlines the importance of a treatment structure which aligns with individuals’ needs for both support and autonomy.

Keywords: agency; Canada; disengagement; early intervention for psychosis; mental health and illness; qualitative research; service engagement; structure
Contribution of this paper:

What is already known about the topic:

- Specialized early intervention services for psychosis prioritize service users’ engagement, generally defined in terms of attendance, therapeutic alliance, treatment adherence, and treatment completion.
- Good relationships with the treatment team and supportive relationships may increase engagement in services.

What this paper adds:

- Engagement in recovery goes beyond engagement in services, and requires negotiating and renegotiating competing priorities, e.g., spending time at the service versus at school or work.
- Discontinuing services may not always be a negative outcome.
- Agency, a person’s ability to exercise choice, and structures, which constrain and support the ability to make a choice, interact to produce a variety of presentations of engagement.
Engagement in specialized early intervention services for psychosis as an interplay between personal agency and critical structures: A qualitative study

Within the last two decades, evidence has prompted widespread efforts for reform in services and treatment approaches for early psychosis (McGorry et al., 2008). Specialized early intervention services for psychosis have been designed to provide treatment and support for individuals experiencing a first episode of psychosis (McGorry, 2005). There are over 200 early intervention services worldwide, focusing on the unique needs of young people with psychosis and their families (McGorry et al., 2008). These services provide an 18-month to two-year package of evidence-informed interventions that include multidisciplinary case management; low dose, atypical antipsychotic medications; and psychological and behavioural therapies for individuals and their families (Malla et al., 2010). Clinical guidelines for early intervention services accord central priority to service user engagement, generally defined in terms of attendance, treatment adherence, and treatment completion. Early intervention services, consistent with other models like assertive community treatment and strengths-based case management (Bond, Drake, Mueser, & Latimer, 2001; Rapp & Goscha, 2004), have conceptualized engagement in terms of continued contact with services and emphasized therapeutic alliance. Compared to regular psychiatric care, these models have evidence for higher rates of service engagement thus defined (Doyle et al., 2014; Herinckx, Kinney, Clarke & Paulson, 1997, Rapp & Goscha, 2004). However, these definitions are limited as they potentially prioritize the concerns of providers/systems of care over those of users and fail to acknowledge the ability of individuals to recover independently, with or without professional help.
In a perspective paper, Lal and Malla (2010) describe engagement in more nuanced terms as a multi-dimensional construct that waxes and wanes and manifests in several ways. For instance, individuals can engage with all aspects of early intervention services — case management, medication, and group therapies — or some combination thereof, and this combination may change over time. In this regard, while early intervention services in their entirety are beneficial, little research has investigated which components benefit which service users, and at which stages in treatment (Iyer et al, 2015). Lal and Malla (2010) also acknowledge that engagement is a concern along the continuum of care, from initial engagement in services, throughout follow-up, to during transfer to other services. There may also be differences in how providers and users conceive of engagement.

However, these variations are not traditionally captured in most studies of engagement and, more commonly, studies of service disengagement. Much of the research in this area has relied on observable metrics, typically defining service disengagement as non-completion of the recommended course of early intervention follow-up (see Doyle et al., 2014 for a review). The question of how individuals with psychosis perceive their engagement with specialized early intervention services, and how this changes over time, remains poorly understood. A few qualitative studies have explored engagement in early intervention services from the perspectives of service users and their caregivers, providing insights on the factors promoting engagement (e.g., therapeutic relationship; caregivers' role in supporting engagement) and hindering ongoing engagement (e.g., distress, confusion, stigma) (Loughlin et al., 2019; Tindall et al., 2018b). However, these studies focused on individuals who are engaged with or attending services, leaving the experience of individuals inconsistently engaged with or disengaged from services...
unexplored (Tindall et al., 2018b). Also, how the engagement process develops over time remains unclear (Tindall et al. 2018b).

In the present study, we therefore sought to explore how individuals currently using a specialized early intervention service and those who left the service before the end of their recommended treatment experienced and perceived their engagement. To control for preconceived notions about engagement and disengagement, and to open the possibility for new understandings we purposively explored perspectives of individuals who had been regularly attending appointments, those who had been inconsistently attending appointments, and those who had completely quit the service before completing the recommended duration of follow-up. Guided by an inductive approach, at first, our epistemology was grounded in participants’ lived experience. As the analysis evolved, we explored participants’ perspectives through the lens of their experience of agency, and the structures that supported or constrained their choices. In this manuscript, agency is defined as the person’s ability to exercise choice. Such choices can be restricted and supported by structures, such as caregiver support/disapproval or mandated treatment, which interact to shape the person’s engagement with clinical services.

Methods

In this qualitative descriptive study (Sandelowski, 2000; 2010), informed by the literature on service engagement in psychosis (Dixon, Holoshitz, & Nossel, 2016), we examined the dimensions and processes that guided service users’ decisions to use, remain involved with, and/or leave early intervention services. Individual interviews were conducted to gather potentially rich insights into participants’ experiences and perceptions. This study was approved by the institutional research ethics board [name to be added following peer review]. Research
Agency and Structures in Early Psychosis Services

Staff with no prior relationship with the participants conducted the interviews, and data was not shared with treatment team members except in aggregate form.

The perspectives and/or position of the researchers can shape the research process. Through reflexivity, a practice promoting rigor and trustworthiness in research, researchers acknowledge the influences their positions have on their research. We adapted Reinharz’ multiple selves reflexivity framework (1997) to unpack the different identities that we brought into the field and generated during the research process. We recognize that participants may have perceived the researchers as members of the service where they were being or had been treated, and that this may have impacted their sharing. However, the interviewers were close in age to the participants, facilitating friendly and open discussions. Finally, the research team comprised people from diverse backgrounds, including those with qualitative research and clinical experience. This helped contextualize participants’ treatment experiences, whilst also enabling a critical examination of current clinical practices in light of participants narratives.

