

Clinical practice in youth mental health

Shared decision making

“ Even if I’m really not doing very well, or really confused, you know, having trouble making decisions ... I’m not a hundred percent gone. There’s a proportion of me there that can still make some little decisions.

Young person,
EPPIC, Orygen Youth Health Clinical Program

Introduction

The active involvement of people in making decisions about their own treatment is increasingly being viewed as an ethical imperative in all areas of health care, including youth mental health. Shared decision making is a semi-structured process that can promote such involvement. Yet it is often misperceived as simple ‘collaboration’; Some may view shared decision making as a time-consuming, unrealistic ideal, believing there is no benefit to be gained by implementing a more structured clinical approach.

This clinical practice point provides clinicians with more detail about the rationale and purpose of shared decision making and how to practically include it in your work with young people. Ultimately, shared decision making is a way to facilitate both evidence-based care and person-centred care, and incorporating this approach into treatment decisions can only enhance clinical practice.

What is shared decision making?

Shared decision making is a process that promotes the selection of a treatment choice that is based on both relevant evidence and the preferences of the young person. At its core is the principle that self-determination (i.e. that the young person is able, willing and allowed to make their own decisions) is a desirable clinical goal, and one that young people should be supported to achieve.¹

Shared decision making involves a clinician and a young person working together in a deliberate way to make decisions about the young person’s treatment. Multiple health professionals, family members and other supports may also be involved. One of the common misperceptions held by mental health professionals is that shared decision making is simply ‘collaboration’, and that this is something that is already done in day-to-day practice. Although a shared decision making is a collaborative approach, and engagement and psychoeducation all are used in shared decision making, **these practices alone are not enough to be classified as shared decision making**. Shared decision making is a conscious, semi-structured approach to helping the young person make decisions about their treatment, based on the most relevant evidence and their unique needs, preferences and values.





TIP Shared decision making in youth mental health can be used to make decisions about all aspects of a young person's care – not just medication. It can be used to make decisions about psychotherapy, social or vocational interventions, and the involvement of other services.

What are the benefits of shared decision making?

For many young people who develop a mental illness, the experience might be the first time they have been involved for an extended period with health care services of any kind. They are unlikely to have needed ongoing treatment before or had much contact with mental health services. In this context, coming into contact with the mental health care system can be daunting, and young people may feel that they don't have control over the situation, or may lack the confidence to speak up about what is happening. There is therefore an ethical imperative that the service makes the effort to engage young people in decisions. One of the benefits of shared decision making is that it provides a clear process that can be used with every young person, from those who are highly engaged with their care to those who seem reluctant or uninterested in participating in making decisions about their care.

Much of the evidence for the efficacy of shared decision making with regard to outcomes comes from studies in physical health areas. The evidence base in mental health is still small, and more research is needed,² particularly into the use of shared decision making where young people are the active decision makers (i.e. rather than parents making decisions for their children).

However, the evidence that is available (from adult studies) indicates that shared decision making in mental health may improve:

- how involved people feel in treatment decisions^{3,4}
- decisional conflict⁵
- clinicians' awareness of the preferences of the people in their care⁶
- satisfaction with treatment decisions, among both individuals and treating clinicians⁷⁻⁹
- individuals' understanding of their own values⁵
- attitudes towards recovery¹⁰
- knowledge about conditions and treatment^{3,7}
- levels of concern about medications^{3,8}

- adherence to medication in the short term⁸
- severity of substance use and psychiatric problems in people with substance use disorder¹¹
- paranoid ideation in people with psychosis¹⁰
- uptake of psychoeducation and social interventions.³

Shared decision making in practice

Requirements for shared decision making

To be carried out effectively, shared decision making relies on a number of factors, related to the clinician and the young person, as depicted in Figure 1. The most important requirement is a good therapeutic relationship between the clinician and young person. If they are not able to communicate openly with one another, it is unlikely that a proper shared decision-making process can take place. It also requires 'buy in' by clinicians and services to person-centred care and evidence-based practice, including the benefits of shared decision making, and commitment to all aspects of the shared decision-making process. Finally, effective shared decision making requires willingness and ability on the part of the young person to participate. It is important to note that both of these attributes may need to be cultivated by the clinician, as many young people may be initially reluctant to take part in decision making, or may not understand the different ways in which they can be involved. See also Box 1, 'Activation'.

