Get on Board

Engaging Young People and their Families in Early Psychosis

Orygen YOUTH Health
Research Centre

EPPIC
Early Psychosis Prevention and Intervention Centre

The EPPIC National Support Program of Orygen Youth Health Research Centre has produced this document as part of its work to support the scaling up of the EPPIC model within headspace, the National Youth Mental Health Foundation, in Australia.

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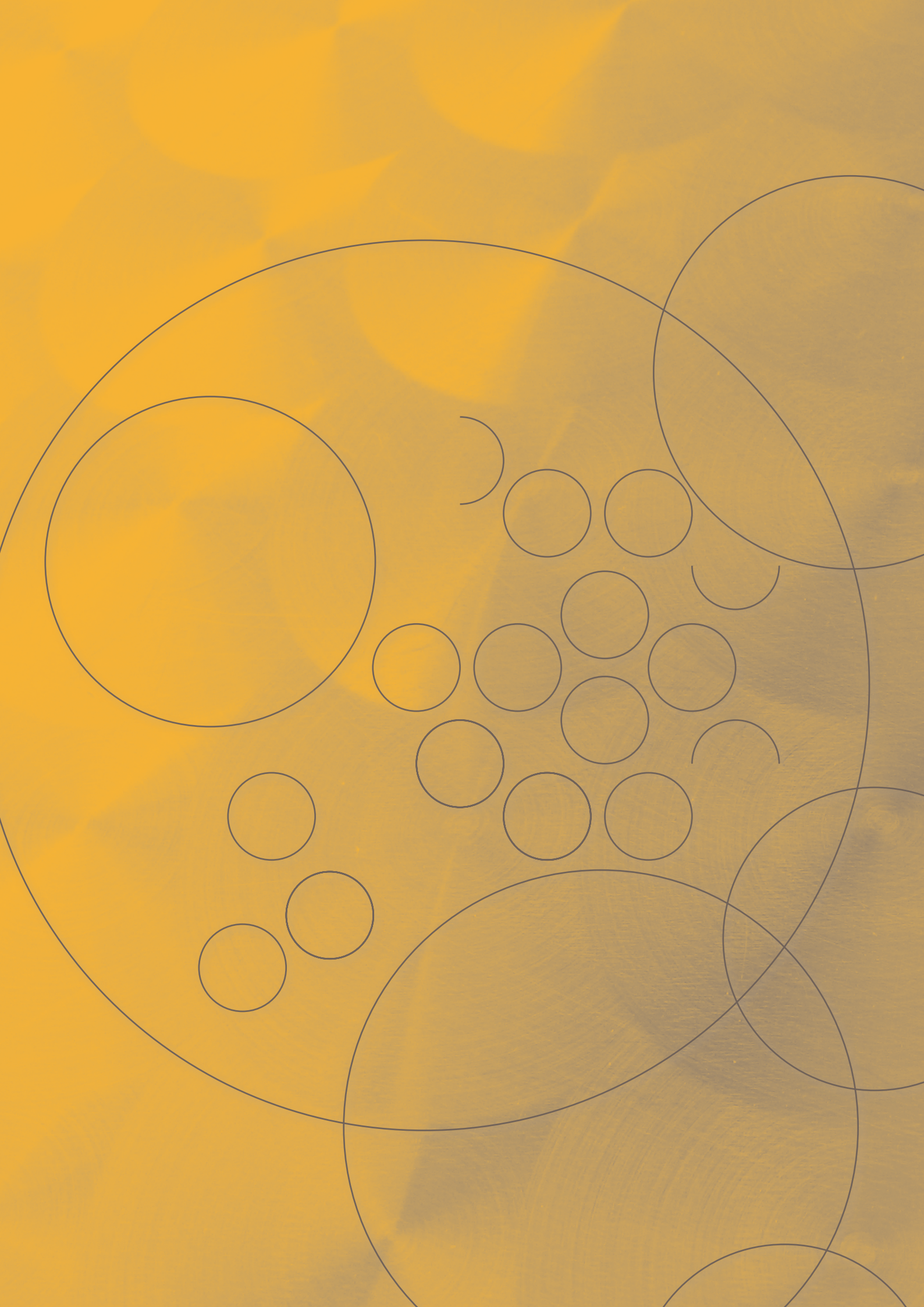


Contents

Introduction

The onset of psychosis in a young person can be a traumatic experience for them and their family. It represents a serious disruption to normal life, and a potential derailing of hopes and expectations for the young person's future.

However it is not only the symptoms of psychosis that contribute to this traumatic experience. Often the experience of the mental healthcare system – admission (voluntary or involuntary), assessment and treatment – can be just as traumatic as psychotic symptoms themselves. Given this, it is understandable that a young person may be reluctant to participate in such treatments or systems. The process of engaging young people, both with early psychosis services and with treatment, can therefore be challenging, but is also an essential part of clinical care.

'The core of all treatments, biological and psychosocial, lies in the clinical relationship which develops between patients and professionals.'

– McGlashan et al. (1990)[1]

'Techniques per se are barren; … what counts more heavily is the nature of the interpersonal context in which they are embedded.'

– Strupp (1995)[2]

About this manual

Get on board: engaging young people and their families in early psychosis is a manual designed to help early psychosis services and clinicians maximise the engagement of young people and their families within a service. It is one of a series of manuals produced as part of the EPPIC National Support Program (ENSP) to help with implementation of the Early Psychosis Prevention and Intervention Centre (EPPIC) Model in early psychosis services. The EPPIC Model is a model of specialised early intervention in psychosis developed by Orygen Youth Health in Melbourne, which has over 20 years' clinical experience in planning, implementing and delivering early psychosis interventions to young people and their families. Engagement of young people and families or other supports is one of the 16 core components that make up the EPPIC Model.

There is considerable evidence that engagement and the formation of a strong therapeutic alliance are critical in the outcome of psychological interventions.[3] However, for a number of reasons this can be challenging to achieve and maintain in work with young people with early psychosis.

This manual provides an overview of approaches to engagement of young people and families in early psychosis. It combines theoretical models of therapeutic engagement with clinical experience derived from the EPPIC program. It offers evidence-based, practical advice for service providers and clinicians to enhance the engagement of young people and their families with an early psychosis service.

How to use this manual

This manual has been developed as a resource for service providers and all clinicians working in an early psychosis service. The material presented here should be valuable to clinicians new to working with young people in early psychosis.

This manual provides an overview of the definition and importance of engagement in therapeutic work in early psychosis, examines the numerous challenges to this, and suggests a number of methods that can assist in engaging young people and developing better therapeutic relationships. Case scenarios are presented throughout to illustrate real-world experiences of engaging young people. Clinicians are encouraged to consider the young people they are currently working with, or have worked with in the past, when reading this manual and to reflect on what they could do to promote engagement and maintain strong therapeutic relationships with this population. It is also advised that clinicians seek supervision when undertaking this challenging but highly rewarding work.

Service providers should read this manual in conjunction with the *EPPIC Model and Service Implementation Guide* for more detail on how to facilitate engagement in an early psychosis service.

It should be noted that for the purposes of this manual, the term 'early psychosis' encompasses both young people who have experienced a first episode of psychosis and those who are at ultra high risk of developing psychosis (UHR). However, as most research and evidence in early psychosis deals specifically with first episode psychosis (FEP), many of the interventions described will focus on FEP. It is expected that issues and interventions in FEP do, however, apply to young people identified as UHR. Further information specific to the UHR population can be found in the manual *A stitch in time: interventions for young people at ultra high risk of psychosis.*

Engagement in the context of early psychosis

Adolescence, the onset of psychosis and the rationale for early intervention

Psychotic disorders are most likely to emerge in late adolescence and early adulthood, a developmental stage often associated with considerable turmoil.[4] Specifically, adolescence often involves significant cognitive, neurological, emotional, social, and physical changes (reviewed in Macneil et al. 2009[5]).

Developing any significant health disorder, and a mental health disorder in particular, during early adulthood can be problematic, due to its potential impact on developmental milestones. While adolescence is often defined as a stage in which people increase their independence and autonomy, developing a psychotic disorder clearly has the potential to interrupt and delay this trajectory. Indeed Jackson et al. (1999) reported, 'the effects (of first episode psychosis) ... on the self and development may be potentially cataclysmic, causing derailment, truncation, deflection or paralysis of the person's developmental trajectory'.[6]

The National Advisory Council on Mental Health's Early Psychosis Feasibility Study Report (2011) also described the potential impact of psychosis. It stated, 'Left unrecognised, untreated, or poorly treated, psychotic illnesses during this critical developmental period not only lead to considerable personal and family distress and increased severity of illness, but also contribute to poor academic performance, premature exit from school and higher education, unemployment, sustained disability and premature death'.[7] Research has therefore emphasised the importance of early intervention in psychosis, with Birchwood (1998) describing a 'critical period' early in the course of psychosis (see Box 1) that is 'particularly malleable to intervention, with major implications for secondary prevention'.[8]

As a result of such research, the past 20 years has seen an international explosion of services providing specialised early intervention for psychosis. This has largely been well received, with the UK's Schizophrenia Commission (2012) stating 'Early Intervention is crucial to improving outcomes. The Commission's view is that Early Intervention in Psychosis has been the most positive development in mental health services since the beginning of community care'.[9]

BOX 1 THE CRITICAL PERIOD HYPOTHESIS

The critical period hypothesis proposes that symptomatic and psychosocial deterioration occurs rapidly in the early years of psychosis and plateaus thereafter.[10] The period of rapid deterioration is a 'critical' period during which the disorder is more responsive to intervention.[11] Therefore, targeted intervention, especially within the first 2–3 and even up to 5 years following a first episode of psychosis is considered crucial in the prevention of long-term symptomatic and psychosocial disability.[8,11]

While there may be a number of challenges to engaging young people who are experiencing early psychosis, there are also significant opportunities for biopsychosocial interventions with young people early in the course of psychosis. There is also significant evidence that intervening early with psychotic disorders not only is ethically or morally correct, but also has the potential to achieve the best symptomatic outcomes and limit the impact of psychosis on a person's long-term functioning. International evidence has indicated the effectiveness of specialist early psychosis services to improve symptomatic and functional outcomes, [12-15] lower inpatient admission levels [16] and significantly lower levels of drop out,[17] at a lower cost than treatment as usual.[18,19]

What is 'engagement'?

There are a number of terms that are commonly used to describe the concept of client or patient engagement with therapy. For the purposes of this manual, the term 'engagement' will be used as a broad term that includes engagement with treatment (medical, psychosocial or other interventions), with the early psychosis service and with individual members of the treating team. It applies equally to young people and their families or other supports. The term 'therapeutic relationship' (also known as the therapeutic or treatment 'alliance') specifically refers to engagement at an individual level between a young person (or their family) and a treating clinician. It is also important to note that 'family' may encompass a range of relationships, not only the young person's immediate family. Family may include for example, extended family, partners or significant others, children, close friends, housemates and other guardians or carers. Note that it does not include formal supports of the young person, such as Department of Human Services case support workers.

Engagement has long been recognised as a crucial element in developing and maintaining successful therapeutic interventions.[20] Understanding and managing the concept of transference (in which the patient directs particular thoughts and emotions on to the therapist) was described by Freud (1912) as being critical to the process and outcome of psychodynamic therapy.[21] Freud and others later expanded this concept, and described the concept of countertransference, or the way in which the clinician responds to the client, based on his or her own previous relationships.[22] More recent research has focused on the importance of 'common' or 'non-specific' therapeutic factors which impact on outcome irrespective of the therapeutic model used by the clinician.[23]

Engagement can be seen as the dynamic process in which a therapeutic relationship is built. Although engagement has traditionally been viewed as relating solely to the beginning of the therapeutic alliance, it can more accurately be seen as an ongoing process.

Psychological theories of engagement

Historically, the concepts of engagement and the therapeutic relationship have gone through a number of evolutions and revisions. Ferenczi (1919), elaborating on Freud's theories, wrote on the importance of sharing countertransference with patients and on the concept of the emotionally reactive therapist (as opposed to Freud's concept of the therapist as 'impenetrable' or a 'mirror').[24]

Carl Rogers (1951) can be seen as having a significant role in the development of the concept of engagement and the therapeutic relationship, emphasising the importance of empathy, congruence and unconditional positive regard.[25] These concepts are consistently reported in the therapeutic alliance literature and form the basis for much of the related research questionnaires.

In 1956, Zetzel developed the concept of the therapeutic alliance and described this as relating to realistic and stable aspects of the therapeutic relationship.[26] This was in contrast to Freud's concepts of transference and countertransference as potentially being unconscious and representative of other relationships in the person's life rather than of the actual relationship between client and therapist.