Participants

Current and former users of a Canadian specialized early intervention service for psychosis were recruited. The service operates on easy, rapid, and open access policies. This service operates in an outpatient facility that, like all other specialized early intervention services in Canada, is part of the public healthcare system that provides services free at the point of delivery. Eligible individuals are between the ages of 14 and 35; have an intelligence quotient of at least 70 on a standardized intelligence test (as offered services are not tailored to the needs of the intellectually disabled); have a non-affective or affective psychotic disorder neither substance-induced nor attributable to an organic brain disorder (e.g., epilepsy); and have taken antipsychotic medication for 30 days or less. Comorbid substance misuse is not an exclusion
criterion. The service offers two years of treatment comprising case management, family psychoeducation, medication, and individual and group psychosocial interventions (Iyer et al, 2015).

We used purposeful sampling (Coyne, 1997), seeking individuals from three groups based on their level of contact with the service. We initially conceived of these three groups with different levels of contact as representing different levels of engagement, but our analyses suggested that such a definition of engagement may have been too simple. Nevertheless, the initial three groups included: engaged (at least nine months of consistent contact with the service at the time of the interview), partially engaged (at least nine months of inconsistent contact with the treatment team) and disengaged (at least three continuous months without contact). Forty-eight current service users were approached in person or by phone. Former service users (those who had stopped using the service) were phoned. In total, 24 participants consented to an interview: 19 participants were still within their follow-up period and maintained some level of contact with their treatment team and five participants had stopped using the service before the end of follow-up. Of those still in contact with the treatment team, seven participants were categorized as “partially engaged” and 12 were categorized as “fully engaged”. Participants’ ages ranged from 17 to 34 years (M = 22.67 years). Table 1 presents detailed demographic information.

Table 1. Demographic characteristics of participants (N = 24)

<table>
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<tr>
<th>Characteristic</th>
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AGENCY AND STRUCTURES IN EARLY PSYCHOSIS SERVICES

<table>
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<tr>
<th>Outcome</th>
<th>Frequency</th>
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<tr>
<td>Women</td>
<td>190</td>
</tr>
<tr>
<td>Trans</td>
<td>6191</td>
</tr>
<tr>
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</tr>
<tr>
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</tr>
<tr>
<td>No</td>
<td>194</td>
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*Note. Some demographic data are missing for two participants.

Procedure

The interview guide was created iteratively and collaboratively by all authors, drawing from past research on service engagement. Feedback on the guide was also sought from clinicians, service users, and families. The last evolution of the guide is available in Supplemental Materials (Table S1), though it is important to note that the guide was used flexibly. After providing written informed consent, each participant engaged in a single semi-
structured individual interview (Whiting, 2008) exploring their perceptions of the early
intervention service and treatment team; their level and definitions of engagement; their
disclosure to, and subsequent involvement of, friends and family; their experiences with stopping
or considering stopping treatment at the service; their understanding of the experiences that
brought them to the service; their definitions of being well; and their current life context.
Participants were informed that the interviews sought a better understanding of their experiences
to improve services.

Interviews took place at the early intervention service with only the interviewer and the
participant present and were conducted in English or French (or a combination), according to
participants’ preferences. They were audio recorded and lasted around 55 minutes (the shortest
was thirty minutes and longest two hours). A transcript of the interview was provided to one
participant who requested it. We continued to recruit participants until reaching data saturation
Morse (1995) defines data saturation as ‘adequate’ data achieved through specific
methodological practices. The recruitment process was designed to reach and involve a variety of
participants with different experiences: participants who had been regularly attending
appointments, those who had been inconsistently attending appointments, and those who had
completely quit the service before completing the recommended duration of follow-up. We
ended recruitment when we felt that participants’ narratives provided a range of experiences that
adequately addressed the study aims and helped create a collective narrative of shared and
unique experiences. The recruitment strategies created a rich and full dataset for analysis (Morse,
1995). Participants were not involved in analysis.

Analysis
Interviews were professionally transcribed and checked for accuracy by TC. We used Atlas.ti (Version 1.6.0) to organize the data. The thematic analysis framework used was based on Braun and Clarke’s (2006) approach. As Braun and Clarke (2006) described, thematic analysis seeks to describe patterns across qualitative data that can be used within different theoretical frameworks to achieve different aims. Our analysis process moved from inductive to theoretical analysis, beginning with inductive analysis to create a codebook. Four interviews were coded line-by-line by both TC and KM, with frequent meetings to discuss codes and any discrepancies that arose. TC coded the remaining 20 interviews independently; however, regular meetings took place with coauthors to review codes and relationships between themes and sub-themes, and to discuss the analysis process. TC kept notes and memos throughout the interviews and analysis.

As suggested by Braun and Clarke (2006), visual methods such as mapping can be used to better sort codes and themes and to consider how different codes can be combined to form an overarching theme. We used data mapping (Clarke et al., 2016) as an analytic methodological device to re/define codes and themes, and explore their relationships. Using this mapping methodology allowed us to unpack the relationships between service users’ understandings of coming to, remaining in, leaving, and returning to the service (Figure S1), and created a more nuanced definition of engagement that went beyond service use. Though this process, we shifted from a preliminary coding structure informed by our interview guide that focused on practical barriers to and facilitators of service engagement to how the journey through treatment reflected a variety of engagement experiences. As mentioned, this exercise helped challenge our preconceived notions of engagement, opening up new understandings that we sought to deepen.
through theoretical analysis using agency and structure (e.g. Cockerham, 2005; Fuchs, 2001), which led to the development of our final coding tree (see Figure S2 in supplemental materials).

Fuchs (2001)’s and Cockerham (2005)’s theories further support our analysis by offering a solid theoretical foundation to understand how agency and structures impacted/shaped participant’s decisions. According to Fuchs (2001) and Cockerham (2005), agency represents an individual's actions or capacity to act independently driven by their personal desires and values, whereas structures are all factors that limit or constrain individual choices and those which support the ability to make a choice. Our analysis attempted to integrate agency and structure, thereby challenging common understandings of the two which either see structure and agency as dualistic, opposing forces or see agency as a microelement (i.e., individuals’ behaviours) of macrostructures (i.e., states, institutions, class, etc.) (Fuchs, 2001). According to Fuchs (2001), in using agency/structure to understand everyday interactions, scholars should not see choices/behaviors as being entirely subjected to structures (where agency acts as a subject of determinism, structuralism, and mechanism) or as being entirely agentic (driven solely by one's awareness, consciousness, and/or willpower), but should instead acknowledge that most choices/behaviors involve both structures and agency (Fuchs, 2001). Originally, we sought to explore the choices that participants made and what influenced these choices. However, as our analysis progressed, we realized that some structures entirely prevented certain choices and strongly encouraged others. Moreover, we saw that structures were not always external to but also within the person. Following Fuchs’ suggestion to go beyond the traditional framing of agency/structure, we organized our analyses around how and why participants negotiated agency and structure at key points along their journey through the service.