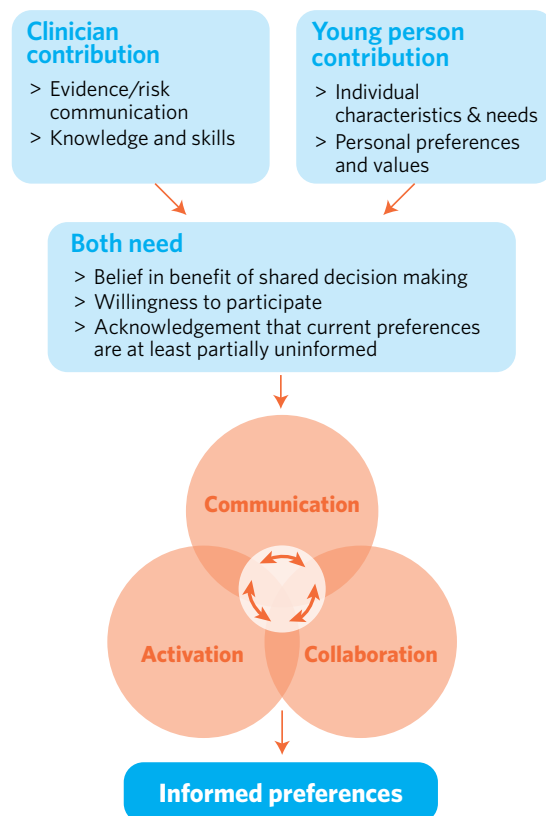


Figure 1. Requirements for effective shared decision making.

Box 1. Activation

The process of 'activation' is perhaps the most important feature that distinguishes a shared decision-making process from simple 'collaboration'. Activation acknowledges that young people will not necessarily already have the experience or skills to make informed decisions about their care. Some of the skills the activation process tries to cultivate in young people are:

- how to ask questions about their condition and treatment
- how to seek out information
- how to evaluate information regarding treatment and decisions
- how to discuss treatment options with their treating clinician, including being able to question the reasoning behind treatment decisions
- how to communicate their needs, values and preferences to clinicians.

It is the role of the clinician to impart these skills to the young person, and in turn, the young person uses these skills to educate the clinician further about what they need to reach an informed decision.

Structured training programs for activating people who are receiving mental health care have been researched and found to be effective.¹² While not all services will be able to offer this, some of the techniques used in these programs are:

- presenting case scenarios and ask people to identify issues or decisions that are relevant to their own care
- role-playing to get people more comfortable with asking questions
- assuring young people that asking questions is okay, and in fact is necessary and helpful for clinicians, as it lets them know what the young person needs.

Models for shared decision making

There are a number of models that can guide clinicians when implementing shared decision making in practice. While they may differ in detail, they all include the following core stages:

1. A two-way exchange of information between the clinician and young person

The clinician communicates information about the suitable treatment options and the potential risks and benefits of these options, while the young person communicates information about their values and preferences regarding these treatment options

2. Deliberation on this information

The clinician and young person discuss the possible outcomes, their values and preferences

3. Selection of an option that is consistent with the values and preferences of the client^{13,14}

4. Time taken to review this decision

This happens both immediately after the initial decision is made and at future points as needed.



You can still use shared decision making if a young person says they don't want to make the decision.

Who makes the actual decision is less important than the processes that lead to the decision being made. Decisions made using a shared decision-making approach will take into account the young person's needs and preferences regardless of who made those decisions.