Luborsky (1976), utilising empirical research methods, identified the concept that the therapeutic alliance incorporates two different parts. The first, type 1 alliance, refers to a client's experience of the therapist as 'supportive and helpful'. The second, type 2 alliance, describes 'a feeling of shared responsibility' and sense of working together.[27]

Butler and Strupp (1986) also identified that outcomes of psychosocial interventions are a result of two separate aspects of therapy. Firstly is that of 'specific' therapeutic factors, or particular techniques inherent to the therapy. The second aspect is that of elements of the therapeutic relationship that are 'non-specific' to a particular psychological interventions model, instead relating to factors such as 'warmth, empathy, acceptance, respect, and the like …'[23]

Barrett-Lennard (1962), writing on elements relating to change in therapy, suggested that '… the client's experience of his therapist's response is the primary locus of therapeutic influence in their relationship'.[28] Five main aspects of 'therapist response variables' were defined by Barrett-Lennard, namely: empathic understanding (or awareness of the other person), level of regard, the extent to which this regard is comprised of positive or negative feelings towards the other person, congruence (or degree of integration between client and clinician) and willingness to be known (the degree to which experiences and perceptions are shared).[28]

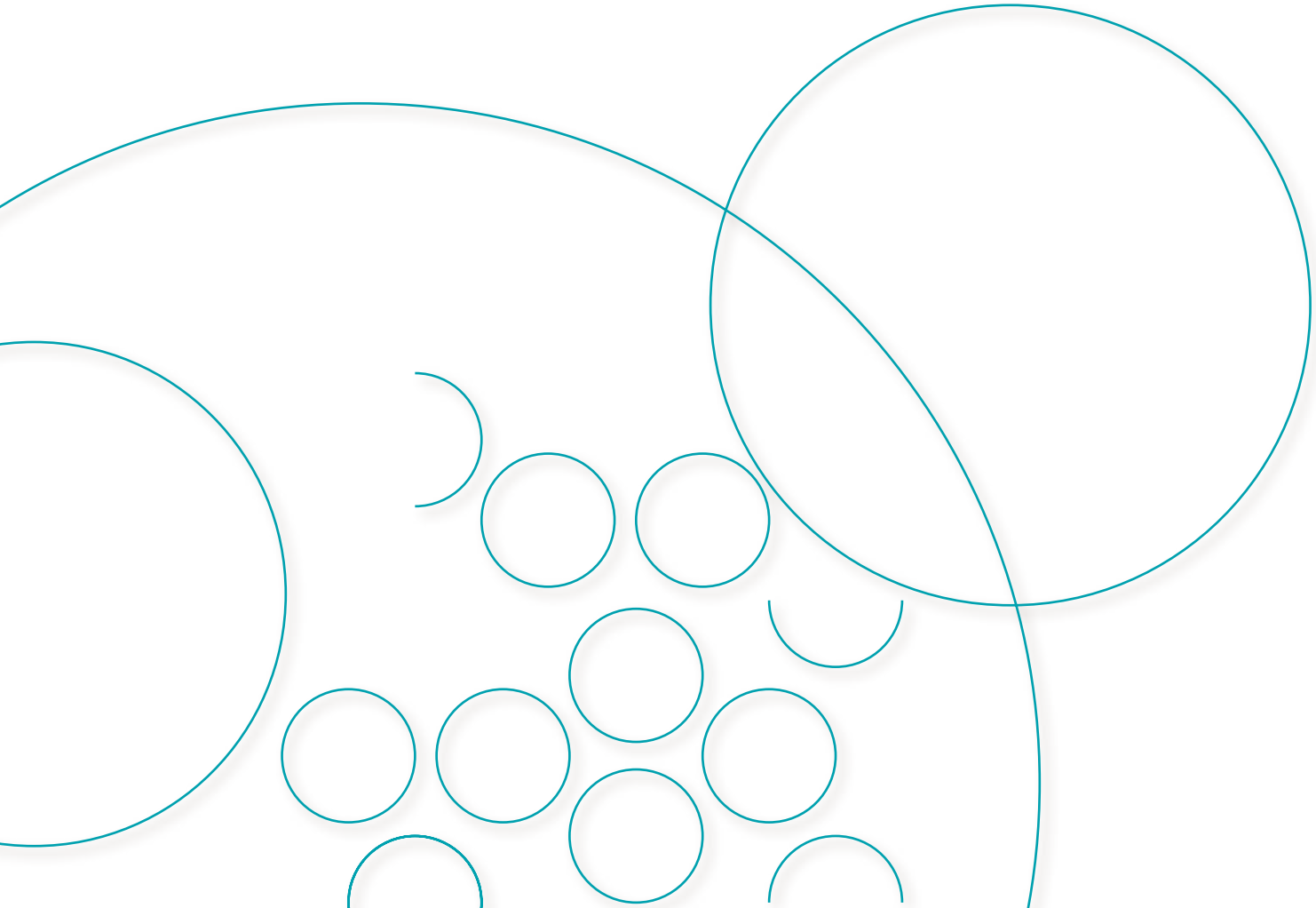
Bordin's (1976) definition of the therapeutic alliance is one of the most widely accepted, and is considered 'pan-diagnostic', or applicable regardless of the individual therapist's preferred model.[29] It focuses on three key related concepts:

- the *bond* between patient and clinician, which includes 'common commitment and shared understanding in the activity' and 'mutual trust acceptance and confidence'[30]
- the patient's willingness to undertake *tasks*, or activities agreed upon by both client and clinician to create change, and
- the shared *goals* for intervention.

Bordin's definition remains a useful model that is used in much of the literature examining components of the therapeutic relationship. Furthermore, aspects of Bordin's model are evident in measures of therapeutic engagement, with bonds, tasks and goals being valuable concepts for clinicians to reflect on in their engagement of young people experiencing early psychosis.

REFLECTIVE EXERCISE

Think about a young person you are currently working with. What are the BONDS, TASKS and GOALS that you can identify?



Rationale for engagement in early psychosis treatment

The impact of engagement on clinical outcomes

There are many evidence-based treatments for psychosis, but with up to one-third of people with serious mental health difficulties disengaging from care,[31] many people will not be adequately treated.

Rates of 'disengagement' from mental health services have been evaluated in the literature, focusing on both failure to attend follow-up appointments after a hospitalisation and 'drop out' rates from ongoing care.[31] An average of 58% of people fail to make a first outpatient appointment after psychiatric hospitalisation,[31] and approximately 30% of patients disengage from services over the long term.[32] Young people in particular appear to be more likely to disengage from services or not attend appointments.[32]

Rates of non-adherence to medical treatment in people with schizophrenia have been shown to be as high as 43–74%, depending on which medication they are prescribed.[33] Reasons for this include adverse effects of the medication, lack of client involvement in treatment decisions and their not being provided with adequate information about their disorder, the service, their rights or the potential benefits and side-effects of medication. On the other hand, a positive therapeutic relationship and support of family or significant others have been shown to improve adherence.[33]

Clearly, if a young person is not engaged with a service and treatment, their outcomes will not be optimal. Disengagement from service can lead to exacerbation of symptoms, relapse and hospitalisation, homelessness, violence against others and suicide.[31] Various interventions that successfully increase engagement (to be discussed in more detail later in this manual) have been shown to reduce hospital admissions, reduce homelessness and improve some aspects of quality of life.[31] Studies that look at interventions in young people with early psychosis have shown that improved engagement can lead to better treatment adherence[31] and improved outcomes regarding hostility risk, well-being and functioning.[34]

Disengagement from service can lead to exacerbation of symptoms, relapse and hospitalisation, homelessness, violence against others and suicide.

Engaging people experiencing psychosis early on in treatment is also critical. *The Australian Clinical Guidelines for Early Psychosis* (2010) emphasise the importance of engaging young people from their initial assessment with a service, saying that first contact with a service should 'serv[e] as a solid foundation for ongoing rapport'.[35] Frank & Gunderson (1990) found that people who formed good therapeutic alliances within the first 6 months of involvement with services were more likely to remain in treatment, be reliably taking medication, and achieve better outcomes at 2 years.[36] If a strong therapeutic relationship was not formed within the first 6 months of treatment, it was unlikely to form after that – and clients subsequently more likely to drop out of treatment.[36] Clearly, this has significant implication for both functional and symptomatic outcomes, relating back to Birchwood's 'critical period' hypothesis (page 7).

Not only is engagement crucial to better treatment adherence, it is also important for other health outcomes. People taking antipsychotic medication will experience a range of physical side effects that they should be monitored for. If young people feel engaged with a service, they are more likely to attend appointments, be open to family involvement, take medication and discuss side-effects with their treating team. Reducing the impact of side-effects will in turn have a positive effect on the young person's engagement with treatment and adherence.[33]

Services therefore need to ensure they have strategies in place to engage young people, not just immediately following a first presentation for psychosis – although this is crucial – but also throughout their episode of care with the service.

The therapeutic relationship

The therapeutic relationship, or alliance, has been the subject of much interest regarding its effect on treatment outcomes. It is of particular interest as a means of better engaging people with their treatment – not just in psychological interventions, but also in medical treatments for a range of diseases.[5]

A large National Institute of Mental Health study on depression concluded, 'Therapeutic alliance was found to have a significant effect on clinical outcome for both psychotherapies and for active and placebo pharmacotherapy'.[37] Similarly, Blatt and colleagues (1996), in their research on characteristics of effective therapists reported, 'therapeutic gain … is significantly influenced by interpersonal dimensions of the treatment process – by patient and therapist capacity to establish a therapeutic relationship'.[38] There is now evidence from over 70 research studies that the therapeutic alliance is the strongest predictor of outcome in psychological therapies.[3]

Research has also shown that new patients with severe mental health problems had lower rates of rehospitalisation if they described a good therapeutic relationship with their clinicians[39] and that people with a diagnosis of schizophrenia who report a good therapeutic alliance with their health professionals have lower levels of drop-out from treatment, better medication adherence, and better functional outcomes.[36]

Ackerman and Hilsenroth (2003) describe a number of key components associated with a positive therapeutic alliance, many relating to the client-centred psychotherapy literature already described.[25,40] These include the clinician's ability to:

- express accurate empathy
- be clear in their expression
- connect with the person
- work collaboratively, and
- be respectful, warm, flexible, genuine, trustworthy, friendly, interested, and alert.

Furthermore, they reported that some therapeutic techniques can impact positively on outcome, regardless of the clinician's theoretical model, including:

- accurate interpretation
- exploration
- depth
- identifying past successes
- being active in therapy, and
- respecting and acknowledging the client's experience.

Rhodes and Jakes (2009) acknowledge that while clinicians may be concerned about completing a full and accurate assessment of people experiencing psychotic disorders, this is perhaps secondary to engagement and developing a good therapeutic relationship.[41] They state:

> In the case of clients with psychosis, initially their assessment of us is much more important than our assessment of them … The overriding question [of clients] will be 'Will it be helpful or unhelpful to attend these sessions?'[41]

As Davidson and Chan (2014) recently noted, 'There is a long-standing, consistent, and robust evidence base – dating back to 1936 … – suggesting that a set of common factors is involved in practically all forms of psychotherapy … and that these factors account for more of the variance in the effectiveness and outcomes of these interventions than any of the more technical, theory-based or targeted components.'[42]

Measuring engagement

Although there has been some debate over the definition and measurement of engagement and the therapeutic relationship,[43] there are a number of widely-available questionnaires, used mostly in clinical trials, that appear to have reasonable validity for measuring engagement. While it is not necessarily recommended that clinicians regularly use these tools in their work with young people, it can be useful to be familiar with the parameters they use to measure successful engagement and consider how these factors may be inhibiting engagement.

One of these is the Working Alliance Inventory, a 12-item, seven-point questionnaire to be completed both by the client and clinician, relating to Bordin's three key themes of shared goals, tasks and bonds.[29,44]

Another widely used, and more expansive measure is the Barrett-Lennard relationship inventory,[28] a 92-item questionnaire measuring 'empathic understanding', 'level of regard', 'unconditionality of regard', 'willingness to be known' and 'congruence'.[28]

The Penn Helping Alliance Questionnaire[27,45] is a 19-item, client rated scale that has been found to have high internal consistency and inter-rater reliability.[43,45] It asks clients to rate on a six-point scale from 'strongly disagree, to 'strongly agree' perceived therapist experience, whether the client feels that the therapist understands them, whether the work that they are undertaking is meaningful, and whether the client believes that the therapist likes them.[45]

Similar themes are assessed in the California Psychotherapeutic Alliance Scale (CALPAS).[46] The CALPAS is a 24-item, self-report scale measuring clients, and clinicians, ratings of patient commitment (motivation and confidence in therapy), working capacity (disclosing information), therapist understanding and involvement, and working strategy consensus (agreement on goals and process of therapy), on a seven-point Likert scale.[46]

However, clinicians should be practical about 'measuring' engagement. If a young person isn't particularly forthcoming, if there is no flow or back-and-forth or active conversations between them and the clinician, or if they don't show up, don't take medication, don't return calls, then it is likely something is amiss. The clinician may then need to consider what is causing this poor engagement and how it can be improved.

Barriers to engagement

‘Why should I bother?’ Barriers to engagement from a young person’s perspective

Engaging young people in therapy, and adolescents specifically, is widely recognised as a potentially challenging task.[47,48] As Yalom (2003) notes of challenges to engagement in psychological therapy generally, ‘Some fear intimacy because they believe there is something basically unacceptable about them, something repugnant and unforgivable’.[49] Given this, the act of revealing oneself fully to another and still being accepted may be the major vehicle of therapeutic help. Others may avoid intimacy because of fears of exploitation, colonisation, or abandonment.

