Orygen
The National Centre of Excellence in Youth Mental Health

Clinical practice in early psychosis

Working with clinical complexity and challenges in engagement

Introduction

Engagement is fundamental to successfully treating early psychosis. If a young person is well engaged with their treatment, they are more likely to attend services, participate meaningfully in therapy and adhere to medication, all of which increase their chances of recovery. Unfortunately, engagement is not always straightforward, and up to a third of young people may disengage from early psychosis services in the long term.[1] The reasons for this are numerous, complex, and – although there may be themes in common – unique to each young person's circumstances. Although it is easy to blame disengagement on simple factors such as the young person's attitude or symptoms, viewing engagement in such simplistic terms represents a lost opportunity to intervene and enhance engagement. Rather, clinicians and services need to consider the challenges and complexities of poor engagement and find ways to address them.

This clinical practice point is designed to help clinicians who work with young people with early psychosis to understand:

- the complexity of the factors that influence a young person's engagement with services
- how to promote engagement
- the importance of working with the young person's system, including their family and other services
- what to do when young people continually won't engage.

> "It's hard work, but also rewarding when you can turn around a young person's experience of care and give them an opportunity to engage in a different way to what they are used to.
>
> Senior clinician
> Orygen Youth Health Clinical Program

Engagement: the cornerstone of treatment

Evidence suggests that engagement and the formation of a strong therapeutic alliance between clinicians and the young people they treat is associated with improved attendance, adherence with biological and psychological interventions and resulting improvements in symptomatic and functional outcomes.[2-4] Furthermore, engagement and the quality of the therapeutic alliance improves information-gathering, increases clinicians' contextual and aetiological understanding of the young person's presentation, assists the young person to seek help in future, aids collaboration with family and support agencies and is experienced by all involved as a more congenial way to interact.[5]

Factors that hinder engagement

There are many reasons young people do not engage with clinicians or services, and it is important that clinicians understand and acknowledge that each young person, and the circumstances associated with their presentation, is unique. Clinicians should be mindful that engagement is likely to fluctuate throughout the young person's period of care. Some young people might not engage from the beginning, some young people may disengage from services as their functioning improves and others may engage well initially, but disengage later on.

Having a contextual and informed understanding of the difficulties that are affecting a young person's engagement will help the clinician to address these issues with the young person, their family and other supports.

Practical challenges

Young people commonly experience practical challenges that prevent or hinder their engagement with clinicians and services; this may be especially true for young people with complex needs.

Unstable housing or homelessness may be obstacles, as changeable living arrangements can hamper attempts to develop initial and ongoing therapeutic relationships.[6,7] Safe and stable accommodation and other basic needs must be met before services can expect a young person to engage therapeutically. Limited finances can prevent young people from attending services: for example, they may not be able to afford the cost of transport. Employment and educational goals and pursuits pose a different type of challenge: while they may be an encouraging sign of functional recovery and a positive goal to works towards, they may also limit the young person's time or availability to meet with clinicians and therefore affect the therapeutic alliance.

If the young person has competing demands on their time from other services, for example, compulsory attendance with correctional services, legal services, drug and alcohol counselling or community-based orders, attending a mental health service may not be a priority. Services therefore need to collaborate to streamline the young person's care and ensure that demands on the young person's time are not excessive (see 'Working with the young person's system' on page 8).

Box 1. Working with a chaotic or disorganised young person

Some young people with complex needs can be disorganised or chaotic in their presentation. In these instances, it is advisable to:

- take time with gathering information or assessment
- seek information from other sources
- be clear and direct in interactions with the young person
- repeat instructions or questions if required
- present the young person with options, as they may find it difficult to make decisions
- focus on help with practical issues
- be consistent and predictable in your approach to engagement, including setting regular appointment times
- observe the young person's behaviour in different settings to understand their context, rather than relying on their answering questions
- focus on outreach or home-based care as modality of service delivery.

Disorder-related factors

There are a number of factors related to the young person's experiencing psychosis that can significantly affect engagement. These include symptoms and the side effects of treatment. Comorbid issues, such as personality or substance use issues, can also impact on engagement and need to be addressed.

Symptoms of psychosis

Psychotic symptoms distort a young person's reality and are often incompatible with help-seeking. For example:

- paranoid, persecutory ideation and grandiose themes can make it difficult for young people to establish trusting relationships with clinicians or believe treatment is helpful
- thought disorder, disorganised thinking, distractibility and preoccupation may affect a young person's organisational skills and capacity to seek help (see Box 1)
- depressive symptoms, negative symptoms of psychosis, cognitive difficulties, amotivation, avolition, abnormal energy levels (high or low) can impact on capacity and willingness to engage.