**Results**
Our findings challenged our assumptions about engagement and led us to question our pre-existing categorizations (engaged, partially engaged, and disengaged). While the literature has generally used the terms “engagement” and “disengagement” to refer to service users’ relationship to an early intervention service (either attending the service/being in contact with a treatment team or leaving the service before agreeing on timing of departure with the treatment team; e.g. Priebe et al., 2005), our findings suggested that participants did not necessarily experience engagement in such a binary way.

We identified three main themes regarding engagement: fluidity and temporality in engagement and disengagement, which describes how participants construct engagement and disengagement; engagement as an ongoing negotiation, which further unpacks fluidity and temporality by describing engagement as an ongoing process of re/negotiating personal choices and therapeutic recommendations; and the critical structures and agency which shape engagement through personal choices and/or factors that limit, constrain, or facilitate such choices. Each theme will be explored as it relates to both coming to/staying in the service and leaving the service.

Fluidity and temporality in engagement and disengagement

Coming to the service and staying

While typical definitions of engagement are based on observable, measurable behaviours related to service use (e.g., appointment attendance), participants had a variety of conceptions of engagement in which service use was intertwined with personal values. These conceptions also changed over time, as participants’ priorities shifted. Some participants agreed with the standard conception of engagement defined in terms of service use and attendance. When asked if they were engaged and what that meant to them, one participant said:
“[I’m] very involved […] I come every week, so every appointment I have” (M.) *(see Table 2 for another example)*

For others, the most important actions they took to improve their well-being occurred outside the treatment context. These participants often perceived the depth of their personal commitment to self-improvement as the primary barometer of their engagement, rather than attending appointments and therapeutic activities:

“I think I’m doing a lot better, and I really feel like I’m helping myself, more than anything else.”*¹ (A.)

During the interview, A. made it clear that she worked very hard to invest in her well-being and recovery, both by attending appointments and by using self-care strategies. However, while her regular attendance and good relationship with the team made her appear highly engaged with the service, she was unsure about her service use and reported having competing priorities:

“I’m very busy, so it’s hard… to just have a one hour appointment and go back, it’s like two and a half hours of my day that I could have done a lot of stuff [with], and often, Tuesdays after school are really the only time I’m a little bit free, but now I always have an appointment.”*¹ (A.)

The more competing life commitments, the less A. wanted to prioritize service use as her primary form of self-care. However, her ambivalence was not evident because she maintained consistent service use. Thus, diverse internal experiences could result in the same observable engagement behaviors.

¹ * indicates quotes translated from French. All translations were done by TC.
Conceptions of engagement often revolved around what participants felt was most helpful and needed. E. was initially hesitant about service use, but once she decided it was necessary, she developed a strong bond with her psychiatrist and described the service as critical to her well-being:

“At the beginning, I hated being told what to do, but now I understand that [case manager] is doing it for my own good […] I tell myself this is what I need, I have to come to my appointments, all that… I was really sick, I need that support.”* (E.)

What participants felt they needed, however, could change over time. This fluidity was apparent among participants whose engagement with the service was intermittent. One participant, C., described taking time away from the service and later returning:

“I was tired of the emotional work that I put in coming here…. I was just kind of tired of being a patient…. I just […] took off…. My symptoms got a lot worse and I couldn’t ignore them anymore, and I started missing my therapy sessions and I started emotionally missing them… okay, I think I’m done running away from this. I clearly was there for a reason and I clearly need more help, and I think this has – this has gone on long enough.” (C.)

Over time, C.’s priorities shifted away from the service, and then back to it. Thus, what seemed like a period of service disengagement was actually an engaged choice on C.’s part. While this ebb and flow of priorities was most obvious in individuals who had intermittent contact with the service, even outwardly engaged participants, like A., experienced fluctuations.

* Leaving the service
As with conceptions of engagement, disengagement also had different attendant narratives that changed over time and with individuals’ changing needs. Leaving the service could be temporary or permanent, and the participants who left temporarily typically left with the knowledge and feeling that they could return at a later time when they felt that services would once again be useful to them. The five participants who left the service permanently had distinct experiences and motivations. Three participants stopped using the service because they felt that the service was not giving them enough benefit, or they were unhappy with it. They perceived the decision to leave as a sound and empowering one. F., who reported a particularly fraught relationship with his team, said:

“I told myself I don’t have the same symptoms as before, so why come?
To see a doctor who gives me more and more medication, more diets to follow. I told myself f*** that, I feel better now, so it worked.”* (F.)

F. described the team and the psychiatrist as an imposition. He described assessing his needs and goals for service use and, deciding that they had been met, felt no need for continued services. In this case, disengagement from the service, while in part motivated by a negative experience with the treatment team, occurred when the participant felt particularly empowered and well. In contrast, two participants felt that they had not improved, but found it uncomfortable to confront their problems. They both later regretted leaving the service. As one of them described this tension between using the service and avoiding problems:

“There were definitely some cons… even if I wasn't on anything, talking to somebody always makes you feel better….like I said, it was just stupid of me, like I just went back in denial and I started drinking again…. there were no pros and definitely a few cons [to having left].” (G.)
This participant’s denial seemed to support his self-perception as someone who did not have problems that needed addressing. Even temporary leaves from the service could be motivated by avoidance (see Table 2, for an example). Like coming to the service, leaving the service could also arise from different motivations and needs, and could look and feel different for different participants.

The various conceptions of engagement and the fluid boundaries between them are depicted in Figure S1. Some participants were content to not use the service, and described that as a stable choice, unlikely to change. Others were uncomfortable with having left the service and were considering returning. Among those who had an ongoing relationship with the service, some were steadfast and certain that that relationship was helpful. Others had a more fluid relationship with the service, either alternating between service use and disuse, or pursuing multiple paths to well-being, one of which was service use. Many participants moved from one of these circles to another during their treatment journey as they became more or less comfortable with what was being offered and as their needs, priorities, and preferences evolved.