For young people, the obstacles to engagement can be numerous, and it is understandable that a young person may be hesitant about engaging with a service. Young people may not be help-seeking and could arrive at mental health services due to having been brought by concerned family, or via the police or hospital emergency departments. There are a number of issues relating to the individual (cognitive, emotional, behavioural), mental health services (availability and approachability), the disorder the young person is experiencing (neurobiological issues, delusions, hallucinations, and disorganisation), and practical issues (such as finances, housing or access to transport) that make engaging and work with these young people challenging in addition to being highly rewarding. These challenges are described in more detail below.

Stage of development

The period of adolescence and early adulthood is one of the healthiest phases of human development, with a number of young people potentially having had no contact with health services since childhood. Furthermore, adolescence, while paradoxically at times being a period of self-doubt and increased anxiety, can be also be a time of increased confidence and risk-taking, sometimes characterised as the ‘immortality of youth’. Therefore, the idea of being ill and attending a health service (and a mental health service in particular) may be challenging to a young person. Mental health continues to have significant stigma, particularly in young people. This can stem from past experiences, negative portrayals of disorders such as psychosis in the media and the peer group. The concept of being ‘different’, and specifically of having a psychiatric diagnosis, can be particularly distressing for young people, and may understandably lead to avoidance of services.

> 'I didn't understand why these people kept coming over to my house to talk to me about how I was feeling … It was really weird. But like my case manager said, of course it felt weird – I can't even remember the last time I saw my GP.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Critically, a major developmental goal of adolescence is that of increasing independence and self-directedness, and separation from authority figures. In addition, young people with emerging mental health difficulties may often have had contact with adults that is punitive or directive (for example with police, child protection services or at school). Clearly, therefore, the concept of being 'reliant' or dependent at this time on anyone, particularly mental health services, while peers are becoming significantly less involved with adults, could be seen as counterintuitive and challenging for a young person.

Disorder-related factors

The challenges of engaging young people generally in mental health treatment can be further complicated when a young person is experiencing an episode of psychosis, with research showing that up to 80% of people drop out of treatment in their first year of care.[50] There are a number of reasons for this. Firstly, and perhaps most obviously, are issues related to psychotic disorders themselves, which may include lack of insight, disorganisation, paranoia and grandiosity. Specifically, paranoia may result in suspiciousness towards services and unfamiliar people, and to related social avoidance. Grandiosity and poor insight are also likely to result in avoidance of services, as the young person may not agree that they are experiencing a mental health disorder.

> 'In the hospital, the doctors and nurses are asking you about how you feel … How am I supposed to tell them, when I have no clue what is going on? I was freaking out, and scared they wanted to kill me.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Furthermore, there are significant side-effects associated with antipsychotic medications, including weight gain, raised cholesterol, heart difficulties, and loss of libido,[51] all of which are likely to have an increased impact on young people. Recent evidence has also suggested that antipsychotic medication may result in amotivation and apathy even in people without psychotic disorders.[52] Clearly these are issues that are not only likely to impact on a young person's ability to attend services, but also likely to have a significant impact on young people's trust of their clinician and therefore of their engagement. See also Box 2 for the implications of trauma for engagement.

Illicit substance use may also be an additional complicating factor, with high rates of cannabis or excessive alcohol use being reported in FEP cohorts.[53] This can have a clear impact on finances, organisational skills, and the ability to cognitively and emotionally engage with services.

BOX 2 TRAUMA AND PSYCHOSIS: IMPLICATIONS FOR ENGAGEMENT

Trauma has a particular significance in people experiencing psychosis, with estimates of post-traumatic stress disorder (PTSD) rates in this group ranging from 11–67%.[54] There appear to be three main reasons for this.

- Firstly, young people who develop psychosis are more likely to have experienced trauma prior to the onset of their symptoms.[55] This may include experience of sexual or physical abuse, neglect or escaping from violence (e.g. young people who are refugees).
- Secondly, the experience of psychotic symptoms can itself be traumatic and the concept of attending regular meetings to discuss this with a case manager or doctor could be understandably distressing.
- Thirdly, pathways to care, engagement with services and experience of the mental health system can in itself be traumatic, particularly if this involves involuntary treatment, police involvement, hospitalisation or chemical or physical restraint. Qualitative research indicates that people often initially have negative experiences in their first contact with mental health services, citing 'lack of compassion', 'being locked up', and 'lack of belief' by health care professionals as being particularly distressing.[50]

It is important that clinicians consider these sources of trauma and how they might affect engagement or inform a clinician's approach to engagement. They should also note the third point regarding the potential iatrogenic (the concept that treatment itself can cause further harm) effects of pathways to care and initial contact, and the need to monitor and manage these effects.

When engaging young people who have experienced trauma, clinicians should consider:

- when and how to discuss the issue of trauma with the young person (e.g. by asking them if they have had experiences that cause flashbacks or nightmares)
- what can help young people to feel like they have more control in a situation (e.g. by becoming involved in peer support or giving feedback to the service, either through the case manager or by a formal complaint process).

It is important to note that if a young person is experiencing PTSD symptoms (whether related to an admission, psychotic experiences or previous trauma), any interventions must be paced in a way that feels safe and containing for the young person to avoid further traumatising them through treatment. It is also important for clinicians to consult with senior team members and seek supervision so that they can best address the issue.

Sociocultural factors

As Kleinman et al. (1978) note, 'Illness is culturally shaped in the sense that how we perceive, experience and cope with disease is based on our explanations of sickness ... They have been shown to influence our expectations and perceptions of symptoms, the way we attach particular sickness labels to them and the valuations and responses that flow from these labels'.[56]

There can be cultural and gender issues across a number of populations that can impact on likelihood of engagement. Andary et al. (2003) highlight some cultural difficulties inherent in assessment and diagnosis of mental health problems.[57] These include passivity, belief in spirits, avoidance of eye contact, and over-familiarity with, or physical contact with the clinician, and concepts of psychopathology that are '... rooted in Western diagnostic systems'.[57] While shame regarding mental health problems is common across a number of cultures, some hold this more strongly than others,[57] providing additional challenges to engagement. Additionally, some other cultural groups who have faced persecution may have difficulty in presenting to mental health services as because of past experiences of 'services' as punitive or damaging, rather than supportive.

Even in cultures where spiritual beliefs are not particularly dominant there can still be stigma and subcultures that look negatively upon help-seeking, having mental health problems, or talking about emotions. For example, Australia has the concept of the 'battler', and Britain that of the 'stiff upper lip', which may result in men in particular avoiding mental health services.[58]

Issues of shame and stigma can be particularly important for young people experiencing mental health difficulties. Adolescence and early adulthood are associated with a growth of the importance in the peer group and a move away from family of origin. Many young people describe experiencing significant difficulty in approaching health professionals, choosing instead to confide in peers.[59]

> 'My family were so worried about me, about the white walls, that I might get strapped up ... There wasn't an interpreter there to explain to my parents why I was in hospital. The doctor tried to speak with them in Mandarin, but his Mandarin wasn't that good. They were confused and worried.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Barriers to engagement for the family

While we recognise that some young people have a poor relationship with family members and that families can also impact negatively on a young person's mental health,[60-62] families can also be very valuable treatment allies. Specifically, families are able not only to inform the treating team of any concerns about the young person, and of any fluctuations in their mental state, but can also assist engagement in practical terms, particularly early in treatment, through transport to appointments and encouragement to attend appointments.

Ideally, families should be engaged from the initial point of contact with an early psychosis service. They should be acknowledged, where appropriate, as having a role in the treating team, and can inform the young person's assessment by providing crucial background or family information, timelines about onset of illness, baseline information about pre-morbid functioning and symptoms and insight into risk. Making sure families are empowered by including them in the assessment process and treatment approaches can help to engage them.

Throughout a young person's episode of early psychosis care, families can also support the young person to adhere to prescribed medication and assist with reinforcing psychoeducation about illness, treatment and recovery. As Conus et al. (2010) note, '... it has now become evident that family support is a critical element of success in treatment of FEP. In order to be able to play this role, families should however receive support and information regarding the illness, and the specificities of its early phase'.[63]

However, in the same way that young people may feel shame and stigma due to experiencing mental health difficulties, families are likely to experience similar challenges, with Ostman and Kjellin (2002) describing 'stigma by association'.[64] These researchers found that 83% of family members described some distress associated with stigma of being related to a person with a mental health problem. Clearly, therefore, a wish to avoid such distress by family members, by having little contact with mental health services, is understandable. Some family members may also be in denial that their loved one is unwell, which can also lead to avoidance and limited engagement.

Similarly, there is a considerable body of literature regarding the sense of 'loss' felt by family members where a young person has experienced mental health difficulties.[65] Miklowitz and Goldstein (1997) describe the onset of a major mental health disorder as 'a disaster' for the family system, with it again being understandable that engaging with an early psychosis service could be difficult.[66] While this is not necessarily the case for all families, it is important to be mindful of the potential impact of a mental health diagnosis and to be sensitive to families as they come to terms with this.

> 'You don't realise until it happens that you have had all these dreams about what your daughter is going to do with her life, what kind of a person she is going to be ... and then she gets unwell, and you don't know what to think...'
>
> – Family member,
> EPPIC, Orygen Youth Health Clinical Program

Consideration should also be given to how individual family members are experiencing engagement with the early psychosis service, and their understanding of what has happened to the young person. Family members may each have a different level of understanding or be 'processing the news' in different ways. To assume all members of the family are at the same point of this process and that their explanatory models are the same may cause distress or conflict within the family and will not be conducive to effective engagement or family work.

CASE SCENARIO **ANNA AND JUNE**

Anna is 15 and has been receiving treatment from an early psychosis service since experiencing a first episode of psychosis during end-of-year exams. In a conversation with Anna's case manager, Anna's mother, June, confides that at the same time that her daughter commenced treatment for the psychotic episode, a friend's daughter was diagnosed with cancer. She says all their mutual friends and supports were active in supporting this friend and her daughter, visiting regularly and providing meals and other help. June expresses grief that although she felt sad about her friend's daughter's diagnosis, her own daughter was 'shunned' by her social supports. She feels resentful that the same activation of resources didn't occur for her own daughter's illness.

Acknowledging that there is still a lot of stigma attached to mental illness in the community, Anna's case manager suggests that June gets in touch with one of the service's family peer support workers. That way she can receive support from someone who has had similar experiences to hers, and also not feel so alone in having to cope.

A further issue that clinicians should be aware of as a potential challenge to engagement of families is that members may previously have had contact with mental health services themselves. Research has found that there is an increased likelihood of developing a psychotic episode in families where a first-degree relative also has the disorder.[67] If family members have not had a positive experience of treatment, for example experiencing unpleasant medication side-effects, distressing inpatient admissions, involuntary treatment orders, or poor outcome, this is likely to impact significantly on the engagement process.

Conversely, families who have no experience of mental health services may have certain expectations of an early psychosis service that are not met, which may affect engagement.

For more information on working with families in early psychosis, please see the ENSP manual *In this together: working with families in early psychosis.*

Barriers at the clinician level

It is important to note that, like young people and their families, clinicians bring their own histories, experiences and biases into therapeutic relationships. It is likely that this will impact on who they are likely to engage well with, and who they are not. Schoenewolf (1993) suggests that '... therapists need to focus less on analyzing the patient's resistance and more on analyzing their own'.[68] Foreman and Marmar (1985) advise similar introspection by clinicians, suggesting that they should look at their own roles if there are difficulties in engagement, 'make appropriate interpretations, and avoid the invitation to cajole, advise, direct, seduce, or attack the patient'.[69] It is important to recognise that engagement involves a relationship between two or more people, and will be influenced by all.

'It took some time to work it out through reflection and supervision, but I realised that what was getting in the way of my engagement with a particular young person was that we were from similar cultural and family backgrounds. You'd think this would be useful in engaging with him and his family, but I think it actually was the opposite! Using supervision really helped me process this and be mindful of whose "stuff" was whose.'

– Clinician,
EPPIC, Orygen Youth Health Clinical Program

In addition, clinicians need to be mindful of factors pertaining to themselves (burnout, personal issues, fatigue) and practical factors (seeing young people 5 minutes before the shift ends, time constraints) that may impact on engagement and interactions with young people and families.

REFLECTIVE EXERCISE

What are your beliefs about young people with psychosis?

What 'mottos' or beliefs have been passed down in your family of origin about human nature, success, responsibility, and our relationships with other people?

How do these affect who you are able to engage easily and who you are not?

Consider a young person that you are currently working with, or have worked with in the past, with whom you were not able to develop good engagement and maintain a positive therapeutic relationship

- What were the characteristics of the young person?
- What difficulties emerged in the development of/maintenance of the relationship?
- Where did responsibility sit for these difficulties?
- Could you have done anything differently?