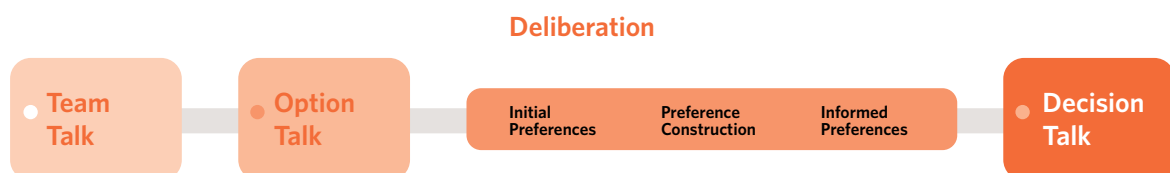
“ Don't make assumptions about the person when trying to tailor their care (e.g gender, sexuality, religion and other personal preferences). You could miss something because you didn't ask.

Youth peer worker

Here we present two models for shared decision making that are well regarded in the field. The first, a stepwise model developed by Elwyn et al. (2012)¹, proposes three key types of 'talk' that need to take place in the shared decision-making process:

1. Choice/team talk
2. Option talk
3. Decision talk

As shown in Figure 2, the aim of this process is to bring about an informed preference in the young person and to use that preference to make a decision.



Team talk: Explain the intention to collaborate and support deliberation

Option talk: Compare alternatives

Decision talk: Elicit preferences and integrate into subsequent actions

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Figure 2. A 'collaboration talk' model of shared decision making.

Another step-wise model, developed by a group at the national shared decision making symposium in October 2013 and based on a book aimed at health care consumers,^{15,16} uses a series of questions, which clinicians can pose to young people to guide the process (Figure 3).