**Engagement as an ongoing negotiation**

**Coming to the service and staying**

Rather than making a single decision about it, participants continually renegotiated various aspects of their service use, re/questioning and re/confirming behaviours, therapeutic practices, and personal choices. They often spoke about having to decide whether to attend appointments or therapy groups, take medication, or be forthcoming with clinicians. This subtheme was described most explicitly in relation to the choice to take medication. A participant who had consistently attended the service for just under a year had notable trepidation about using medication, and said:
“At first, because I didn't believe in taking medication it was kind of hard. So, at first, I never used to take it…. But even then, I still went online, and I still researched to hear other people's point of view like taking this medication and - that had kind of like helped me… screw up the courage to take them every day. Because I don't want to go back in that state of mind again.” (H.)

Before agreeing to take the medication, H. had to feel comfortable that it was the right choice. Even then, it took experience, exposure to the perspectives of other service users, and some courage. Other participants described similar trepidation, having negative initial impressions or experiences and requiring further research or medication changes until they felt comfortable enough to take medication. Even then, taking the medication required remembering the pill daily, or attending appointments for an injection, and balancing side effects with concerns of relapse. If the perceived benefits did not outweigh the perceived costs, the medication was sometimes deemed unnecessary. One participant described how arriving at such a conclusion about medication caused tension between him and his psychiatrist:

“I told [the psychiatrist], face to face, I feel better, I don’t need the medication, and he still gave me a prescription. So, I threw it in the garbage.”* (F.)

This participant saw the medication not only as unnecessary, but also as symbolic of the psychiatrist's disregard for his concerns. Eventually, F. stopped attending the service because of this issue.

Participants also described choosing whether to attend the service or accept a given intervention based on whether they needed it at a given juncture. B., who had stopped using the service several times, described the choice thus:
“Sometimes I won't come for months on end because I'm feeling so great, and I can handle everything and then sometimes, I just have breakdowns and I feel like I need something extra, but then that's where [the service] comes in [...].” 

(B.)

This participant, and others like her, described having busy lives that could be rewarding, therapeutic, or overwhelming (see Table 2 for another example). These participants attended the service when other aspects of their lives did not provide needed support, but they otherwise perceived services as an unnecessary expenditure of time and energy.

Some others perceived services as complementary to their own self-improvement efforts and engaged in both in tandem. I., who had asked his doctor to stop his medication, said:

“It’s true, the doctor can help me, but I need to do something to get better too. So the doctor, he helps, but not 100%. It’s about 30% the doctor and 70% yourself.”* (I.)

For this participant, as for others, negotiating the competing contributions of their lives and their treatment to their well-being resulted not in intermittent service attendance, but in seeing the service as something else in which they could consistently and competently participate.

Overall, participants engaged in an ongoing process of negotiation that entailed weighing different considerations and priorities, with respect to both treatment and self-care. This deliberation (explicit or implicit) suggested that individuals were aware of their needs at various junctures, and actively reflected on whether they could fulfill those needs themselves, needed the treatment team’s help, or both.

Leaving the service
While the decision to leave the service was final for five participants, most who left the service at one point or another saw that choice as an impermanent one. When asked if it would be hard to leave the service, J. said,

“Not necessarily, because they do keep the file on like standby for a like couple of years so it’s easy if you need to come back, [...] considering they still had the file.” (J.)

This participant’s comfort with leaving the service stemmed from her perception that returning to the service would be easy. Participants’ agency in negotiating service use was thus supported by the treatment team clearly communicating the possibility of returning to the service, by continuing to reach out to those who left, and by facilitating the return of those who wanted to come back.

Another participant described feeling worried about how her treatment team would respond to her return, but being reassured by their reaction:

“Even when I haven't come for like months on end, they always end up taking me back, when I feel like they're going to think I'm using them but they're always like, ‘This is what we're here for’, so I really appreciate that. And they're - they're good, they're flexible and they're understanding.” (B.)

Feeling that her choices were accepted made it easier for this participant to both leave and return to the service. The treatment team’s flexibility may have been instrumental in this regard (see Table 2 for an example). The majority of participants who returned to the service after leaving engaged in some kind of negotiation as to how they would reintegrate with their treatment team. Some were concerned about being accepted and regaining the team’s positive
regard, while others used the time apart to reassert their independence and their role as integral members of the team. Regardless, they often saw the space and time entailed in renegotiation as enabling them to prioritize what they felt was most important for their well-being. Participants also spoke of choosing to leave particular aspects of the service rather than services as a whole:

“I found [the social group] wasn’t for me, that it didn’t help. At the beginning it was to help me socialize better, but afterwards I didn’t find I liked it.”* (O.)

When offered a flexible treatment plan, participants were able to discontinue interventions that did not meet their needs without having to discontinue services as a whole. This allowed them to choose the service components that were best able to serve them at a particular time.

Critical structures and agency

Coming to the service and staying

Several narratives presented earlier highlight the intertwining of structures and agency. Participants’ experiences of the service were affected by structures that limited and controlled, or facilitated, the choices they could make, and the times when they could exert their agency. Participants identified several influential structures that shaped engagement experiences, including the service itself, social relationships (families and friends), treatment orders, and societally held conceptions of mental illness. Court-mandated treatment and involuntary hospitalizations also critically limited the choices that individuals could make (see Table 2 for an example). These societally imposed structures often resulted in minimal engagement – individuals would meet the criteria imposed by the treatment order, but not necessarily engage in
services beyond that. Coercive measures thus served as structures shaping engagement (e.g., attending appointments, agreeing to injectable medications), but beyond that, individuals still exercised their agency. While participants identified these structures as factors which influenced their experience with the service and their engagement, they did not explicitly identify them as structures. In contrast, some participants did explicitly describe instances where they exercised agency (such as choosing one thing or another). Identifying structures and experiences of agency was thus a framework which was integrated by the researchers.