Barriers at the service level

There are a number of factors that can affect engagement from the initial point of a young person's contact with an early psychosis service. These include:

- the nature of the young person's referral to the service (e.g. self-referred, or by family, hospital or police)
- the setting of the initial contact (e.g. police cell, over-crowded emergency department, school, general practitioner's office)
- the young person's pathway to care: how they found the appropriate service
- whether the young person was admitted to an adult in-patient unit (meaning they may have mixed with people who have more chronic illness or been exposed to iatrogenic factors, e.g. have been over-medicated)
- Side-effects of any initial medication given for symptoms (e.g. sedation)
- the workload of staff in the service (leading to hurried assessment process)
- the involvement of multiple service providers
- lengthy waiting periods
- disorganised delivery of care.

Ensuring that services are 'youth friendly' is a significant element of early psychosis interventions (see Box 3 on page 41). Traditionally, health services have not had this focus, tending to appear austere and clinical. Young people often describe experiencing long delays in unwelcoming waiting rooms with decade-old copies of irrelevant or uninteresting magazines;[59] these are preconceptions that services may need to work hard to overcome.

In addition to the interpersonal and sociocultural factors mentioned in previous sections, engagement can also be impacted upon by practical factors relating to service provision. The location of a service, ease of accessibility, transport issues, cost of attending, and the degree to which the service appears 'youth-friendly' can have significant implications for engagement.

> 'I found that travelling was often a burden … the distance coming here [to the early psychosis service] meant that I sometimes missed appointments.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

As Cummings and Kang (2012) note, 'Accessibility means more than just being able to get there. A "youth friendly" health service must be accessible geographically, physically, culturally and in all its procedures including financial and administrative arrangements'.

CASE STUDY **AHMET**

Ahmet is an 18-year-old Turkish-Australian man living with his mother and three younger siblings. The family moved to Australia when Ahmet was 12. Ahmet and his mother identify strongly with the Islamic faith, and since the death of his father, Ahmet has seen himself as, and has taken on the role of, the 'man of the house'.

Ahmet was initially referred to mental health services via the police, having been capsicum-sprayed, handcuffed, involuntarily admitted to an adult psychiatric unit and commenced on depot medication. He had reportedly been behaving bizarrely and aggressively during the previous weeks, and was apprehended by the police in the city late at night, having been shouting that 'jinns' were trying to harm him.

Although Ahmet appears to have had some friends with whom he smoked cannabis, none visited him while he was in hospital. He has not been able to return to his electrician apprenticeship since the onset of his psychotic symptoms, and he has not claimed government unemployment benefit payments. His mother works part-time in a restaurant.

Ahmet very reluctantly attends an outpatient appointment at an early psychosis service, having been brought by his mother. The service is around 20 kilometres from Ahmet's home, and required two different trains to get there and a travel time of around 45 minutes. Ahmet's mother, who has limited English, describes her son as a 'good boy', but is concerned about the friends that he is spending time with, and says she was frightened by his behaviour when he was psychotic. Ahmet presents as irritable, slowed in his speech, disorganised, and with notable response latency. He says little spontaneously, but does say that he 'hates' the medication he is taking, as it has made him gain weight and makes him feel 'like a zombie'.

Describe the challenges to engaging Ahmet and his family under the following categories:

- Biological (medication difficulties and neurocognitive difficulties)
- Psychological (cognitions and emotion around seeking treatment)
- Social
- Logistical
- Other

Engagement in clinical practice: techniques to assist with engaging young people and families

Overview

Despite the barriers highlighted above, there are a number of approaches and techniques for enabling engagement that can be undertaken both at a clinician level and a service level to maximise successful engagement of young people and their families experiencing early psychosis. These range from practical considerations, such as the timing of appointments, to consideration of factors concerning the interpersonal relationship between the young person and clinician.

This section presents approaches and techniques that will help with engagement at two levels – at the level of the clinician–young person/family interaction and at the service provision level. It also provides information on using information communication technologies and social media in engagement, followed by a small section on engaging young people during the acute phase of a psychotic episode.

CASE STUDY **STEVE**

Consider the following case.

Steve is a 19-year-old man currently living in a share house. He was recently discharged from a psychiatric inpatient unit following a 2-week admission in the context of increased psychotic symptoms. Steve reported that he had been using increased amounts of cannabis and had taken amphetamines at a dance party, following which he experienced paranoia and voices, which were calling his name in a way that he experienced as threatening. There is some tension in Steve's share house, with housemates describing annoyance that he has not paid his rent in the past 2 months, and saying he was quite verbally threatening when he was experiencing psychotic symptoms. Steve also incurred some legal charges for property damage he committed while unwell. He is now minimising his symptoms, does not feel he has a 'mental problem', and appears likely to disengage.

What would you do to engage Steve?

Maximising engagement between the clinician and young person

The following describes approaches that clinicians can use that may be helpful in enhancing the engagement of young people and their families with early psychosis services. Although it contains only a small section on family-specific interventions that may help engagement, it is likely that all the approaches described in this section, and the common themes of respect, sensitivity and collaboration, are equally applicable to engaging young people experiencing early psychosis or their supports. Please see the ENSP manual *In this together: family work in early psychosis* for further details of family-specific work.

REFLECTIVE EXERCISE

Consider a young person that you are currently working with or have worked with in the past with whom you were able to develop good engagement and maintain a positive therapeutic relationship.

- What were the characteristics of the young person?
- What did you do to assist the development of/maintain the therapeutic relationship?

Do not assume 'psychological mindedness' or motivation

Many therapy manuals and intervention guides are written for clinicians working with adults who are help-seeking, psychologically-minded and motivated to make changes regarding life difficulties; however, this cannot be assumed about young people experiencing early psychosis.[5] It is largely the job of the clinician to create an environment in which the young person becomes psychologically minded, motivated, and help seeking. As Whiteside and Steinberg (2000) note, 'to label a client as difficult, resistant or impossible is an abrogation of professional duty. It is ultimately the therapist's responsibility to find the way to success'.[70]

Acknowledge the young person may be frightened, confused, or feeling hopeless

It can be a useful starting point to acknowledge that young people presenting with psychosis may be experiencing distressing symptoms including paranoia, hallucinations, depression and anxiety. Even when young people present as irritable, dismissive or aggressive about their symptoms, it is important for the clinician to formulate this in the context of their previous and current experience. Therefore, particularly during initial sessions, clinicians should present as calm, gentle and professional, and be strongly aware that their behaviour may be misinterpreted through a lens of agitation or a distressed emotional state. Information should be kept brief, with messages repeated if necessary, visual cues offered (using a white board, drawing, writing down main points), and regular reviews made during the session to 'check in' with the young person and ensure they understand what is being discussed.

CASE STUDY **PROVIDING WRITTEN INFORMATION**

Clinician: 'We have talked a lot today about ideas of what may have contributed to you becoming unwell. I'm someone who writes things down, it helps me to explain and remember what I'm saying. Would you like me to do this for you? Is that ok?'

Young person: 'Yes.'

Clinician: 'Do you want to take this home with you so you can think about it a bit more if you like?'

Address confidentiality issues

When working with young people, being clear about confidentiality and information-sharing can be particularly important, and failure to address this could impact negatively on engagement. Young people are often apprehensive about how information will be shared, particularly information relating to sexual health and drug use.[59] A commonly voiced concern is the degree to which disclosed information will be discussed with parents or other family members. Young people may be reluctant to have information shared with their family because they don't want to get into 'trouble' or they don't want to worry their family. It can be important to address concerns about family involvement specifically, noting that information relating to risk is likely to be shared with family or supports if it relates to them, but that this would generally be done with the young person's awareness, and with some discussion about how this would be undertaken. Young people who have symptoms of paranoia may also need to have confidentiality issues spelled out for them to reassure and help them be more forthcoming.

> 'My case manager always let me know whether she was going to talk to my family and she always asked what is appropriate and what's not appropriate to say … so I felt really comfortable.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Clinical experience in the EPPIC program has found that most young people understand and are reasonable about the need to share information relating to risk. Whatever a young person's concerns about information-sharing, it is important that clinicians are clear that their primary concern is the young person, and that they are sensitive to the young person's concerns.

'Set the scene'

It can be important to begin therapeutic work by explaining clearly to the young person and their family or supports how the service operates. Specifically this can include discussing the length of care, regularity of appointments, the degree to which appointment times and locations are flexible, how the young person and supports can make contact with the service during work hours and out of hours, and what the clinician can offer therapeutically and practically (note that accessibility and response time from services can be very important to engagement).

Ideally, a service will have handouts that contain all the information young people need to know about a service, which can be useful as there are often high rates of emotion in initial sessions and young people and supports may not be processing information effectively. A handout that can be given to young people and families by all parts of the early psychosis service (e.g. by the intake, assessment and ongoing treatment teams) will also ensure that everyone is given the same information no matter who they receive it from. Time should be taken to assess what the young person and their family would find helpful, as offering 'therapy' too soon in the therapeutic relationship may not be welcomed by young people who do not perceive that there is a problem.

The early phase of involvement with young people and their families can also offer a valuable opportunity to address some potential misconceptions or concerns. People may have unhelpful understandings of early psychosis treatment or the nature of 'therapy' from the media, which can include everything from hypnosis to recovered memory work and regression.[71]

Other misconceptions that can also be addressed in the early phase of a young person's contact with a service include concerns about cost, frequency of appointments, the nature of voluntary/involuntary treatment and the likelihood of hospitalisation or re-hospitalisation.[72]

Explaining the professional qualifications and experience of the clinician can be helpful for families and supports, but caution should be used when discussing these with the young person. Information from focus groups held at Orygen Youth Health with young people who had left the service suggests there is a risk that discussing qualifications may be viewed as arrogant; it may widen the gap between the clinician and the young person (by creating professional distance and a power relationship) and therefore lead to disengagement.

> 'I really liked that my case manager told me that she was a social worker and that she had worked at the service for a few years … It meant I knew that she was interested in working with young people and also that I might want to know that she was qualified. But another worker I saw while my case manager was away talked a lot about their Masters in blah blah … I felt like they were showing off.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Attend to the young person's 'hierarchy of needs'

Maslow (1943) developed the concept of a hierarchy of needs, acknowledging that individuals have a number of requirements, ranging from basic physiological needs (such food and shelter) to safety needs (such as emotional support) and esteem and self-actualisation (including the need to be understood and for our lives to have meaning).[73] Engagement can be assisted by the clinician's awareness and attention to each young person's needs.

Aside from the obvious need to get well (symptom relief, mitigation of side-effects etc.) young people will have other practical needs that should be considered. For example, it is not unusual for young people to experience legal, accommodation or financial difficulties following a first psychotic episode. The young person's trust towards their clinician and development of the therapeutic relationship can be assisted by the clinician's practical support with these concerns.

In the case example of Steve (page 24), it appears likely that engagement could be assisted significantly by attending to and assisting Steve with practical issues, including working out a payment plan for his unpaid rent and helping him to write letters to mitigate his legal charges. These steps can help the clinician to be perceived by Steve as someone who is helpful, which may assist with later, more challenging work, such as addressing his substance use or issues around insight into his psychosis.

Be aware of the young person's goals

Following a first psychotic episode, young people are unlikely to be motivated by the same factors that clinicians are when they arrive in the care of an early psychosis service – i.e. they may not care about the assessment process or medication, which are clearly priorities for clinicians. Clinicians therefore need to be aware of what a young person hopes to achieve by accessing an early psychosis service. Acknowledging these goals can lead to a more fruitful therapeutic relationship. For example, acceptance and commitment therapy focuses on the importance of building clinical sessions around the goals set by the client, with discussion around attendance, medication adherence and diagnosis being incidental to helping them reach these goals.[74] Goals to focus on could include assisting a young person to achieve the vocational goal of getting an apprenticeship.

Avoid 'psychiatric' or medical language (at least initially)

Although professionals may be comfortable using psychiatric and diagnostic terms, clinicians need to be sensitive that young people may not be aware of these terms, and that they can have stigmatising connotations. 'Psychosis' and 'psychotic' are often misused in the media and have implications of violence and unpredictable behaviour. In engaging a young person and their families, it is therefore extremely important to listen carefully for the language that they use in relation to their experience of psychosis, and check how they feel about other people such as case managers using it. For example, some young people will use terms such as 'things got a bit weird', 'I wasn't making much sense', 'I was so paranoid', 'I was stressed out', or 'I was doing stuff I wouldn't normally do'. In the beginning at least, it can be useful for clinicians to use this kind of terminology and also explore what young person means by it. It is not unusual for young people to use terminology that they have heard, for example in an inpatient unit, by peers or the media, without necessarily having the same understanding of it as a clinician might.

A conversation exploring this kind of language might run as follows:

> **Clinician:** 'So John, I just wanted to ask, what was it that happened for you to end up in hospital/ coming to our service.' (Note the clinician's avoidance of expressions such as 'sick', 'psychotic', or 'unwell'.)
>
> **John:** [pause] '... I don't know. Maybe I had a psychotic episode.'
>
> **Clinician:** [smiling] 'Is that what you think, or is that what people have said to you?'
>
> **John:** [smiling] 'That's what people have said to me.'
>
> **Clinician:** 'So what do you think?'
>
> **John:** [pause] 'I think that my mum overreacted ... I had been smoking a bit more [cannabis] and I was maybe saying some weird stuff but there's nothing wrong with me.'