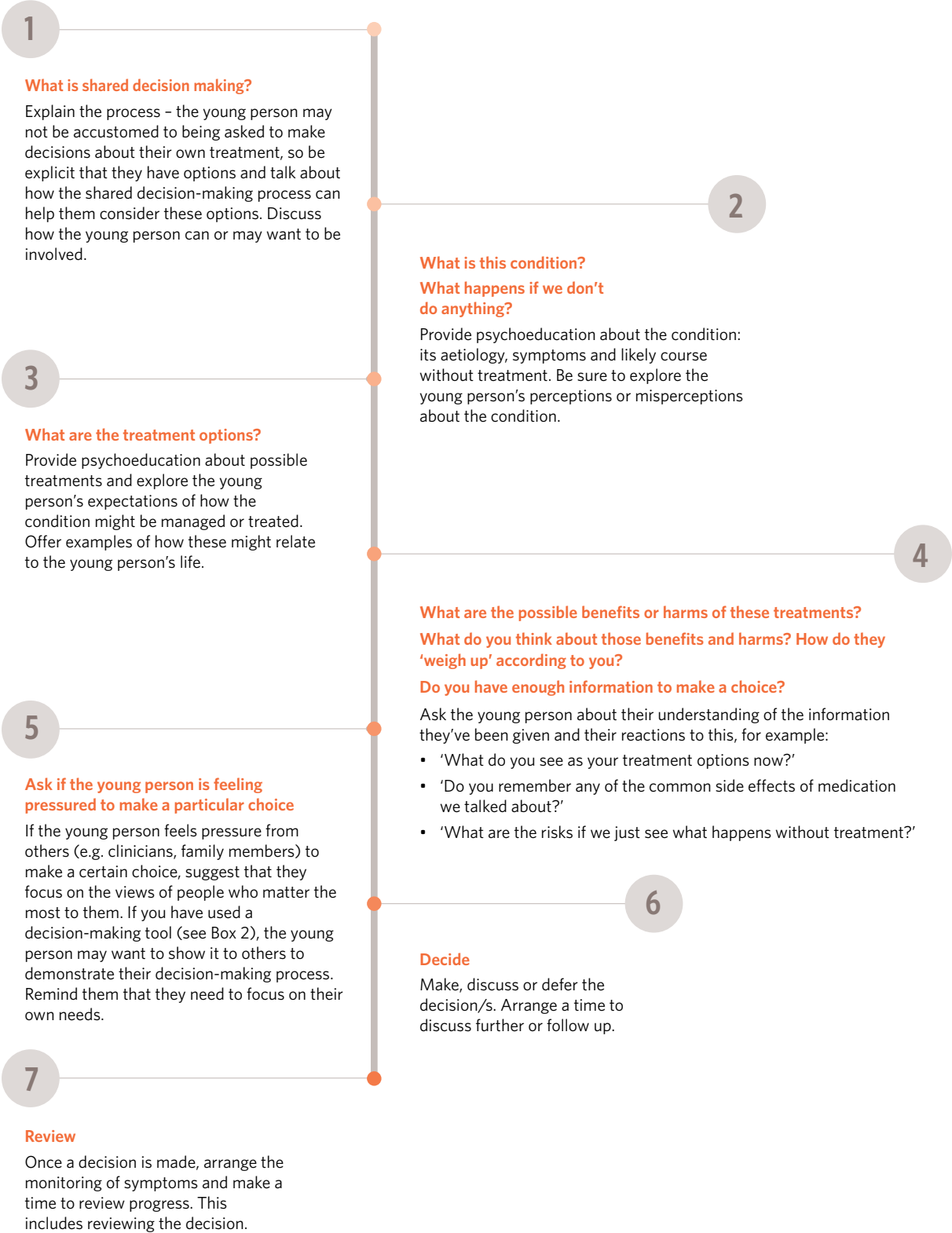


Figure 3. Questions to guide the shared decision-making process



TIP It's important to be clear that no decision is final and the decision-making process is ongoing. Always offer to revisit decisions with the young person and specify when this will be done.

Box 2. Decision aids

Decision aids are tools that have been designed to facilitate a shared decision-making process. It's important to note that the use of decision aids alone does not necessarily constitute shared decision making: they are one part of the process.

Decision aids aim to make the evidence regarding a decision available and understandable to a young person. They also aim to elicit and clarify the young person's values to help them decide what is best for them. Although published evidence summaries such as clinical guidelines or reviews can provide an overview of the evidence for clinicians, it is preferable to use tools that have been designed to communicate the evidence clearly to young people and to help with making decisions. More information about decision aids, including international standards for their design, can be found at the [International Patient Decision Aid Standards website](#).

How do I contribute to shared decision making as a clinician?

The clinician's role in the shared decision-making process is to ensure the young person is able and equipped with what they need to make an informed decision. This means more than being a conveyor of evidence, and relates to the concept of 'activation' discussed in Box 1. You need work with the young person to help them make sense of the evidence and consider from all angles how it is relevant to their situation and their needs.

It is possible that young people and families will ask your opinion on what is the best decision to make. It is important to be clear that, although based on professional experience, it is an opinion, and that the decision is ultimately made according to the young person's preferences. For example, it might be helpful to explain how you have previously found the experience of delivering psychotherapy to young people, or how you have seen other young people cope with the side effects of medication.

What if I don't agree with the young person's choice?

It's important to remember that there is rarely one right choice in any treatment decision, particularly in mental health, where presentations may be complex and treatment outcomes vary. In this context, therefore, most decisions are valid. Furthermore, if the young person is being treated voluntarily, it is their right to make decisions about that treatment, which includes the right to make a decision that you believe is not the best one.

“ [If I'd had more information] I think I would have tried another brand with less side effects maybe. Instead of just taking the first one that was offered to me.

Young person,
EPPIC, Orygen Youth Health Clinical Program

If you disagree with a young person's decision, it is crucial that you are not dismissive or disapproving of the young person's choice. If the young person perceives a conflict between their clinician's view and what they have decided to do, they may not feel that they can later disclose that the decision may not have worked for them and they might need to try something else. Instead, emphasise again that no decisions are final, and that the young person's treatment and symptoms need to be monitored so that the treatment can be refined if necessary. Be optimistic that the chosen treatment option will be effective, and also clear that if it isn't, the decision can be revisited.