The service acted as a structure by providing specific interventions in a physical, tangible space and by rendering other forms of help, such as with housing, employment, finances, and transportation. In so doing, they could support participants’ choice to attend the service (see Table 2 for an example). The service also structured relationships between service providers and service users. A key aspect of these relational structures was the perception of authority. The authority that providers were seen to have because of their expertise was experienced as positive by some participants, who saw it as a source of guidance and support:

“If they give me advice, I follow it. […] The advice is about my nutrition, what I eat, who I should hang out with. Because before I didn’t have good friends, the people I was around took drugs, drank, things like that […] Now I have good friends.” *(K.)*

Some participants valued the authority of their treatment team, contrasting their current experience of service use with past ones:

“This is what I've been looking for, somebody who actually knows what they're talking about when it comes to mental illness and prescribing things.” *(L.)*
These participants tended to make choices aligned with the suggestions of the treatment team, while still feeling empowered. To others however, the expertise and/or perceived authority of their treatment team could feel alienating:

“Because… [psychiatrist] tries to be very jovial and nonchalant about things, but… it’s putting me in a place where I feel the need to play along as if I’m okay with [psychiatrist] when I’m not. […] Maybe not talking about me in the third person to my case manager when I’m right there. Maybe not ignoring things that I say are real problems, just because [psychiatrist] doesn’t understand them. Maybe not… talk […] in these big scientific words and then like wave them off when I ask [psychiatrist] to explain things…” (C.)

This participant’s perception highlights how a prescriptive stance from providers can feel disempowering, and the importance of a collaborative approach. Such an approach is reflected in the experience of another participant, who felt valued as a member of the decision-making team when discussing medication:

“My psychiatrist isn’t really like a medication-pusher, [my psychiatrist said] ‘if you want medication, I can suggest medication but if you don’t think you need it you don’t need it’ […][my psychiatrist] trusts my judgment, so it’s helpful.” (J.)

Overall, the authority of the team could be experienced as either a supportive and collaborative structure or a disempowering one.

In contrast, social relationships were largely experienced as supportive structures, or as being distinct from the service experience. Some participants said that their friends and family were not involved in their treatment, sometimes because of their negative reactions to treatment or a lack of trust. This did not influence participants' service use, which was still largely their
own choice; however, it did impair their relationship with those friends and family members. In large part, friends and family accepted and supported the decision to use services and demonstrated this through instrumental supports and encouragement of service use. One participant, for instance, reported that when she was feeling badly, her romantic partner would encourage her to seek out the service:

“Because my boyfriend knows that I have clinic here, he'll tell me to come to talk to my doctor because that really is the only person that can help me in the way I need.” (B.)

Societal conceptions of mental health and internalized stigma may have been structures limiting comfort with service use and interfering with help-seeking and disclosure. This narrative was especially prevalent when discussing medication. Participants described holding preconceptions about psychiatric medication that were deeply influenced by mental illness stigma, and as one participant described, that stigma leads to wanting to avoid medication:

“Try everything and if really nothing is working, then try medication. Because medication, like for me, who’s a young like [teenage] girl, when you take a medication that’s for 50-year old schizophrenics, I kind of feel crazy….” (A.)

This participant described several ways in which stigma forced her to reckon with who she was, and how she was perceived by others (see Table 2 for another example). Other participants voiced similar stigmatized views of medication and receiving services at a psychiatric facility, and for some, this was countered by information and experience and did not impede engagement.
All participants described external structures that influenced the choices available to them, but which structures were most salient and how they influenced their choices differed from person to person. In general, the treatment team and the service were typically the most salient, in that they were most proximal to the choice of attending/staying in and leaving the service and could counteract stigma and provide conditions and relationships facilitating treatment use.

Leaving the service

The agentic choice to leave the service may also be influenced differently by different structures, primarily the treatment team and societal attitudes about mental illness. The team, as mentioned above, may support the decision to end services. However, even when supported by the treatment team, not everyone exercised that choice. D., who had not finished the entire program but seemed to have recovered, described a conversation with his case manager:

“[Case manager] was saying ‘right now you seem okay, you don’t have to continue being a part of the program’. And even though I was having like meetings with [case manager] every two months, […] I always kept it there just in case. I’m aware enough to know this is something that could happen again and I think […] just a little evaluation with the mental health professional, and that self-evaluation and that little bit of reflection I think was good.” (D.)

The team could also act to prevent the impulse to leave the service. N., who was considering leaving, said:

“…they [psychiatrist and case manager] saw that I didn’t want to be there so what they did was they took a step back and told my parents, ‘let him do what he wants to do until he realizes.’” (N.)
Paradoxically, the strategy of decreasing familial pressure and supporting the participant’s agency increased the participant's comfort with using the service. Friends and family could also support the participant’s agency in leaving the service, by for instance, encouraging or accepting that choice (see Table 2 for an example).

Internalized stigma was another structure contributing to discontinuation of services. Two participants who had stopped attending the service cited concerns about what it said about them to be seeking mental health services:

“[…] I just felt uncomfortable knowing that there was something wrong with me so I just kind of went back to hide it again.” (G.)

In these cases, participants saw being recipients of services as a stigmatized identity, which inhibited their engagement with the service.

Table 2. Supplemental supporting quotes

<table>
<thead>
<tr>
<th>Theme/Subtheme</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fluidity and Temporality in Engagement and Disengagement</strong></td>
<td></td>
</tr>
<tr>
<td><em>Coming to the Service and Staying</em></td>
<td>“I'm engaged because I come to my appointments, I take my medication. What else? I take part in, like, whatever activity they ask me to, or any survey or anything.” – H.</td>
</tr>
<tr>
<td><em>Leaving the Service</em></td>
<td>“I was tired of dealing with my shit. I was tired of the emotional work that I put in coming here. Therapy was amazingly helpful,</td>
</tr>
</tbody>
</table>
but I was still crying by the end of it, so it’s still emotional labour. I was just kind of tired of being a patient.” – C.

**Engagement as an Ongoing Negotiation**

*Coming to the Service and Staying*

“It was fine. I was in school, I was working, friends were fine, everything was good. […] It was more like I was really busy and there wasn’t enough to say during sessions that warranted me coming in, because everything was basically the same, month to month, I didn’t have much to add.” – J.

*Leaving the Service*

“I wasn’t coming because I told myself ‘[the case manager]’s just going to tell me what to do’. [The case manager] called me and […] explained, ‘listen, I just want to see you to see how you are, to hear your news, for your benefit. I’m not here to harass you’.”* – E.