Clinicians should be very cautious about the timing of discussion about diagnosis. While it can at times make the clinician feel more secure to use diagnostic labels, for young people it is not necessarily helpful, particularly early on in treatment. Even when asked by young people for a diagnosis (which in our experience does not happen that often) clinicians should consider whether it is appropriate (see case scenario 'Jake'). There are in fact a number of other reasons for being highly cautious about diagnosis in early psychosis, not least that it can be highly unstable. For example, McGorry et al. (2008) reported that psychosis is a variable syndrome and that only a limited number of an FEP sample meet criteria for schizophrenia.[75] Yalom (2003) suggests that clinicians should 'avoid diagnosis (except for insurance companies)', expanding on this to say:

> A diagnosis limits vision; it diminishes ability to relate to the other as a person. Once we make a diagnosis, we tend to selectively inattend to aspects of the patient that do not fit into that particular diagnosis, and correspondingly overattend to subtle features that appear to confirm an initial diagnosis. What's more, a diagnosis may act as a self-fulfilling prophecy.[49]

If a young person or their family do ask for a specific diagnosis, or find terms such as 'psychosis' too vague, it may be helpful to explain to them the reasoning behind using such terms in early psychosis rather than the names of specific conditions.

'Diagnosis is such a huge thing, and will follow you for the rest of your life.'

– Young person,
EPPIC, Orygen Youth Health Clinical Program

CASE STUDY **JAKE**

Jake is a young man who experienced an involuntary inpatient admission due to hallucinations and persecutory delusions. During his sixth session with his case manager, he and the case manager have the following interaction:

Jake: 'So what do you think I have?'

Case manager: 'Do you mean diagnosis?'

Jake: 'Yeah.'

Case manager: 'Can I tell you what I think in a minute? I'm really interested in hearing what you think first.' [Note that the case manager avoids expressing her own opinion initially in favour of seeking Jake's understanding first].

Jake: [pause]'... I'm not sure. Maybe... I don't know. [pause]... Someone said 'psychosis' on the inpatient unit'.

Case manager: 'What do you think they meant by that?' [clarifying the level of Jake's understanding of the term].

Jake: 'I don't know... Maybe when you think things are not real and stuff... And when you see stuff'.

Case manager: 'Does that sound like what was going on for you?' [ensuring that the clinician and young person have a shared understanding of Jake's experience, and not assuming that Jake agrees with the professional opinion].

Jake: [pause] 'Yeah.'

Case manager [noting that Jake appears to have become slightly more withdrawn]: 'Jake, what does it feel like to have this discussion?...[pause] Do you think that you were experiencing psychosis?'

Jake: 'I don't know. I definitely had some weird stuff going on... I'm just not sure about "psychosis". It sounds like "psycho" or something'.

Case manager: 'Oh, ok. I think that the media sometimes gets confused between "psychosis" and "psychopath". They're two totally different things. Does that make sense?'

Jake: 'Yeah.'

CASE STUDY **JAKE** CONTINUED

Case manager: 'Psychosis is just a label for when people are having a bit of trouble knowing what's real, but it has nothing to do with being aggressive or cruel to people. It's also really important to know that it doesn't actually mean that much, as what's most important is recovering, which is what's happening for you. For some people an episode of psychosis only happens once and they never experience it again [clarifying misconceptions around permanence of symptoms]. Am I explaining it ok?'

Jake: 'Yeah. It makes sense.'

Case manager: 'Personally, I'm not that bothered about labels. Some people find them helpful and some people don't. What's it like for you?' [checking in with Jake's experience of the discussion].

Jake: 'Yeah it's ok. I just wanted to know what's going on.'

Case manager: 'We can definitely discuss it again if that would be useful, and you might have some more questions. There's also some stuff I could give you to read if that would be helpful' [clinician ensuring that the diagnostic discussion can remain 'on the agenda' if Jake wishes this, and also offering material in another format to aid understanding and recall].

Understand the young person's explanatory model and work on a shared formulation

Related to the previous point, engagement is assisted by the clinician taking time to understand the young person's explanatory model of what has happened to them. While it can be tempting early in the therapeutic relationship to use medical terminology, particularly with families, it can be more valuable to take time to understand what young people and their families have been told, what they have read (including online), and what they understand about the young person's psychosis, causation, treatment and prognosis. While most young people experiencing a first episode of psychosis will not have a first-degree relative with the same disorder,[76] some people may have a family member who has been diagnosed with a psychotic disorder or other mental health issue. Understanding the young person and family's previous experience of psychotic symptoms in such cases can be important to a clinician's approach to engagement. For example, if the relative's experience with medication or treatment was negative or their outcome was poor, the clinician may want to explore what happened and try to address concerns and provide reassurance if possible.

CASE STUDY **HECTOR**

Hector is 19 years old and has experienced auditory hallucinations and other phenomena consistent with early psychosis. During his initial assessment, Hector states that his experiences are related to a head injury that occurred when he was 8 years old. The assessing clinician later asks Hector's father, who is also present, about the injury. He, however, only has a vague recollection of a minor accident when Hector was younger, but says it had no significant effect on him.

Although Hector's explanatory model is unlikely, the clinician does not perceive any benefit in arguing directly that the accident did not cause his symptoms. She instead takes a collaborative approach, accepting at face value Hector's explanation and focusing on the need to address his symptoms with treatment. She uses the 'bucket' metaphor (see below) as a way of helping Hector incorporate the need for treatment into his explanatory model in a way that is acceptable to him.

Collaboration between the young person and clinician to develop a case formulation has been identified as a significant factor in the development of engagement.[77] This emphasises the need for shared decision-making with the young person. Part of formulation can also involve normalising and helping young people understand potential reasons for why the psychotic episode occurred. Indeed, normalisation was identified by Lincoln et al. (2012) as a key factor in successful outcomes in cognitive-behavioural therapy for psychosis.[78] One method of undertaking a normalising formulation is that of the 'bucket' metaphor, involving the client and clinician work together to identify and visually chart potential contributing factors to the psychotic episode. Appropriate emphasis is given to each factor, by the young person, with this 'filling' the bucket until it overflows. When formulation is undertaken in this way it can be valuable and destigmatising. For example, when the 'bucket' contains school stress, family history, cannabis use, relationship break up, and the death of a grandparent, it can help the young person understand that there were a considerable number of stressors and that under similar circumstances, anyone could be expected to have experienced mental health difficulties. This approach can be particularly helpful for engagement, as it demonstrates that the clinician is keen to understand the young person's unique predisposing, precipitating, perpetuating and protective circumstances. Furthermore, it normalises the experience for the young person and gives a rationale for further work rather than indicating only that the young person has 'something wrong' with them or 'needs help'.

'It felt like my case manager saw what I was going through as a journey that they were on with me. It was like a partnership towards my goal.'

– Young person,
EPPIC, Orygen Youth Health Clinical Program

Have awareness of cultural factors

As noted already (in the section on sociocultural barriers) it can be important for clinicians to be aware of cultural beliefs about psychosis and how the young person and their family interpret what is happening within this framework. For example, the concepts of spirits, communicating with ancestors, and of devils and visions, are not unusual in particular religious communities, and insensitivity towards this is likely to lead to disengagement. In addition, young people or families from some cultural backgrounds may be more deferential to the role of doctors or other clinicians and expect direction in how they engage with a treatment.

High rates of schizophrenia and other psychoses have been repeatedly found in migrant populations.[79] It is therefore important for clinicians to ask the young person, and their family or other supports whether beliefs expressed by the young person are commonly held within the cultural group and for the clinician to research the culture of the young people that they are working with. Often this can be confirmed with family or 'cultural interpreters' – see case scenarios 'Imran' and 'Ahmet')

CASE STUDY **IMRAN**

Imran is a 21-year-old man recently arrived in Australia from Iraq. He has been attending an early psychosis service and recently his case manager notices he has become manic, reading the bible and the Koran with very extreme interpretations. Because Imran has few family supports, his case manager gets in contact with the Imam from the local mosque that Imran attends. The Imam agrees to meet with Imran and the case manager to discuss Imran's interpretation of the Koran. He is able to give some very useful perspective on religious or spiritual views and compare them to what might be a delusional interpretation from the Koran.

CASE STUDY **AHMET** (CONTINUED)

Clinician: 'Mrs Ozkan, can I check something with you, as I'm really keen to understand your culture better? Ahmet has mentioned being worried about jinns. Is that something that happens a lot in your culture and religion?'

Mrs Ozkan: 'A little bit. In Islam, the Koran mentions desert spirits ... (pause) But I think that Ahmet is more worried than usual. He was never worried about this before. He's a good boy, but he's not normally very religious.'

Clinician: 'Are jinns something that you would normally talk about much as a family?'

Mrs Ozkan: 'No. Not really. I just tell him not to worry.'

Avoid confrontation

While this may appear an obvious comment to make, mental health professionals may inadvertently find themselves in conflict with young people experiencing early psychosis about issues of diagnosis, substance use, medication adherence or involuntary admission. The motivational interviewing literature discusses the importance of 'rolling with resistance' and of avoiding confrontation.[80] This may be particularly important in discussions of diagnosis or medication, as if a clinician insists that the young person has an illness, and this belief is not shared by the young person, disengagement is likely to occur. As Miller and Rollnick (2002) note, '... client behaviours that are labelled as "resistance" represent, in motivational interviewing, a signal for the counsellor to shift approach. Resistance is an interpersonal phenomenon, and how the counsellor responds will influence whether it increases or diminishes'.[80]

Ask about previous treatment experiences and pathway to care

It can be very valuable to ask a young person early in their involvement with their treating team what their previous interactions with mental health professionals has been like.[58] Sometimes it can be useful to ask young people and their families questions like, 'You've spoken to lots of people before coming to see me. I don't need to know any names, but it would really help me if you could tell me what has been helpful and what hasn't'. Often, valuable information, both positive and negative, can emerge, such as, 'This nurse was asking me all these questions and talking to me like they knew me', 'A psychologist I saw kept giving me all these forms to fill in and it really pissed me off' or 'I spoke with lady who was really nice. She took her time and it was like she was really interested instead of just doing her job'. This can give the clinician valuable insights into what types of interaction are likely to be effective with the young person.

Address concerns about medication

As noted above, a significant challenge to engagement can be related to side-effects that young people can experience with antipsychotic medication. As Mitchell and Selmes (2007) note, significant predictors of medication non-adherence are, '... the desire to manage independently of the medical profession (self-efficacy), disagreement with or low trust of clinicians, and receipt of low levels of information ...'.[33] It is therefore clearly important for the clinician to take time to discuss medication benefits and concerns with the young person. This should include a clear presentation of possible side-effects, possibly with a comparison of the different antipsychotics. It can also include offering choice in terms of dosages, type of medication prescribed, and even whether the young person wishes to take antipsychotic medication at all.[81] Clinicians also need to give the young person time to consider this information, especially if they appear ambivalent about medication. It appears likely that if this is not discussed, and concerns addressed, not only is medication adherence likely to be poor but risk of disengagement may be increased. Further information about medical treatments for young people with early psychosis can be found in the manuals *Medical interventions in early psychosis: a practical guide for early psychosis clinicians* and *Medical management in early psychosis: a guide for medical practitioners.*

Be open in the therapeutic process

While it is clear to clinicians why they need to ask particular questions of a young person, it is unlikely that the young person will be aware of this, and questions can therefore at times come across as intrusive. Clinicians should be mindful that they are often asking people extremely personal, and at times, confronting questions. This may be particularly challenging to a young person experiencing paranoia, or even for a young person who has never had the experience of sharing quite personal thoughts and feelings (or discussing side-effects from medication) with others, especially adults. Therefore, being clear why particular questions are being asked, and considering the timing of some questions, can be important, as is asking permission to ask personal questions, especially regarding past trauma, sexual assault, sexuality, sexual side-effects or mental state.

Similarly, discussion about sharing of documents and giving the young person a copy of any letters written on their behalf can be helpful and do much to reduce the power imbalance. Discussion around key wording of documents (e.g. in letters of support, whether the word 'psychosis' is used or not) can be important to encourage a sense of trust and collaboration. Due to freedom of information legislation, young people are generally able to access any documentation relating to them anyway, so it can be valuable to explicitly involve the young person in this process.

CASE STUDY **MARIKA**

Marika was applying for special consideration for assignments for her TAFE course in digital design. There was an option of her submitting a letter in support of her application from her case manager or doctor. Marika and her case manager sat and wrote the letter together, so that Marika was clear about what was included in the letter, and felt like she had control over what personal information was shared about her situation.

Have a 'structure'

It is not unusual for clients and clinicians to have different recollections of a session, to focus on different aspects, and at times, have completely different viewpoints on what occurred.[82] Cognitive-behavioural therapy advocates a model in which sessions begin with a review of previous contact, lead into the setting of a collaborative agenda, and conclude with a summary (ideally provided by the young person). This can be very valuable in terms of assessing what has been recalled by the young person in addition to giving an opportunity to address any misunderstandings that may have occurred during the sessions.[58] It can be useful to ask questions such as 'What are the main things that we talked about today from your point of view?', 'What stuff has been useful today?', and 'What did we talk about that wasn't that helpful?' Even if the young person is not able to give specific answers due to cognitive difficulties, mood difficulties or psychotic symptoms, it can be important for the clinician to demonstrate that they are interested in the young person's experience of the session and point of view. Structure can also help the young person to understand what they can expect in each session.