The type of onset can also affect engagement, as typically, young people who experience insidious onset have more difficulty recognising the need for help. Poor insight, anxiety and distress can also impact on a young person's willingness to engage.

Medication

Medication side effects may result in the young person's disengaging, especially if they are not promptly or adequately addressed by the treating clinicians.[8] Medications can affect motivation and self-esteem, or cause significant sedation and weight gain, which all can affect the young person's willingness and capacity to engage.[9]

Comorbid issues

Young people considered to have complex presentations, whether they be early psychosis or other disorders, commonly experience comorbid issues. Schley et al. (2008) found that 33–63% of the young people who services found difficult to engage were engaged in problematic substance use.[10] Substance misuse often has a negative effect on people's finances, cognition and organisation. Importantly, behaviours associated with obtaining substances or the effects of withdrawal may also hinder engagement. Similarly, the presence of full-threshold personality disorder or sub-threshold personality traits that result in behavioural difficulties is not conducive to conventional help-seeking or the development of therapeutic relationships, as often these young people have significant history of adversity or trauma (See Box 2).[11]

Box 2. Working with young people with maladaptive help-seeking strategies

Some young people may present with self-harming behaviour, frequently damage property or use other behaviours as a means of getting help or eliciting care. Although in a sense effective, these help-seeking strategies are not helpful for the young person or service, and young people need to be supported to find more adaptive and appropriate ways of seeking help. It is important to take the young person seriously, acknowledge their distress, normalise the maladaptive behaviour as an attempt to manage feelings, calmly enquire about the behaviour to ascertain the psychological intent behind actions (e.g. suicide attempt, coping mechanism) and assess risk. Importantly, the young person's physical/medical needs must be addressed. Clinicians should be supported to manage their own and the service's response to the behaviour, to avoid inadvertently reinforcing the problem. For more information about managing difficult behaviour, please refer to the ENSP manual *A different way of thinking: working with borderline personality disorder in early psychosis*.

Beliefs, past experiences and expectations

Beliefs that young people and families have about psychosis, and past experiences of involvement with services, including experiences of mental health services, can affect their willingness to engage. For young people who have experienced childhood trauma, neglect or significant personal losses, long-term psychological and social difficulties in the form of attachment difficulties can be common.[12]

> "I felt pressured … like how I answered certain questions could have a certain reaction … which is very frustrating because you don't know, you feel as if there is a right answer but you're just not getting any response about what you should say
>
> Young person
> EPPIC, Orygen Youth Health Clinical Program

Adolescence and early adulthood is a time in which young people are developing independence from family and become increasingly self-reliant and reliant on friends. Ongoing involvement with clinicians and services during this time may be counterintuitive and compete with social and developmental expectations. Concerns about confidentiality can also stop some young people engaging fully with clinicians.[13,14]

Beliefs and attitudes about mental illness and treatment are likely to be based on the views and values of peers, personal and social stigma, ill-informed stereotypes in the mainstream media and personal experiences. Stigma can make it difficult for the young person and family to initially accept a diagnosis of a serious mental illness. There may be a period of adjustment after diagnosis where the young person avoids services and tries to carry on as normal to 'prove them [family, services] wrong'.[8]

A young person's and their family's previous experiences of mental illness, mental health services or other services (e.g. child protection, correctional or forensic, medical) can influence their perceptions and expectations about services, treatment and outcomes. They may also determine whether the young people sees any value in engaging in a meaningful and therapeutic manner with mental health workers and services. Young people who have never been helpfully engaged with services may feel hopeless about the possibility of any change in their situation, and therefore may have difficulty investing in the therapeutic relationship.

> "Sometimes we don't think that a young person is well engaged because they are chaotic, or seem to ignore all of our attempts to help them ... but it's important to remember that your engagement might be the best they've experienced, despite all the challenges.
>
> Senior clinician
> Orygen Youth Health Clinical Program

Box 3. Working with anger

Past experience with services, particularly coercive treatment, can often make young people hostile towards services or clinicians. Young people may also express anger when they perceive that they are not receiving the help that they need. It is important to acknowledge that anger is often an expression of other emotions, such as frustration or fear.

Setting limits about acceptable behaviour is important; however, this may only be possible after the situation has been de-escalated. It is advisable to reduce any interventions or actions that are contributing to the young person's anger, if possible, and the priority is to keep everyone (including the young person) safe. Make sure that staff and the young person are able to easily exit the situation if necessary. Try to find common ground with the young person and align yourself with their viewpoint, rather than being confrontational or polarising.