**Critical Structures and Agency**

*Coming to the Service and Staying*

“I didn’t have to go to the [Program], I didn’t have to go to see [the case manager]. I was only going to see him because I had a condition to go see him once a month.” – P.
“Because my caseworker, he's always making sure that I'm on time, like going to my appointments. Sometimes he comes for me like to pick me up and take me to my doctor's appointments” – H.

“I’ve often thought about stopping because of what other people could think, because I have friends, and I often have appointments, and I don’t want to be “that girl” who is always at the hospital… The fact that I have to come to the hospital makes me feel like I haven’t improved, I haven’t gotten better, because I’m still here every week”. – A.

**Leaving the Service**

My mom said “Congratulations”, she was thinking the same thing as me. She thought it was just a pill-based therapy, not really a normal therapy. […] She said “Good job, I’m 100% in agreement. I’m on your side… I’ll fight for you.”* – F.
This study explores how participants understand and perceive their engagement with an early intervention service for psychosis and how this changes over time. Our analysis revealed that participants’ experiences of remaining in or leaving the service were fluid. The variety of experiences that participants described transcend the simple engaged/disengaged dichotomy often focused on in past research relying on measurable indicators of engagement (Doyle et al., 2014). Further, engagement was a process that entailed ongoing negotiation and renegotiation as needs changed over time, as competing priorities arose, as attitudes around treatment practices evolved, and as individuals themselves changed. Our findings are thus congruent with more recent, recovery-oriented approaches that challenge narrow, provider-defined conceptions of engagement (Dixon et al., 2016; Roe & Davidson, 2017).

Using the lens of participants’ experiences of agency and the structures that supported or constrained their choices yielded new understandings of engagement. The service users in our study were aware of and articulated their needs and how they were or were not being met by the service. Their choices were also shaped by structures that included the service itself and societal conceptions of mental illness. Using or leaving the service was a manifestation of participants’ own agency within these structures. Participants exercised choice within structures, engaging in ways that were personally meaningful and expressed their conception of well-being. By virtue of its philosophy of engagement, respect for autonomy, and flexibility, the early intervention service itself becomes a structure that facilitates people’s agency with respect to engaging with, disengaging from, and importantly, reengaging with treatment, a choice that is not usually so flexibly accommodated in other types of psychiatric care (Correll et al., 2018; Craig et al., 2004). Our findings reveal that service use is only one part of an individual’s life, and that a variety of
factors can limit or shape engagement. We have also explored how participants negotiate the structures within which they live to enact their agency.

One of our most critical findings is the variety of internal experiences of engagement that are not always congruent with externally observable service use behaviours. Thus, seemingly disengaged individuals may have discontinued services because they felt well and no longer perceived a need for treatment, just as seemingly engaged individuals may be considering leaving. Also, some individuals may prioritize other aspects of life and self-care over services but still see themselves as “engaged” in their recovery journey (Roe & Davidson, 2017).

Our findings have profound implications for treatment providers and services. To properly support service users’ engagement, it is necessary to understand what engagement means to them, how it relates to their self-concept, and the structures and competing priorities that they have to negotiate. On their chosen path to recovery, youths’ lives outside services may be as important as, or more important than, their use of services. Therefore, service providers can offer youths more choice by smoothly integrating services into their lives and supporting their priorities outside treatment. At the same time, they can collaborate with service users’ families, friends, and others to facilitate their engagement in services. Service providers should recognize that individuals may disengage for a variety of reasons, some of which are positive. Preventing disengagement by default will not serve these individuals.

Our findings about what participants experience as fundamental to engagement echo the principles that early intervention services aim to embody: flexibility; respect for service users’ choices; acknowledgment of various aspects of an individual’s life; recovery orientation acknowledging that recovery can be variously defined; medication as only one (albeit often important) component of treatment; and various routes to engagement (Iyer et al., 2015; Marshall
et al., 2004). While some participants identified the service as adhering to these tenets of care, others did not perceive the service as having been congruent with these principles. Participants often identified the psychiatrist as the authority figure and explicitly mentioned their relationship with medication as playing a key role in, or as being a marker of, their engagement in services. This despite the avowed philosophy of early intervention services that sees medication as but one part of a flexible, individualized treatment plan to which service users may or may not choose to adhere, and the psychiatrist as but one member of a larger team with other equally important members. However, a degree of tension between this avowed philosophy and service users’ perceptions is inevitable because psychiatrists are responsible for prescribing medications and enforcing coercive measures (e.g., involuntary hospitalization) when necessary, both of which are points of pain for many service users. Overall, relationships with service providers constitute a critical structure. The quality of these relationships depends on an individual’s needs for structure, authority, autonomy, and contact, all of which may evolve during their journey through treatment.

Concrete recommendations for service providers that emerge from our analysis include being flexible and understanding of the journey that each service user is navigating, acknowledging that the priorities of individual service users may differ from one another and from those of the treatment team, and understanding that those priorities may shift over time. Frequently asking what a service user wants and needs from treatment can provide clarity. Even after an individual has left the service, service providers can support smooth transitions in and out of the service and even facilitate return to the service by communicating the possibility of return and continuing to maintain at least minimal contact. Most participants who had left the service at one point or another saw their departure as impermanent and were relieved that service
providers were understanding of their time away. Table 3 contains actions and policies that participants specifically identified as helpful. Some of these actions and policies challenge administrative strictures (not just structures) imposed not only on service users, but also on service providers, especially with respect to the definition and irreversibility of “discharge”.