> 'When I go to see my case manager we'll set an agenda together so then we know exactly what we're going to talk about, how heavy it's going to be or how light it's going to be. I know if it does get too heavy I can just say "Look, I'm struggling I just need to go grab a glass of water" or something and take five minutes out.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Acknowledge strengths

With psychiatry and other mental health professions having emerged from a medical model that often focuses on pathology, diagnosis and treatment, there is a danger that the strengths and protective factors brought by the young person experiencing early psychosis are overlooked. As Wachtel (2011) notes, '... the overall vision of most psychotherapy is too one-sidedly focused on the negative. Effective psychotherapeutic effort must have an equally clear vision of patient's strengths. It is on those strengths that change is built, and failure to see them clearly can make change extremely unlikely'.[83]

A key underpinning of solution-focused therapy is that of identifying strengths, and moving away from 'problems' or pathology.[84,85] This model describes the importance of identifying exceptions to difficulties, what people are doing when things are going well, and summarising positive strategies that the client is using. For example, the clinician could say something like 'I've noticed that we have been talking a lot about your voices, and it seems like this might be hard for you sometimes. Can I ask you a different question? When do you not hear voices? What's going on, or what are you doing differently?' This type of approach can be extremely valuable in changing the tone of the session, and of allowing young people to feel more positive about, and engaged in, treatment.

It can be important, particularly when engaging and developing a therapeutic relationship with young people that the focus of sessions is not primarily on pathology. This is likely to make sessions feel negative to the patient and lead to increased pessimism and confusion.[76] Instead, it can be very valuable to give young people the opportunity to educate the clinician about their interests and areas of expertise, whether this is pop culture (TV shows, music, sport and video games often being areas of particular knowledge) or other interests. As Yalom (1999) notes 'learn about their [i.e. patients'] lives; you will not only be edified but you will ultimately learn all you need to know about their illness'.[86]

Recognise the individuality of each patient

There is a danger that clinicians over-rely on manuals or diagnostic categories when considering treatment. Diagnostic categories can assist the clinician to some degree, and experience of particular disorders can influence clinicians in what kind of interventions are likely to be effective. However, its recommended that clinicians are cautious about assuming similarity between people or diagnoses, and the likelihood of specific interventions being successful based on this. Erickson and Rossi (1979) advise, 'Each psychotherapeutic encounter is unique and requires fresh creative effort on the part of both the therapist and patient to discover the principles and means of achieving a therapeutic outcome'.[87]

Take time to develop a relationship

While it can be tempting, particularly given workload pressures, to attempt to gain maximum information about the young person at the start of treatment, there is a risk that this is rushed, which can leave the young person feeling overwhelmed and not listened to. Depending on the period of care offered by an early psychosis service, it can be important to take the time to build a therapeutic relationship gradually.

It is also important for the clinician to be mindful that, given the high rates of trauma, abuse and attachment history difficulties present in young people experiencing psychosis,[88,89] gaining trust is unlikely to occur quickly. The clinician should not expect the young person to be comfortable disclosing personal information before they have 'earned' this.

> 'If I could go back and do my first meeting with my case manager over again, it would be more of a "breaking the ice" kind of thing, maybe trying to develop some trust a bit and have a casual conversation – that would have made me feel a lot more at ease.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Formulate issues that could challenge the therapeutic relationship

Part of a good formulation in mental health is the identification of potential challenges to engagement and the therapeutic relationship. Specifically, understanding the young person's attachment history can be very valuable and inform the clinician of potential ruptures, such as perceived abandonment when the clinician goes on holiday or is late for a session.

Formulation of potential challenges to engagement could also include awareness of practical difficulties. These include awareness that cognitive difficulties may impact on attendance, and that the young person may view interactions through a delusional belief structure. Formulation can allow for identifying ways to address these potential barriers, whether they involve practical measures or psychotherapeutic ones.

Foster optimism and hope

It is notable that hopelessness is commonly experienced by people with a diagnosis of schizophrenia, appears to be particularly prevalent in people following a first episode psychosis (reviewed in White et al. [2007]),[90] and can be predictive of suicide.[91]

Hope and optimism therefore appear to play a significant role in mental health and early psychosis outcomes, with May (2004) noting, 'Hope is a key ingredient in successful recoveries, but, traditionally this has been lacking in mental health services'.[92]

Importantly, people's experience of hopelessness has been found to be mediated by their beliefs about their experience.[92] Specifically, themes of 'entrapment', 'attribution of self versus illness', 'loss of autonomy' and 'humiliating devaluation of self' were found to be predictive of higher rates of hopelessness in people experiencing psychosis.[90] This has clear implications for clinical work. Specifically, it may be important for clinicians to focus on helping young people and their families to modify these unhelpful cognitions, with recognition that they could become self-fulfilling prophesies if not addressed.

It is therefore important for clinicians to focus on what young people and their families can do to impact the course of psychosis positively. Phrases like 'We expect things to get better', and 'We expect your son to recover', can be valuable. Providing anecdotal clinical scenarios about how other young people have coped or recovered may also be helpful and reassuring.

The literature on acceptance and commitment therapy for psychosis emphasises the importance of spending time with people to identify their values and what is important in their lives.[74] This appears important for a number of reasons. Firstly, it focuses people on what matters to them, and on issues that they care about, which appears likely to aid engagement and make sessions feel relevant. Secondly, it directs clinical work away from being purely pathology-based, which again may reduce the chance of drop out. However, it also allows for clinical work to then focus on goals and on ways for the young person and clinician to work collaboratively to reach these, thereby maintaining a strong focus on optimism and how to attain meaningful outcomes.

In addition, psychoeducation around outcomes in early psychosis can be very valuable, particularly to counteract some of the negative or catastrophic preconceptions that might be held by the young person or their family. For example, a seven-year follow up study of young people who experienced FEP found that up to 68% of people were in paid employment and up to 60% had symptomatic remission.[93] Outcomes appear to be even better when there has been a short duration of untreated psychosis.[94]

Another significant aspect in the encouragement of hope is that of working with the young person on their perceptions around perceived likelihood, fear, control, and catastrophisation regarding relapse.[5,95] Recent research has suggested that the likelihood of relapse occurring, and its potential impact, is modifiable, and that cognitive and behavioural factors can influence both whether relapse occurs and its destructiveness.[96] This can be an important message to discuss with young people who may be at risk of dropping out of services due to feeling that they are powerless to influence the course of their disorder.

Use humour and playfulness

Discussing psychotic symptoms can clearly be a difficult topic to discuss with young people, and there can potentially be profound implications for young people and their families. However, engagement can be assisted by being open to moments of humour and fun in therapeutic work, despite the seriousness of the situation. We have found that many young people in the EPPIC program maintain a strong sense of humour despite experiencing challenging situations. In addition to a growing literature of the efficacy of humour,[97-100] it can make work in a difficult area significantly more enjoyable for the clinician.

Bennett (2003) described the use of humour in engagement as a means of '... narrowing interpersonal gaps, communicating caring, and relieving anxiety associated with medical care. Patients also use humour to express frustration with their health and with the medical establishment'.[101] Terr et al. (2006) also describe the importance of humour and playfulness, particularly in therapeutic work with young people, suggesting, 'Sometimes we must remind ourselves that play is the natural language of the young'.[102]

> 'I want to know that my case manager is human.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Service-level considerations for maximising engagement

Continuity of care

Young people's initial entry into a mental health service can be chaotic and confusing, and it is not unusual for young people to have been interviewed by a number of professionals before being finally allocated to their treating team. This process can be extremely frustrating for young people and their families and requires sensitivity by clinicians. Following a young person's entry to a service, it is also important to limit disruption to their care. This will require thought and consideration when allocating resources, such as when clinicians go on leave or doctor rotations. Unfortunately, some discontinuity of care cannot be avoided, in which case early psychosis services should try to limit its impact. Attempting to keep a consistent treating team will assist engagement, and is more likely to lead to the formation of a good therapeutic relationship.

> 'I'm just going to mention how sucky it is getting to know a doctor and then six months later you're with another doctor. You get to know them and then they're off somewhere else. I am someone who prefers a bit of consistency and stability.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Location and timing

While clinicians may be comfortable in an office in part of an early psychosis service or inpatient unit, this may not be particularly welcoming to a young person. While safety and confidentiality issues need to be considered, conducting sessions in a 'neutral' or non-stigmatising environment such as a cafe can help reduce young people's anxiety and make them feel on a more even footing with the clinician. Choosing such a venue can also be very helpful in understanding how the young person copes in the 'real world' and may give insight into anxieties, difficulties, or even strengths that the clinician may not have been able to observe in an office.

Similarly, home visits, while admittedly more time-consuming nearly always yield valuable information and assist with engagement, particularly early in the therapeutic relationship. See the ENSP manual *No place like home: home-based care for early psychosis* for more information.

> 'Going out, even to a café, just feels more casual and less like a patient–doctor environment and it sort of breaks the formality. It makes you feel like you're both just people, and I think it's easier sometimes to talk over a cup of coffee. It makes it a bit more open and kind of like, this isn't something scary. You don't have to be secluded from society … that you can be out in the world and just be like normal people.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Regarding timing of interventions, it can be important that information is discussed at a level with which the young person is intellectually and emotionally comfortable. This can also involve adapting session length to what the young person is able to manage. It is not unusual for initial sessions with young people experiencing distressing psychotic symptoms to be brief in order not to be overwhelming.

In addition, where possible, flexibility around appointment times can be important to improve engagement. Clinical experience indicates that young people are more likely to attend mental health appointments around midday rather than early or late in the day.

Engage the family

As noted, families and other supports can be very valuable treatment allies (see page 18). Specifically, families can inform the treating team of any concerns about the young person and any fluctuations in their mental state. Families can also assist engagement in practical terms, particularly early in treatment through transport to appointments and encouragement to attend. Again, as with formulation for the young person, being aware that family members are likely to have differing explanatory models and beliefs through which they view experience is important. Clinicians can assist engagement significantly by taking time to understand each significant family member's or other supports own experience.

We would again advise the reader to be familiar with the manual *In this together: family work in early psychosis* for more detail of this work.

Youth participation in service provision

Involvement and consultation with youth advocates, and ideally, young people who have been service-users themselves, can provide invaluable information for clinicians and more broadly for clinical services. Specifically, service users are perhaps best placed to advise on the 'youth friendliness' of services, in addition to how services can be delivered, developed, and evaluated in a more youth-sensitive and relevant way.[103] Clearly, an additional benefit is that this also allows young people to discuss their experiences and concerns with peers, which, as noted earlier, can be critically important during this developmental stage. Box 3 (below) summarises strategies to promote youth-friendliness in an early psychosis service.

BOX 3 SUMMARY OF STRATEGIES TO PROMOTE YOUTH-FRIENDLINESS IN AN EARLY PSYCHOSIS SERVICE

Service structure strategies

- Seek the advice of young people in all aspects of service design, including through developing a youth participation program.
- Service location should be in a location easily accessible by public transport and ideally near mainstream youth-oriented activities, leisure and sports pursuits.
- Co-locate with other youth-oriented services to provide a 'one-stop-shop'.
- Provide a warm, welcoming environment which considers the 'look and feel' from a young person's perspective and is stigma-free yet provides privacy and safety.

Service process strategies

- Provide choice and flexibility around treatment options.
- Provide flexibility in the location of care (home-based, school, cafe) and hours of operation (after school or work hours).
- Provide as much clinician consistency as possible throughout the whole episode of care.
- Provide information on access to, and what to expect from, the service in multimedia format.
- Minimise appointment wait times, and if there are any, explain these when the young person arrives for their appointment.
- Provide information on privacy, confidentiality and rights in accessible areas, including online.
- Utilise information communication technology to support engagement and clinical interventions, and support the workforce to utilise this in the most effective and safe manner.

BOX 3 **SUMMARY OF STRATEGIES TO PROMOTE YOUTH-FRIENDLINESS IN AN EARLY PSYCHOSIS SERVICE** CONTINUED

Workforce strategies

- Utilise young people in the whole recruitment process, from position description development through to interview and selection.
- Incorporate expected youth-friendly attitudes, qualities and activities into job position descriptions.
- In interviews, include questions to ascertain youth-friendly characteristics from prospective employees and if possible include young people in interview panels.
- Build links with local academia to promote youth mental health in undergraduate and postgraduate curricula.
- Support staff with training and education related to the necessary knowledge, skills and attitudes required to work in a youth-friendly way.

For more information, see the *EPPIC Model and service implementation guide.*

Consider practical issues

Practical issues including texting to remind about appointments can be valuable if a young person's organisation and planning difficulties are at risk of impacting on engagement. Initial regular appointments at the same time each week can help to create momentum in treatment and build rapport. It can also be useful to involve family members to remind young people and bring them to appointments.