For more information about de-escalation techniques, see the ENSP manual *What to do? A guide to crisis intervention and risk management in early psychosis*.

Clinician-related factors

Clinicians bring their own beliefs, biases and experiences to the therapeutic relationship, and it is important to acknowledge that these can have a significant impact on engagement.[5] Clinician behaviours that can be detrimental to the development of rapport and the therapeutic alliance include:

- prematurely challenging a young person's beliefs
- being judgemental or patronising
- not responding in a genuine manner
- failing to listen to the young person or take their concerns seriously
- failing to include the young person in decision making or goal setting.[8]

TIP

It's easy to see passivity or lack of active participation in their own care as signs that a young person is not engaged. However, every young person will engage differently. For some young people, simply showing up to sessions might be all they are capable of at that time.

Clinicians may find themselves having particular difficulty engaging young people who present with maladaptive coping strategies, who are persistently angry or oppositional (see Box 3), or who present with other behaviours that challenge the therapeutic relationship. The clinician's style or response to these situations can influence young people's willingness to engage. Adopting a non-blaming attitude, one that does not view the young person as 'difficult', may help, and this may also improve clinicians' understanding about the variables that are hindering engagement. Discussion and support from senior clinicians, supervision and a team-based approach to managing these issues can help clinicians deal with situations that they feel challenged by.

An excessive focus on psychopathology or risk management can also hinder engagement. While assessment and information-gathering about these aspects of a young person's presentation is necessary, not showing an interest in all facets of the young person's life can come across as robotic and structured, and you may be perceived by the young person as being only concerned about ensuring clinical accountability. Conveying respect and empathy and showing interest and care for the young person are important for increasing engagement.[5]

> "There is a way that you can [ask about risk] that's more casual and more personal than ... just going 'Oh well, you say you're suicidal,' and then, 'Quickly, we've got to just check, check, check everything' ... It's more important to listen to the person first, build that rapport and then ask those questions.
>
> Young person
> EPPIC, Orygen Youth Health Clinical Program

Service and systems-related barriers to engagement

The collective values, beliefs and fundamental approach of an organisation can affect how clinicians view and work with young people with complex needs. Organisations that do not value engagement with young people, do not recognise or attend to comorbid issues, fail to implement a collaborative approach with the young person and do not actively prioritise psychosocial recovery are likely to miss crucial opportunities to engage young people, tailor interventions and promote recovery.

Systemic barriers and inefficiencies, such as complex and disjointed referral pathways, long waiting lists, disorganised delivery of care and the unnecessary duplication of assessments, can lead to frustration and the formation of negative perceptions and attitudes towards services and help-seeking from the very beginning.

The location of young people's mental health services, systemic complexity of access to services and pathways to care, availability of public transport and costs associated with transport are factors that can influence how easily a young person can access services and therefore affect engagement.[15] Some young people may not engage well with traditional outpatient, clinic or office-based services. Having the capacity to provide mobile outreach to young people and families will maximise the chances of engagement in these cases. Outreach appointments often take longer and more time to prepare than regular appointments, and it is important that the service acknowledges the extra resources needed to provide this level of service and is able to adequately support its staff.[16]

The organisational approach to risk management for complex and high-risk young people can affect the management of potential risks (harm to self, others, vulnerability), how the young person develops coping skills and resilience, and the therapeutic alliance (see Box 4).

Box 4. Using the mental health act

Using the mental health act to involuntarily treat young people or the involvement of emergency services can have a significant impact on engagement. Often it can lead to iatrogenic trauma through the use of restrictive practices such as mechanical restraint, seclusion and injectable medications, all of which can leave long lasting negative impressions about ongoing involvement with services, treatment and help-seeking in the future. The risks of involuntary care should be carefully balanced against the need for involuntary treatment and the available alternatives.

How to promote engagement

Interventions to foster engagement with young people who are presenting as clinically complex or difficult to engage are comparable to those commonly used with all young people attending the mental health services. These include providing information, supporting help-seeking attempts, supporting the young person's family and other supports, and fostering a strong therapeutic alliance. However, it is the intensity and manner in which these interventions are delivered that sets apart the interventions that are described in the following section.

Find out why *this* young person is not engaging

The reasons a young person does not wish to engage with a service, treatment or clinician will be unique to them and understanding this can then help you consider how to adapt your approach to suit.