For some young people, a degree of 'clinically indicated risk-taking' might be appropriate, where it is deemed better to allow a young person to make a decision about treatment that increases their risk of a relapse, rather than risk their disengaging from the service altogether. This kind of decision must be made by the whole clinical team, with a comprehensive risk assessment underpinning it. Frequent review is also essential. See also the manual *What to do? A guide to crisis intervention and risk management in early psychosis*.¹⁷

Case scenario: Sasha

Sasha was referred to an early psychosis service after telling her GP that she was hearing voices that were 'always going on at me'. She is in her second year of university and the voices have caused her to lose confidence in her ability to study. She was assessed as meeting the criteria for a first episode of psychosis and is now meeting her treating doctor again for the first time since being assessed.

Clinician: So we've discussed that you'd like to try medication to help with the symptoms you're experiencing. There are a few different medications we can use to treat psychosis, so what we need to do next is work out what's going to be the best one for you. What do you think of the chart that I gave you?

Sasha: Um, yeah ... it's a bit confusing.

Clinician: I know - there are a lot of them! Maybe we could focus on the side effects column. Unfortunately, because medications affect how your brain works, this means that although they can do things you want, like reduce your symptoms, they might also do things you don't want, like give you side effects. I think these medications [*points*] will be the best for you in helping your symptoms. So probably we should choose one that will cause you the least trouble with side effects. What do you think?

Sasha: Yeah, that sounds good. Like, this one here says it will make me more agitated. I dunno, the voices already make me pretty agitated...

Clinician: Ok, good. That's good to know. So how about we go through all the side effects and think about how each of them might affect you - which ones you might be able to live with and which ones are deal-breakers? Then we might have a better idea of which medication would suit you best.

Sasha: Okay.

Clinician: It's also important for you to know that everyone might react differently to each medication, so these lists are of side effects that we know are *likely* to happen for each medication - they might not necessarily be how you react to them.

Sasha: Okay. So what if the one I choose does end up having really bad side effects?

Clinician: It's okay, we can change it at any time. We'll monitor your progress together, including whether you are getting any side effects, and if it looks like the drug isn't helping with your symptoms, or if it causes side effects, we can think about what to change. We can come back to this decision any time you want. I really encourage you to bring up any problems you're having - that's one of the best ways for us to know how the medication is working for you. And that's also why we need to let you know what kind of things might be side effects, because you might not think something is related to the medication when it is. Keeping this conversation going while you are trialling this medication is really important.



TIP It is important to remember that the aim of mental health care for young people is to promote their overall recovery and psychosocial functioning. Thus, the shared decision-making process should consider the young person's goals for recovery in all domains of functioning, not just symptomatic remission.

Do I need to involve the young person's family?

Ideally, a young person's family will be involved in all aspects of their care, including decisions about that care. Family members may therefore be incorporated into shared decision making wherever appropriate;

however, it is not essential that family members are involved in the process. Ultimately, while the family's views should be considered, and it is important that they are aware of the young person's choices, it is the young person who makes the decision about their own care. See also 'Some young people aren't capable of making these decisions' under 'Common misperceptions about shared decision making'.

When families are involved in shared decision making, clinicians will also need to work with family members, as well as the young person, to help them understand the shared decision-making process. In cases where the family and young person disagree about what is the best option (e.g. if the young person decides not to take medication), the shared decision-making process may help reassure the family about the young person's choice. Sometimes seeing that the young person has gone through a structured, logical process to come

to their decision makes it easier for family members to accept the choice even if they disagree with it. It may also help to be clear to the family that the young person's decision will be reviewed regularly, in accordance with their values and needs, to ensure that it is helping their recovery.

Common misperceptions about shared decision making

One of the most important factors for shared decision making is investment in the concept by both services and clinicians in the service. Clinicians must value shared decision making and want to use it, but there are a number of common misperceptions sometimes held by mental health professionals that lead them to believe that shared decision making is not worthwhile.

It takes too long ('I don't have time')

Time restraints are often cited as a reason clinicians don't participate in structured shared decision-making processes with their clients.¹⁵ However, studies of shared decision-making interventions have shown that they do not increase consultation time.^{7,9,15} It should also be considered that even if consultation length were to increase because of shared decision-making processes, it would arguably save time in the long run. The young person would be more likely to feel involved in decisions, and less likely to end up receiving treatment that doesn't match their values or needs. They would therefore be more likely to be better engaged, adhere to treatment and achieve better outcomes.