> 'I'd get phone calls from my case manager to check up on me, to remind me about appointments and just to see how I was going. That was actually quite useful. You know, just to know that they still cared and they were still looking out for me and making sure I was okay in between appointments.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Similarly, assisting young people with transportation to appointments can be invaluable. This will depend on service budgets and policies, but could include giving details of local public transport services, offering transport, or providing vouchers/ public transport tickets.

CASE STUDY **STEVE** CONTINUED

Reconsider the case of Steve, presented at the beginning of this manual:

Steve is a 19-year-old man currently living in a share house. He was recently discharged from a psychiatric inpatient unit following a 2-week admission in the context of increased psychotic symptoms. Steve reported that he had been using increased amounts of cannabis and had taken amphetamines at a dance party, following which he experienced paranoia and voices, which were calling his name in a way that he experienced as threatening. There is some tension in Steve's share house, with housemates describing annoyance that he has not paid his rent in the past 2 months, and saying he was quite verbally threatening when he was experiencing psychotic symptoms. Steve also incurred some legal charges for property damage he committed while unwell. He is now minimising his symptoms, does not feel he has a 'mental problem', and appears likely to disengage.

What would you **now** do to engage Steve?

Using technology to assist engagement

Information communication technology, social media and engagement

The concept of engagement is not, and should not be, limited to face-to-face interactions and verbal conversations. There has been a significant shift in the way people engage and communicate both with each other on a personal level but also with their schooling, work or with the wider society at large

Young people are extremely likely to own a mobile (and often a smart phone) and/or computer and use these to communicate with their peers, contribute to discussions online, share photos and organise social catch-ups. Communicating through these mediums may not feel 'normal' for some clinicians; however, this is the norm for most young people. Social media sites such as Facebook, Instagram, Twitter, Tumblr, Snapchat and Tinder are used to speak with their friends at school, friends of friends and as a means of meeting new people. Stephens-Reicher et al. (2011) report that approximately 90% of young Australians aged 16–29 use the internet daily, with 90% of those aged between 12 and 17 years accessing social media sites.[104] A snapshot of mobile phone use by those aged over 14 found 3.9 million people used a smartphone to access online services in one month alone.[105]

Given young people are using online networks to socialise and to access information, it makes sense that services aimed at young people engage with young people in a way that reflects how they communicate. This is not to say that online communication should replace face-to-face communication, but rather that embracing the use of technology will make services increasingly more accessible and less stigmatising.

Seeking help online

After friends and family, young people are most likely to seek help and support for health problems through the internet.[104,106] There are considerable benefits provided by seeking information and support for early psychosis or other mental health issues online. These include:[107]

- the ability to be anonymous and ask questions that otherwise may feel embarrassing or hard to ask in person
- easy access to health information in a way that can feel safe
- access for young people who live in rural and remote areas to support that may not be available locally
- access to support that young people may not necessarily seek because they feel worried about parent or support response
- information on how to access further support (e.g. health professionals, health services).

Despite the advantages to accessing support online, there can be some disadvantages. Accessing misinformation or misinterpreting the information at hand can contribute to further stigmatisation and also fear about reaching out for support.

Acknowledging the increase in online help-seeking and accessing of information has led to the development of mental health web-based support services for young people.[106] These services aim to improve the health and wellbeing of young people through:

- enhancing mental health literacy
- increasing resilience
- providing accurate information and support to a large population
- facilitating help-seeking through initial engagement channels.[106]

Using technology and social media to support engagement with young people

Understanding the role of technology and online communication is essential if clinicians are to routinely use them to facilitate engagement. For example, asking about social media use in the initial assessment process can be a useful way of understanding the role technology plays in a young person's life – how they use it to interact with peers and others, or if they have any issues with past or current online bullying. Other possible uses of technology to facilitate engagement of young people include:

- Young people may feel more comfortable making initial or ongoing contact with a service via email or text messaging. They may feel uncomfortable divulging personal information using more traditional methods such as the telephone.
- Asking young people about what social media sites they are using and which ones they use for which purpose places the young person in the role of a teacher to the clinician and can assist engagement.

- The option of communicating with a young person online or using text messages to help with appointment reminders can be very helpful for young people, and also shows that the service is able to be responsive to the young person's needs by using methods of communication they are comfortable with.
- Online psychoeducation material that is evidence-based can be useful to look at with a young person, at the computer, or with a tablet. This also allows an opportunity to sit alongside a young person doing something together.

What can also be helpful is to combine communication modes – for example, any work that is talked about in a session can be jotted down on a whiteboard and the young person can take a photo of it to think over later. Or perhaps during a session with a young person who is struggling to explain their experiences, the young person can show the clinician their blog or Tumblr account to go through their documentation of their experience of early psychosis.

As mentioned earlier, the majority of young people own or have access to a mobile phone and in the majority of cases, a smart phone with internet access. Using text messages can sometimes be a useful tool to enhance or maintain engagement. Young people, no different to any phone owners, may screen their calls for a variety of reasons. As calling from the clinic or service phone number may display a 'private number' on the incoming call screen, the call may be left unanswered or any messages left not returned. Sending a short message via text to inform the young person you are trying to call them directly, or even just to 'check in', can maintain lines of communication and allow the young person to engage on their own terms. It also conveys a sense that the clinician is interested in how the young person is between appointments and is committed to wanting the young person to attend their appointments. Sending the young person a text message as a reminder for their appointment can also be useful. Missing appointments can lead to the risk of continuing non-attendance and disengagement from services.[108] Recent studies have examined the efficacy of using text messaging as a communication option and 'reminder tool'. They found that text messaging can be a safe and viable way of maintaining contact with young people[109] and a time, labour and cost-efficient way of encouraging engagement.[108] However, early psychosis services do need to have policies regarding the use of text messages and/or email when clinicians are communicating with young people or their family.

When considering the use of technology and online means for engagement, it is important to also be aware of some of the possible barriers and disadvantages. Barriers to engaging young people through the use of technology as engagement tools can be found at a number of levels. These include organisational or service barriers such as work computers being blocked from social media sites. There may also be a lack of policies and procedures within services that promote the safe and health-promoting components of technological communication.[110]

In summary, clinicians should have an ongoing awareness of the role technology plays in young people's lives, and how it can contribute to enhancing and maintaining engagement with their treating team. Exploration of a young person's use of technology and social media sites during the assessment period is important, as it will help to inform client preference around communication. To aid this, clinicians should try to maintain a level of digital literacy.

Engagement during the acute phase of a psychotic episode

Engagement of young people who have experienced a psychotic episode can be assisted by awareness of the young person's phase of recovery. For example, it is not likely to be helpful for engagement if the clinician attempts to undertake relapse prevention work with a young person who has no insight into having had a psychotic episode. It is important not only for the clinician to be aware of the pacing of information in sessions, but also to ensure that topics are addressed at an intellectual and emotional level that the young person can manage.

When a young person is acutely psychotic, there may be particular challenges around engagement in terms of whether the young person feels 'believed' by the clinician in their description of what they are experiencing. When a young person holds strong delusional beliefs and is highly preoccupied by them, the clinician walks a difficult line between being open to discussion about these and being careful not to encourage unhelpful discussion or exacerbate concerns. Evidence has found that when people are experiencing acute delusional beliefs, 'challenging' these is not helpful and may in fact increase their intensity with which they are held.[111]

Challenging delusional beliefs is not helpful and may in fact increase the intensity with which they are held.

Rhodes and Jakes (2009) raise the historical concern that avoiding confrontation of a person's delusions could be seen as colluding with them.[41] However, experience within the EPPIC program has found that this is not generally problematic in work with young people with early psychosis. Instead, it can be helpful to engage in a discussion about a young person's delusional beliefs, which simply lets clinicians understand them better, allows them to complete a more detailed formulation, and improves their therapeutic relationship with the young person, who as a result does not feel judged or criticised. As Hepworth et al. (2011) conclude from their research of effective treatments for persecutory delusions, 'These preliminary findings suggest that simply encouraging patients to talk, in the right way, about their delusions can be beneficial'.[112]

It is also notable that it is uncommon for clinicians to be asked specifically by a young person whether they believe a delusion is true. If this does happen, however, a standard reply of 'I believe that you believe it' is generally not helpful, and can be interpreted as patronising or avoidant. Instead, a more helpful response could be:

> I really don't know … and to be honest, there are parts of it that I'm not sure how they work. It also sounds pretty distressing for you, so in some ways it might be good if it wasn't true. But I'd be really interested in hearing more about it. Can you tell me how it is that…?

This approach appears less likely to result in the young person withdrawing or shutting down, and also allows for opening up of dialogue and the commencement of Socratic questioning around elements of the belief that are not congruent. As Rhodes and Jakes (2009) note 'One important quality of the therapist is to be able to tolerate listening to a client talking about paranoid delusions without feeling the need to contradict those beliefs.'[41]

Maintaining professional and therapeutic boundaries

While some therapy training appears to still be influenced by Freud's concept of the therapist aspiring to be like a mirror, and of professional boundaries, we would encourage some reflection and flexibility around this. Therapeutic boundaries are clearly important, and help protect both the young person and the clinician. However there can be a fine line between being having strong boundaries and appearing inflexible, overly rigid, or indifferent to the patient, particularly when working with young people. Yalom (2002) advises therapists, 'Let the patient matter to you', adding '... forget the blank screen! It is not now, nor was it ever, a good model for effective therapy'.[49]

Wachtel (2011) identifies this dilemma, stating 'On the one hand, it is a relationship that is deeply personal and intimate ... On the other hand, it is a relationship that is professional and limited, and that by its very nature asymmetric'.[83]

'You want to know that the case manager is human... When they won't say where they went on holiday, you feel just like some psychiatric patient.'

'They know so much about you, and you know nothing about them...'

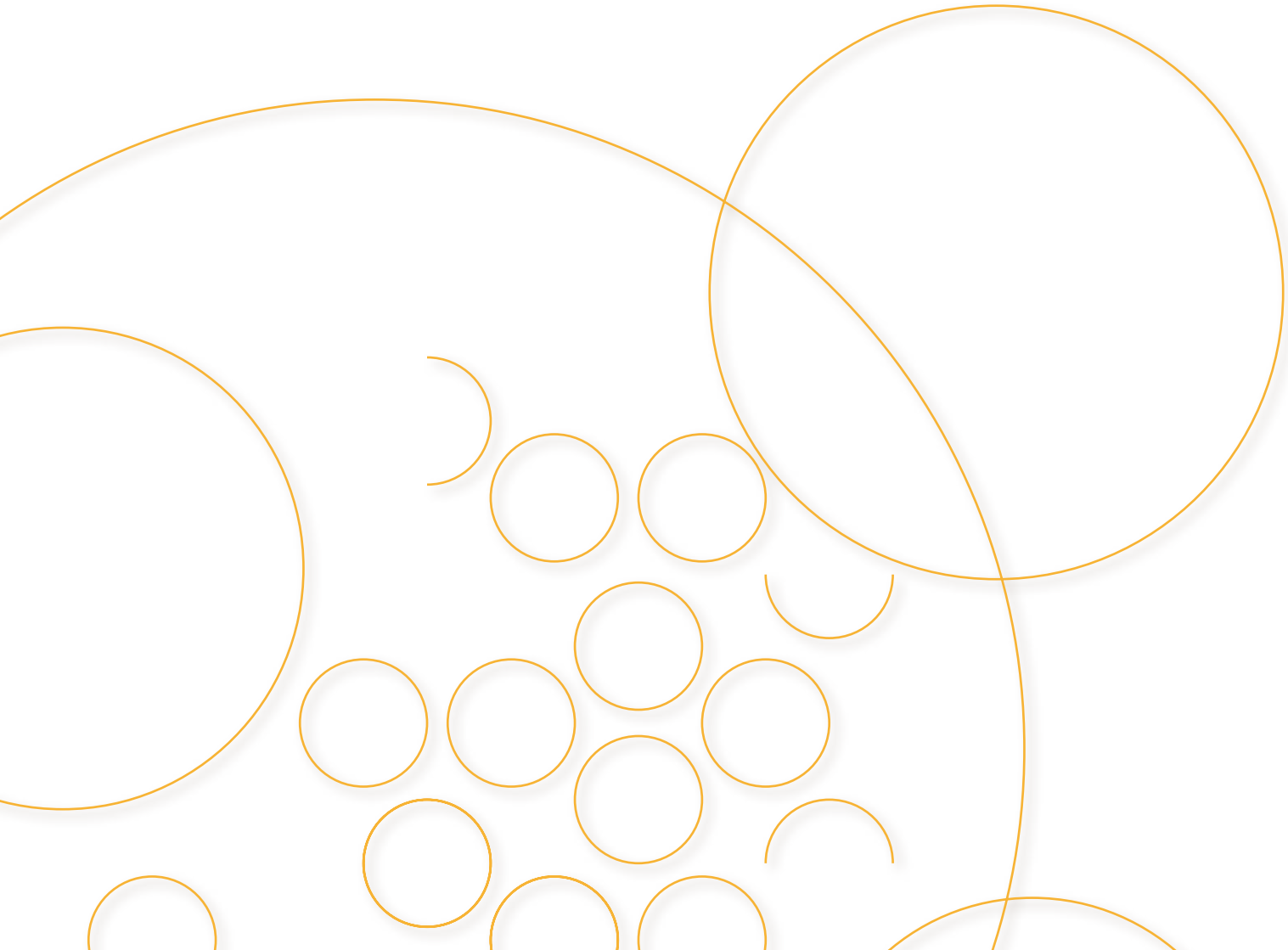
– Young people,
EPPIC, Orygen Youth Health Clinical Program

Ultimately, clinicians need be mindful of developing their therapeutic relationships in a way that is sustainable for them. They should consider, through self-reflection, supervision with their senior and through the process of clinical review, what may be helpful for the young person, their family and the clinician for the clinician to share. If they do bring personal information into the relationship, they should ask themselves why they are doing so, what it can bring, and ensure they are not making it 'about them'. Clinicians can also think about what information might be shared to personalise their relationship with a young person without disclosing parts of their lives that are personal or could leave the clinician feeling vulnerable or exposed. For example: what band a clinician saw on the weekend, or what the clinician thought about the most recent episode of the current popular television show. It is about striking a balance.