- Enquire about the young person's previous experiences of treatment – both positive and negative. Acknowledge their experience, feelings, concerns and reservations about treatment. Knowing this can help you plan successful interventions to avoid these experiences happening again.[17]
- Review the young person's clinical file for any significant events, such as involuntary treatment or information about past patterns of behaviour.
- Consider potential sociocultural issues that may be impacting on engagement.
- Revisit the young person's explanatory model and beliefs about mental illness, and try to identify whether aspects of this might be preventing engagement.
- Collaborate with the young person to develop goals for treatment that are concordant with their wants, needs and values.
- If the young person won't talk to you, or isn't forthcoming about what might be preventing engagement, try to get information from friends, family and other sources.

Focus on something else

If the young person doesn't see a need to engage with a service for treatment, it is often helpful to focus on other aspects of the young person's life or care that you or the service can assist with. Being responsive and assisting with practical issues shows the young person that you want to help and that you can offer them something useful. This can give them a reason to engage with the service where previously there wasn't one.

Practical assistance might include help with legal, financial or housing, transport issues, attending Centrelink with the young person, or providing medical certificates. Some young people may find short term use of medications or learning behavioural techniques for basic symptom relief helpful, for things like distress, anxiety, insomnia or withdrawal from substances.

Assisting with practical issues may enable opportunities to better assess mental state, but it also provides an opportunity to provide some basic psychoeducation and address concerns or expectations about the service the young person or family might have. It also provides an opportunity for the clinician to show genuine interest in getting to know young person and help with gathering information to strengthen the therapeutic alliance.

Avoid focusing solely on clinical issues. Although asking about risk, acuity of symptoms or medication adherence is necessary, dwelling on these parts of a young person's presentation is unlikely to assist engagement.

Offer consistency and structure

Many of these young people have services and adults in their lives already that they feel they can't rely on. It's therefore important to demonstrate that you are respectful, reliable and worth trusting. Providing young people with corrective relationships (safe, positive and nurturing interactions with trustworthy others) can help challenge pre-existing notions of care and attachment and promote and maintain engagement.

It is important to do what you say you will: keep appointments, and if you can't, make sure you communicate this to the young person. It is useful to explain to the young person that you may not always be available during business hours; set up realistic expectations of how quickly you are able to respond, and explain how the young person can access support after hours if needed.

Many service numbers are 'private' numbers. If you are calling a young person using a service telephone, texting them 15–20 minutes prior to calling them will let them know it's you calling, and also gives them a chance to find some privacy before you call.

Be upfront and transparent about processes and expectations regarding safety, attending appointments and frequency of appointments. Setting up a regular appointment time may help the young person to remember appointments, including outreach appointments. If the young person is disorganised, it is easier for them to remember a standing appointment time – e.g. every Tuesday and Thursday at 2 pm – rather than different appointment times each week.

Giving a defined period of attendance, with a clear endpoint for when attendance can be reviewed, may help the young person be patient about having to attend a service and 'give it a go'. For example, you might say, 'We will aim to catch up once or twice a week for about thirty minutes. Why don't we try this for six weeks and then review it? Then if that's not working we could try something else.'

This approach allows time to build rapport without asking the young person to commit early on.

TIP

While mandatory attendance (either due to involuntary treatment or court order) may be seen as a means to an end, this does not mean it cannot be productive, enjoyable or useful. Acknowledge that the young person may not want to be there, but encourage them to use the appointment time as their 'space' to discuss what they want. The trick is to help them see attendance as way to improve their circumstances, to make better decisions and have more positive outcomes (i.e. not going to prison, reducing substance use, maintaining accommodation).

Don't give up too easily

Perseverance and consistency go hand in hand. For young people who are avoidant or reluctant to engage, showing that you will follow through and not give up on attempts to engage is important, especially if the young person has a poor experience of care.

Continue trying to contact young people even if they are resistant or reluctant to accept involvement. This might involve repeated, structured home visits and cold calls, phone calls, writing letters, or text messages. Attempt home visits or phone calls at times when the young person is likely to be home, and leave evidence of your attempt, such as a note on their door. A phone message or business card left each week over a few weeks may encourage the young person to contact you.

Some young people may require a more assertive approach (see Box 5), usually due to level of complexity or risk. It is important for services to be able to 'step up' the level of care as needed, while still supporting the young person in the community.

TIP

Keep it simple – clear, concise instructions on appointment cards or letters work best. For example, if arranging a home visit, write the appointment time down along with instructions to phone you if they're not available. Young people often need help with understanding how to engage with services. Being overt about what the service expects can be helpful.