Table 3. Actions identified as helpful by Participants

<table>
<thead>
<tr>
<th>Concrete Aspects of Service Provision that Participants Appreciate</th>
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<tbody>
<tr>
<td>• Convenient appointment times for service users</td>
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<tr>
<td>• Accessible services (i.e. near public transit, conveniently located)</td>
</tr>
<tr>
<td>• Logistical support for attending appointments (e.g. transit passes, home visits)</td>
</tr>
<tr>
<td>• A warm and welcoming clinic environment (e.g. clients’ artwork on the walls, music playing)</td>
</tr>
<tr>
<td>• Housing and employment support services</td>
</tr>
<tr>
<td>• Support for reintegration after a severe episode (e.g. job training, socialization opportunities)</td>
</tr>
<tr>
<td>• Medication use not insisted upon if the service user is adamantly opposed</td>
</tr>
<tr>
<td>• Access to therapy</td>
</tr>
<tr>
<td>• Scientific jargon explained</td>
</tr>
<tr>
<td>• When working in a team, discussions are happening with the service user, rather than simply in front of and about them.</td>
</tr>
<tr>
<td>• Early in the process of service provision, a description of how the service can be available even if a person leaves (e.g. keeping the file on records for several years) is provided</td>
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</tbody>
</table>
Participants’ recommendations align with those of previous qualitative studies on factors perceived by service users as increasing engagement in early intervention services. Two recent meta-syntheses of studies of engagement in early psychosis highlighted the following themes: the experiences of finding help; factors promoting engagement, including the providers’ abilities to establish an effective therapeutic relationship and to foster a sense of identity and hope; and caregivers’ roles in supporting engagement; and factors impacting ongoing engagement, such as distress, confusion, or stigma (Loughlin et al., 2019; Tindall et al., 2018b). Several early psychosis studies have identified the importance of collaborative relationships with providers that prioritize service users’ perspectives (Lester et al., 2011; Stewart, 2013; Tindall et al., 2018a), and the role of family and friends from outside the service (Lester et al., 2011; Tindall et al., 2018a). Beyond early intervention, a qualitative study in assertive community treatment similarly identified therapeutic alliance, the provision of practical support, acceptance and flexibility as key to engaging clients (George, Manuel, Gandy-Guedes, & Negatu, 2016). This, and another qualitative study (Killaspy et al., 2009), also identified characteristics of the assertive community treatment model such as small caseloads and a team approach as facilitating engagement, perhaps because they interviewed clinical staff/coordinators and not service users.

Our work extends these findings by highlighting how these elements are structures that can support agency to engage in well-being-oriented actions, including, but not limited to,
service use. While these studies are important for improving services, they conceptualize engagement as inseparable from service use, rather than as fluid and multidimensional. As Tindall and colleagues (2018b) described, recovery following psychosis is a process centred in individuals' autonomy and agency. Our study, unique of its kind, explores the role of agency and structures in individuals’ expressions of autonomy, or the lack of it, as they make decisions about their own treatment and recovery. Fostering individuals’ autonomy is essential as it can support shared decision-making in services (Tindall et al., 2018a), which is strongly recommended by clinical practice guidelines (National Collaborating Centre For Mental Health, 2013; Early Psychosis Guidelines Writing Group and EPPIC National Support Program, 2016).

This study has both limitations and strengths that bear consideration. Because we interviewed participants only once, our description of participants’ journeys through the service is based on retrospective accounts. We did not follow participants on their journey through treatment, as for example, Lester et al. (2011) did by interviewing service users six months and then a year after admission into an early psychosis service. Longitudinal qualitative design may be well-suited to yield insights into the evolution of service users’ thinking and experiences. Nonetheless, we gained the perspectives of participants who had a variety of relationships with the service, including, uniquely to our study (see Tindall et al., 2018b for review), those who had permanently ceased contact with the service. At the outset of this project, we sought to explore barriers to and facilitators of engagement in services, rather than how engagement itself may be variously conceptualized and what might influence these conceptualizations. This perspective influenced our interview guide and data collection. Despite this, our analysis revealed that service users embraced a broader definition of engagement which included steps taken towards recovery that were outside the strict purview of services. We made multiple attempts to contact
35 individuals who had permanently stopped using the service. Although only five individuals who had stopped using the service eventually participated (the majority of the 35 being lost to contact), their inclusion allowed us to explore the perspectives of a group that had never previously been included in a qualitative study of service engagement. Finally, recognizing that involving people with lived experience in the research process could greatly enhance the current literature on this topic, we invited feedback from service users and families in developing our interview guide as a first step in this direction.

A breadth of experiences was represented in our study and our sample was notably ethnically diverse. Many participants described understandings of health, service engagement, and engagement in wellbeing that were influenced by their cultural experiences, especially with respect to medication and supplements. Providing culturally competent care through tools such as the Cultural Formulation Interview can enhance engagement in early intervention services. This interview is underpinned by the idea that culture shapes perceptions of mental illness, treatment, and service engagement (Aggarwal, Pieh, Dixon, Guarnaccia, Alegria, & Lewis-Fernandez, 2016). Furthermore, agency and structures are also subject to a person’s culture and contextual background. Service users in other settings may have different perspectives than those of our participants. In places where healthcare is not public and free at the point of delivery, unlike in Canada, costs may be a barrier to accessing and continuing to engage in mental healthcare.

Our study uniquely contributes to the understanding of individuals’ engagement with early intervention services by exploring it through the lens of structure and agency. Using this lens, we unpacked engagement with services as an expression of the interaction between agency and structures. This analysis challenges a common, dualistic understanding of structures and
agency as being in opposition to one another. The boundaries between agency and structures are in fact fluid and subject to contextual and temporal changes. As described, participants’ choices and needs change over time, sometimes independently from structures (e.g., as a result of personal reflection). At the same time, structures (e.g., treatment team authority) can be experienced as supportive by some but as disempowering to others.

Our findings suggest that, far from being static and dichotomous, engagement is a dynamic and complex process that resists simple categorization and cannot be reduced to attendance to appointments, adherence to medication, or other easily measured indicators (which may be better called service utilization, not engagement). Participants' narratives reinforce the value of the philosophy of specialized early intervention and suggest that its true embodiment requires respect of service users' choices and personal recovery journeys; humility and flexibility on the part of service providers; and adjustment of services to individuals’ preferences and needs. Beyond early intervention services, recovery-oriented and person-centred care (Dixon et al., 2016) provide compelling frameworks for prioritizing autonomy and respect and for tailoring services and supports to individuals' unique histories, strengths and preferences.
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American Academy of Child & Adolescent Psychiatry, 45(8), 990-999.