“ It does take a bit of time, but using a structured decision aid can help make things more practical, and the overall outcome is a greater sense of empowerment for the young person, and a more collaborative way of practising.

Senior clinician,
Orygen Youth Health Clinical Program

“ Shared decision making empowers people, because you are in charge of your own recovery

Youth peer worker

Leaving it up to the young person to decide makes them feel unsupported

It is not the intention of shared decision making to leave young people to make decisions on their own, but rather to give them evidence and support so they can be involved in the decision-making process and ensure that a decision is made that is best for them. This includes the decision to not take part in shared decision making. If the young person does say they don't want to be involved, it is important to explore why. For example, the young person may be overwhelmed and distressed by acute symptoms of psychosis, and may feel unable to make decisions about their treatment at that particular time. In this case, the clinician may need to take a more decisive role in treatment until the young person's symptoms improve, at which point they can revisit the young person's decision not to be involved in decision making. The use of advanced care statements can also help the young person have input into treatment decisions when they are acutely unwell.

Further, if a young person says that they do not want to be involved in making the decision, they might not know what involvement means. Providing young people with examples of the different ways in which they can be involved is important to maximise the chances that they will engage in the decision-making processes.



How you frame the process of shared decision making can make a big difference to how a young person perceives it. For example, saying, 'It's up to you to decide' can be quite daunting; instead, explain that you want to get the best possible outcome for the young person, and one way to do this is to get their input and work with them to choose an appropriate treatment.

Case scenario: Sasha (continued)

A month later, Sasha brings up the subject of her medication with her doctor.

Sasha: I know I said I could live with being sleepy, but it's too much. I'm just so lethargic all the time, and it's so hard to drag myself in to uni in the mornings. I mean, it's good, it's helping with the voices, but ... I don't know, do you think I should stay on it?

Clinician: Well, it sounds like there are some good and bad things with this medication, right?

Sasha: Yeah, but I think the sleepiness is actually a deal-breaker.

Clinician: Ok, fair enough. It's great that you've brought this up as an issue - I know that keeping on with your studies was your number one goal. I probably can't tell you definitely what to do - but let's look at the evidence and options again. We can see what might cause less sleepiness. Remember, this is all part of the trial and error we talked about that will help us get the right treatment based on what's important to you.

Not all young people want to be involved in shared decision making

There is evidence to suggest that adults diagnosed with mental disorders want at least some involvement in decisions about their treatment¹⁸⁻²¹ and some studies have in fact shown that people with mental health disorders may be more likely to want involvement than those with general medical conditions.²²⁻²⁴

Young people also express a desire for collaborative approach to treatment.²⁵ However, it is important to remember that few will have much experience of the mental health care system, or of health conditions that require ongoing treatment. Even if they have been involved with other mental health services, they may not have experienced a shared decision-making approach. They may therefore not be aware that they can be involved in decisions about treatment, and may be more inclined to leave treatment decisions up to authority figures such as doctors or case managers (see Box 3). It is therefore important that clinicians educate young people about the shared decision-making process and do not assume that if a young person doesn't express a desire to be involved in decisions that they don't want to.

“ It would be amazing if I could see on a piece of paper options for treatment ... that would be mind-blowing, to discuss what I think would work best with my personality.

Young person with depression, in Simmons et al. 2011²⁵

Box 3. Cultural considerations for shared decision making

Young people or family members from culturally and linguistically diverse (CALD) backgrounds may have expectations of the treating team that can have implications for the shared decision-making process. For example, they might be used to a model of health care where doctors and mental health clinicians are positioned as 'experts' and expected to tell the young person what the best treatment option is.

This does not mean you cannot use shared decision making when working with young people of CALD backgrounds and their families, only that you need to explore with them their cultural value system with regard to treatment decision making. This includes presenting the shared decision-making process as an option for how they might like to be involved in decisions about their treatment.