Box 5. Assertive outreach

Assertive outreach is often described as an intensive outpatient intervention.[3] The frequency of contact may vary from a couple of times per week up to daily or twice-daily (including phone contacts) depending on the current needs or situation. Assertive outreach is usually considered appropriate when a young person is having considerable difficulty engaging with office-based appointments, or where traditional office-based services do not meet the young person's needs. It is also appropriate where there are multiple services involved and the young person presents with complex needs or significant risk issues. These kinds of services are consistently proven effective in engaging adults with serious mental illness and first episode psychosis.[3,18]

For more information, see the ENSP manual *There's no place like home: home-based care in early psychosis*.

Working with the young person's 'system'

Often, but not always, it is young people with multiple and complex needs who are the most difficult to engage. The workers, organisations, frameworks and people that the young person interacts with and which are involved in their care are known as their 'system'. Being involved with many services makes it difficult for a young person to engage with any of those services very well, and they can find it difficult to know 'who to go to for what'. It is important then for services to work together to make engagement as easy as possible for the young person, to provide consistent support and to ensure that the young person is not receiving mixed messages. For example, if the young person is subject to a community based order, the corrective service may convey to the young person that engagement with mental health treatment is compulsory, when in fact the mental health service is trying to build voluntary rapport and engagement. The message about compulsory attendance can negatively affect the young person's engagement with the service.

Interventions always need to be multifaceted and involve the young person, family, other agencies and support systems. Families in particular can be a valuable resource in helping to engage young people; for those young people who might have lost contact with their families, other close supports such as friends or extended family members may be able to help support engagement.

Boxes 6 and 7 present some tips clinicians can use when working with other services and families, friends and other supports.

Box 6. Tips for working with other services

- Maintain regular contact with each service provider.
- Collaboratively develop a shared care plan and clearly articulate each service's roles and responsibilities.
- Schedule regular case conference or review meetings and have engagement as an agenda topic to focus on how to best to achieve this and how other services or supports can help. These should be more frequent when risk issues escalate. A regular meeting helps each service remain consistent and provides an opportunity for any issues to be resolved proactively.
- Don't assume that other services have the same attitudes, goals or understanding of what the young person is going through. You may have a role in providing them with psychoeducation about the young person's difficulties.
- Work collaboratively with other services, and use the skills, experiences and support of the wider team to help the young person achieve their goals.
- Consider engaging another clinician purely for systems work so the treating clinician can focus on therapeutic engagement with the young person.
- Consider seeing the young person at another service they are also involved with. If agreed, arrange a joint meeting with a worker from the service. This is collaboration in action

Box 7. Tips for working with families and friends

- Develop a relationship with families or friends. Explain your role, discuss how they can best help and look at practical ways they can do this. For instance, bringing the young person to appointments, or letting them be seen at home.
- Provide support and help to families or friends so they can be freed up to help with engagement of the young person. This may involve a family or friends meeting or referring them to the specialist family worker for extra support and help.

> When risk issues escalate, services are more likely to dig into their corner, to insist on dealing with the risk the way they know how. So it's really important at those times to make more effort to collaborate with other services.

Senior clinician
Orygen Youth Health Clinical Program

What happens when young people don't engage despite your best efforts?

Sometimes continued attempts to engage a young person can become counterproductive. A young person's disengaging may be an attempt to regain autonomy and can be understood as part of the recovery process. In this context, pursuing the young person may actually worsen their engagement and deter them from seeking help in the future.

After all other efforts have been made, rather than continuing to try to engage the young person, it may be better to discharge them from the service. However, the aim should be to allow room for the young person to re-engage with the service in the future if needed. Careful consideration of the risks and benefits of continuing with assertive engagement and treatment must be weighed against the risks of discharging the young person before they have fully recovered.

In such circumstances, as much information as possible regarding the young person's risks and circumstances should be attained and discussed within the multidisciplinary team. In best circumstances, the young person will agree to a final review with the treating team, which can allow for a more organised and planned exit from services. If the young person is at high risk, the service may decide to continue to monitor the young person via their family or other services for a period of time. A team-based approach to decision making around risk and discharge is recommended. For more information about managing the discharge process, see the clinical practice point *Managing transitions in care for young people with early psychosis.*

In summary ...

Working to engage young people who have complex needs or who are reluctant to engage with services requires persistence, an open-minded and honest approach and an understanding of the many factors that can influence engagement. Furthermore, it requires clinicians to be adequately resourced and supported to invest time and energy in more assertive methods of engagement. While this may prove challenging at times, careful assessment, planning and an individualised approach will ensure clinicians are more likely to be able to identify unique contributing factors, attempt to address these and work with each young person in a more considered manner towards improving engagement.

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