https://doi.org/10.1097/01.chi.0000223015.29530.65


https://doi.org/10.1177/1049732312468337


https://doi.org/10.1080/17522439.2018.1502341


Table S1. Interview Guide

<table>
<thead>
<tr>
<th>TOPIC</th>
<th>QUESTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factors that influenced the interviewee’s decision to not continue/continue with treatment at [BLINDED]</td>
<td>• Why did you agree to do this interview?</td>
</tr>
<tr>
<td></td>
<td>• How do you view the services at [BLINDED]? <em>(relevant? Appropriate? Satisfied/dissatisfied?)</em></td>
</tr>
<tr>
<td></td>
<td>o What are some things you like about [BLINDED]?</td>
</tr>
<tr>
<td></td>
<td>o What are some things you do not like too much or dislike about [BLINDED]?</td>
</tr>
<tr>
<td></td>
<td>o Who do you see here?</td>
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<tr>
<td></td>
<td>▪ Groups?</td>
</tr>
<tr>
<td></td>
<td>▪ Research?</td>
</tr>
<tr>
<td>More generally, what they see as different factors that influence youths’ decisions about continuing or discontinuing treatment such as [BLINDED]</td>
<td>• What did you think of your team here at [BLINDED]?</td>
</tr>
<tr>
<td></td>
<td>o Does your team understand you?</td>
</tr>
<tr>
<td></td>
<td>➢ your needs, your perspectives, your worldview, your background</td>
</tr>
<tr>
<td></td>
<td>o Has this influenced on your thoughts about services offered at [BLINDED]?</td>
</tr>
<tr>
<td></td>
<td>• How do you feel about being followed at [BLINDED]/receiving services at [BLINDED]?</td>
</tr>
<tr>
<td></td>
<td>• How involved are you in your treatment at [BLINDED]?</td>
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<tr>
<td></td>
<td>o Has that level of involvement ever changed? If so, can you tell me about it (when happen, why, how, etc.)</td>
</tr>
<tr>
<td></td>
<td>• Who knows that you have been receiving mental health services or were referred for mental health services?</td>
</tr>
<tr>
<td></td>
<td>o Has your family been involved in your treatment at [BLINDED]?</td>
</tr>
<tr>
<td></td>
<td>▪ If so, how do they feel about you being followed at [BLINDED]?</td>
</tr>
<tr>
<td></td>
<td>▪ If so, in what ways have they helped/supported you? <em>(give examples if needed)</em></td>
</tr>
</tbody>
</table>
If so, what kind of contact did they have with your treatment team at [BLINDED]/Douglas?

- Have any people outside of your family been involved in your mental health treatment (e.g. meeting with doctors, knowing that you’re receiving services)?

- Were you offered medication at [BLINDED]?
  - What is your view of medication now? Has it changed in any way?
  - What was your family’s view of medication?

- Have you ever stopped or thought about stopping services at [BLINDED]?
  - Can you help me understand why you stopped/thought about stopping services at [BLINDED]
  - What do you think you might have gained by stopping receiving services at [BLINDED]?
    ➢ Were there any barriers that made it difficult for you to continue receiving services at [BLINDED]?
    ➢ Were there any practical issues that made it difficult for you to continue receiving services at [BLINDED] (e.g., transport difficulties, timing of clinic, etc.).
  - How were you feeling at the time?

  - Have you ever spoken to anyone stopping services at [BLINDED]?
  - If your family knew, how did they view your stopping of treatment?

  - (for clients who disengaged, then later reengaged) Can you tell me how it came to be that you starting receiving services again? What was that like?
Definition/views of “recovery/wellness” and its components and self-assessment of where the interviewee is with respect to their own definition of “being recovered/being well”.

The role of the family in “being well”

What is the meaning and value of work/school, family and relationships for you and how you see the quality of these in your life?

• Were any efforts made by anyone to try to encourage you to continue with follow-up/treatment at [BLINDED]?
  
  o If so, from whom? What did you think about these efforts?
  
  o What, if anything, has the treatment team done to encourage you to continue receiving treatment?
  
  o What, if anything, has your family done to encourage you to continue receiving treatment?
  
  o Is there anything else that has encouraged you to continue your treatment?

• What do you think you have gained by continuing to receive services at [BLINDED]/Douglas?

• How do you explain/understand the situation that brought you to [BLINDED]?
  
  o How did your family explain/understand the situation that brought you to [BLINDED]?

• What’s going well?

• What’s not going well?

• What does “being well” mean to you?
  
  o If needed, probe: What, to you, are some characteristics of being well? (e.g., sleeping well, eating well, going to gym, etc.)
  
  o Where are you with respect to your own definition of “being recovered/being well”?

• What are the things that currently help you feel well?

• What are some of the things that contribute to you NOT feeling well?

• What are some things that you wish were part of your life that would help you feel better?
<table>
<thead>
<tr>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Who offers you support/help when you need it?</td>
</tr>
<tr>
<td>o How do these people support/help you?</td>
</tr>
<tr>
<td>• Is your family involved in your life in general?</td>
</tr>
<tr>
<td>o If so, how?</td>
</tr>
<tr>
<td>o In what ways is your family’s involvement helpful?</td>
</tr>
<tr>
<td>o In what ways is your family’s involvement unhelpful?</td>
</tr>
<tr>
<td>o Are you satisfied with the type and amount of help/support you receive</td>
</tr>
<tr>
<td>from your family?</td>
</tr>
<tr>
<td>o Is the size or make-up of your family well-suited to providing you</td>
</tr>
<tr>
<td>support? (Are there enough people in your family to support you?)</td>
</tr>
<tr>
<td>• How important is [BLINDED] to your being well?</td>
</tr>
<tr>
<td>• Have you sought services elsewhere?</td>
</tr>
<tr>
<td>o If so, where?</td>
</tr>
<tr>
<td>o How does it compare?</td>
</tr>
<tr>
<td>• Other than mental health services, what are some alternative ways of</td>
</tr>
<tr>
<td>coping with mental health symptoms or problems?</td>
</tr>
<tr>
<td>o Have you used any of these alternative coping strategies?</td>
</tr>
<tr>
<td>o If so, can you tell me about these?</td>
</tr>
<tr>
<td>• What did you think of this interview?</td>
</tr>
</tbody>
</table>
Figure S1.

Model depicting conceptions of engagement

Not using the service, comfortable with that decision

Using the service, considering leaving

Using the service, but also other life resources for well-being

Sometimes using the service, sometimes leaving

Not using the service, uncomfortable with that decision

Valuing the service as main route to well-being

Use of the service
Figure S2.

Coding tree with a selection of codes for each subtheme.