> ‘I’d like to get to know my case manager … She just seems like an interesting person. I’d always wonder what she’d like, like whether she likes the horrible romantic movies or she loves thriller type movies or whether she likes classical music or maybe she likes metal. All those sorts of things – it would be good just to know.’
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Often discussions can be had with the young person directly about what information is or has been helpful to share. This could also include how to handle situations outside the clinical setting where a clinician and young person might accidentally meet, for example, whether the young person wants to acknowledge their case manager in front of their peers. This is particularly a consideration in smaller communities.

Clinicians should refer to their professional bodies for the ethical implications of sharing personal information.



Fluctuations in engagement

Overview

Maintaining an open and healthy therapeutic relationship can be challenging, particularly when there are competing demands or pressures on the young person and clinicians. A young person's engagement with their case manager and the early psychosis service can therefore fluctuate. This might be a result of a rupture in the therapeutic relationship, or due to other factors. As highlighted already, the therapeutic relationship may face challenges from the difficulties that occur in finding the balance between the young person's opinion and clinician or service priorities.

The following sections will look at the concepts of therapeutic ruptures and how to manage a young person's disengaging with a service.

Therapeutic ruptures: engagement doesn't end

Ruptures have been defined as, 'a tension or breakdown in the collaborative relationship between patient and therapist'.[113] They can occur regardless of the therapeutic model the clinician may use, and are contributed to both by the clinician and the young person. Ruptures can lead to disengagement and treatment drop out, with more subtle indications of therapeutic ruptures including withdrawal, increased irritability, not completing tasks discussed during sessions and avoidance of appointments or phone calls from clinicians.

Safran and Muran (1996) write that ruptures are likely to occur '... when therapists unwittingly participate in maladaptive interpersonal cycles that resemble those characteristics of patients' other interactions, thus confirming their patients' dysfunctional interpersonal schemas ...'.[113] They can occur after events such as when:

- a young person is admitted involuntarily to hospital
- a young person or family's immediate needs have not been addressed
- a young person or family demands admission when it is not warranted
- there are disagreements regarding adherence or need for medication.

Ruptures appear to be almost inevitable in therapeutic work with young people experiencing psychosis, given all the challenges identified earlier in this manual. When ruptures are not attended to, and attempts not made to resolve them, disengagement and poor outcome are more likely to occur.[3] However, as Ackerman and Hilsenroth (2003) note, '... ruptures [can provide] ... fertile ground for patient change and an opportunity for deepening the alliance'. Specifically, ruptures are likely to relate to

difficulties that the young person may have in their other interpersonal relationships (e.g. abandonment, perfectionism, entitlement) and can be a valuable opportunity for the clinician to work with the young person on modelling conflict resolution.

Regarding the repair of ruptures, a number of strategies can be helpful. Firstly, the clinician has to be aware that a rupture has occurred by being vigilant for the markers described earlier, and then utilising the concept of 'meta-communication', or 'communication about communicating'[114]. For example Foreman and Marmar (1985) researched cases in which poor initial alliances were either improved or not.[69] They found that in improved cases, the therapist acknowledged what had occurred in the session and connected this with how the client responded, for example, by linking the patient's silence with being annoyed at the therapist. This is where a good summary at the end of a session should include asking the young person how they found the process and how the young person felt about their relationship with the clinician.[49] It can also be important for the clinician to take responsibility for mistakes, acknowledging their own role in the therapeutic rupture, and to apologise if appropriate.[114]

When young people disengage

Ideally young people will remain engaged with an early psychosis service; however, in reality disengagement is common. It is important to note however that it can sometimes form part of a young person's recovery process – when a young person feels well, their functioning improves and they may feel they don't need to be so dependent on the service. There are also times when forcing engagement is counterproductive to the young person seeking help again in the future.

Each service will have its own policies and procedures for managing when young people disengage or drop out from treatment. For example, the *Cognitive Behavioural Case Management in Early Psychosis Handbook* (OYHRC, 2010) advises, 'The clinician must work hard to engage the young patient and assertively maintain contact even when the patient attempts, actively or passively to withdraw from treatment'. It should be remembered that early intervention potentially provides the best opportunity to reduce the impact of psychosis on a person's life, both symptomatically and functionally. It is again suggested that formulation regarding potential reasons why the young person may have disengaged can be important. Clearly, different approaches would be taken regarding a young person who has withdrawn because of distressing paranoid symptoms, compared with someone experiencing marked amotivation relating to medication side-effects or depression, or with a young person who is unable to attend due to transport costs.

It may be useful to consider other ways of supporting young people after they disengage, such as encouraging them to contact another provider (e.g. a school counsellor or their GP). Services should also make it clear to young people and their families that even after a young person disengages, the door is left 'ajar' and that they will always be allowed re-entry to the service for assessment or treatment or referral.

Ending with the service

> ‘The progress a patient makes during therapy should be enriched and heightened by a positive treatment ending. When [treatment ending] issues are ignored or mishandled, the whole of therapy is jeopardized.’
>
> – Kramer (1990)[115]

One focus of this manual has been on the challenges of engaging young people experiencing early psychosis into clinical services, and how clinicians can overcome some of these. However, as noted above, it is not unusual for this population to have experienced trauma and difficult attachment histories. For this reason, finishing with the early psychosis service, and ‘disengagement’, can also pose some challenges, particularly when the clinician, young person and family or supports have worked hard to build a mutually trusting relationship. Interestingly, while much has been written on engagement in therapy, surprisingly little has focused on the conclusion of therapy in a way that is helpful to the service user.

Ending treatment with individuals that have experienced trauma or difficult attachment histories is arguably the most important part of psychological and therapeutic treatments. If managed well, finishing involvement with a particular service or clinician can give the young person a sense that endings need not be traumatic or inevitably involve a profound sense of loss. As Mathews (1989) notes, ‘Despite its attendant complications, therapist-initiated termination, like other endings, provide potentially important grist for the growth mill’.[116]

As Kramer (1990) notes, ‘To each patient, termination means something different…’. It can therefore be useful in working towards ending treatment with a young person following a first episode of psychosis to revisit the formulation to help anticipate potential issues that are likely to emerge, whether these be disappointment, anger, hope, or relief.

> ‘When I got discharged, my case manager and I wrote letters to each other and then gave them to each other. There was still the awkward walk away at the end, but the letters were a nice conclusion to everything.’
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Again, as with issues affecting engagement, a young person's ending with a service can also raise a number of issues for clinicians, and is likely to activate particular core beliefs, reciprocal roles, narratives, or countertransference. As Kottler (2003) stated regarding the conclusion of therapeutic work, 'The clinician may feel guilt, failure, disappointment, sadness, pride, apprehension, hope, jealousy and relief – all at once. And there is the constant cycle of growing immensely fond of people and then turning them loose'.[117] For these reasons, it is understandable that clinicians may find the process challenging, delay or avoid discussing this with the young person, or minimise its impact. It is not uncommon for clinicians to cite platitudes such as 'I'm sure you're going to keep going well', or 'You're going to be fine', rather than addressing some of the emotions experienced by the young person, family or the clinician him/herself.

REFLECTIVE EXERCISE

Are there particular strategies you use in your work with young people when thinking or talking about ending case management or treatment with you?

What do these involve?

Do you and the young person write a letter to each other, or is it more a dialogue?

Noting the above challenges, service considerations are likely to be highly influential in the length of treatment that young people with early psychosis receive. However, a number of factors can assist in maximising the chances of positive disengagement.[118] These include raising the issue of how long the early psychosis service can remain involved early on in a young person's treatment and discussing when it might end with them at regular reviews. Importantly, the conclusion of treatment also provides a valuable 'cards on the table' opportunity for the young person, family and clinician, regarding what has gone well and what can be learned from the relationship and intervention. Specifically, rather than providing impersonal, generic feedback, it is important for the clinician to reflect on what has been learned from this particular therapeutic encounter, and for the clinician to be clear what he/she believes has changed and how to maintain gains.

Finishing treatment and ending with a service and case manager can be a challenging time for the young person, their family, and the clinician. However, if it is managed sensitively, with an awareness of the young person's formulation, potential difficulties can be anticipated and managed. It can also provide the clinician with a valuable final opportunity to consolidate goals and potentially give the young person something that they may not have often experienced before: the experience of a 'good ending'.

CASE STUDY **REBECCA**

Rebecca's episode of care with an early psychosis service is coming to an end in 2 months. Finishing up with the service that has supported her over her episode of care of 2 years is something that Rebecca and her case manager have been talking about over the last few months. The following discussion happened during one of Rebecca's sessions with her case manager.

Rebecca: 'I can't believe that I won't be coming here to see you any more soon! That's going to be weird ... I mean, I've been catching the train here nearly every week for over a year!'

Clinician: 'I know, it is a long period of time ... and like we've been talking about, finishing up can bring up feelings and thoughts. And everyone's response is different ... I mean you and I have talked about this before, but it can feel a bit scary not coming in to the same office, to see the same people any more ... But other people find they are excited about the idea of 'starting afresh'. Often people find they experience both ... what about you ... what do you think about that idea?' [Clinician reflecting on how finishing up with a service can bring up a number of feelings for people]

Rebecca: 'Yeah, I find sometimes I'm like, awesome, I don't have to come in for appointments anymore! No offence! But it's really exciting to think about how I feel, like I know that I feel good and Mum and I feel like we know what to look out for if I start to get paranoid again ... But then sometimes, like if I'm having a bad day I feel a bit worried that I can't just ring you or know that I am coming in to see you in a few days to talk about it. That's a bit sad ...'

Clinician: 'Yeah, I think it's a bit sad too. A year is a long time isn't it! And I think it's important that we talk about that it does feel like both a bit sad and also exciting. Because I also feel really excited for you and all the great things that you are going to be doing with your life.' [Reflecting back the young person's ideas about finishing with the service. Also using the self in the dialogue in being open and acknowledging that the young person and clinicians relationship is genuine].

Rebecca: 'Exciting ... and scary ... I also like the fact that I will be seeing my GP regularly and that if I need some extra support that I know that I can make an appointment with the psychologist at the headspace centre and that me, Mum and my GP all have a plan about what happens if my weird thoughts come back or I start to hear things again.'

Clinician: 'I wonder if it helps you to feel like you have more power over the weird thoughts and voices rather than the other way around, like when we first met. That's not to say that things are going to be perfect, but you should be really proud of yourself with having achieved what you have!'

Summary

In conclusion, growing evidence points to the importance of engagement and the formation of a positive therapeutic relationship to improving clinical outcomes. This applies across a number of disorders including, and we would suggest, particularly, when working with young people after a first psychotic episode. As Roche at al. (2014) note, 'The therapeutic relationship is of central importance to service users and represents a robust prognostic indicator for clinicians.[119]

The *Cognitive Behavioural Case Management in Early Psychosis* manual (OYHRC, 2010) advises, 'Establishing a therapeutic relationship can be challenging during the disruption and distress of a first episode psychosis. Engagement requires a calm, reassuring, professional and friendly manner, with a commitment to flexibly negotiating the best initial outcome'.

Engagement requires a calm, reassuring, professional and friendly manner, with a commitment to flexibly negotiating the best initial outcome.

Despite the numerous challenges associated with engaging young people after a first psychotic episode, recent research by Evans-Jones et al. (2009) offers significant reassurance. They found that it was possible to engage people experiencing psychosis in therapy and develop a good therapeutic relationship regardless of symptom severity, number of inpatient admissions, employment status or insight. In addition, and perhaps somewhat surprisingly, clients experiencing psychosis tended to rate the therapeutic relationship higher than clinicians, with this correlating with perceived empathy, expertness and trustworthiness of the therapist.[120] The lack of correlation between the strength of a therapeutic relationship and gender, age or ethnicity is also reassuring, indicating that all clinicians can effectively engage with young people by genuinely focusing on empathy and collaborative goals.

In addition to and despite the challenges described in this manual, engagement and the development of strong therapeutic relationships with young people and their families following a first episode of psychosis can be incredibly rewarding work – work that allows for the real recovery process to begin.

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NOTES

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