Some young people aren't capable of making these decisions

Many clinicians have concerns about young people's decisional capacity, often because of either their symptoms or their age. While it is true that young people with severe mental health disorders may have cognitive or thought disturbance symptoms, this does not automatically exclude them from participating in decisions. A study into the decision-making capabilities of adults hospitalised for depression or schizophrenia found that 76% of the depression group and 48% of the schizophrenia group demonstrated 'adequate' decision-making capacity on tests designed to measure:

- understanding of information
- appreciation of their disorder and of the possible value of treatment, and
- how well they are able to reason about information to decide on treatment options.²⁶

As a group, the individuals with schizophrenia performed worse than the depression group and a control group. However, there was considerable variation in people's scores, and in fact for each individual measure, most of the people in this group performed as well as people in the community; the low average performance was due to a small subset of people who had very poor decision-making capacity.

The important message from this study is that people with severe mental illnesses should not automatically be considered incapable of making decisions about their treatment. Furthermore, this was a study in adults with chronic conditions, and it is possible that the decision-making capacity of young people with emerging mental health issues may be less impaired.

In the case of involuntary treatment, whether or not a young person is decided to be incapable of making certain decisions about their treatment (e.g. the decision to refuse treatment) depends on the mental health act in each state. However, a shared decision-making approach can still be used with mandated treatment (see Box 4).

Box 4. Using shared decision making when treatment is involuntary

Even if a young person has been mandated to receive treatment, it is still possible to use a shared decision-making approach. For example, if treatment with antipsychotic medication has been mandated, the type of treatment (e.g. which particular antipsychotic) can still be decided using a collaborative approach. This can help minimise feelings of disempowerment and the harm to engagement caused by involuntary treatment.

Regarding age, as already mentioned, it is likely that young people want to be involved in decisions about their treatment, and there is no reason that someone's age *per se* should be considered a barrier to involving them in shared decision making. Actively involving young people in treatment decisions is also consistent with their need to achieve the developmental milestones of de-individuation, increased autonomy and responsibility and learning to make decisions in all aspects of their lives.

If working with very young people, it can still be assumed that they can be involved in shared decision making, but more input from family members or guardians might be sought if necessary and desired by the young person. It is the clinician's responsibility to monitor the young person's engagement with the information provided and to present information in an age-appropriate way.



TIP A common concern is that young people may not have the necessary skills to participate in shared decision making. However, these skills can be taught - remember, one of the roles of clinicians in shared decision making is to activate young people to be capable of participating.

Concerns about decisional capacity only highlight the need to tailor the process to each individual. It is not known whether young people with emerging mental ill health have a better or equal capacity compared with adults with established conditions; however, it seems reasonable to consider the known symptoms of some conditions that might affect decision making (e.g. poorer cognitive function is common in people with diagnosed schizophrenia) when tailoring approaches to shared decision making. It may also help to:

- have a range of material and formats available (e.g. visual material, online material, different language translations of resources)
- give young people options for how they might be involved in decisions (e.g. they might be content for their doctor to manage decisions about medication, once they have discussed their values with them, and prefer to be more involved in decisions about psychosocial interventions)
- use peer support programs or workers to facilitate shared decision making. As well as providing a valuable perspective on what it is like to experience mental ill health and treatment, peer support workers can also educate young people about the shared decision-making process.

“ I know I’m not well, but I clearly like a bit of logic.

Young person,
EPPIC, Orygen Youth Health Clinical Program

Shared decision making is already commonplace in youth mental health ('I already do this')

Many youth mental health services emphasise a collaborative approach to young peoples' care; thus, many clinicians and services may think they use shared decision making as part of their routine approach to care. However, it is unlikely that a comprehensive, structured shared decision-making approach is used (possibly because of the misperceptions, already mentioned, about what shared decision making is and requires).

One review of 33 studies (in both mental and physical health settings) where shared decision making was assessed according to patient involvement found low levels of patient involvement.²⁷ Other studies have found that on average clinicians performed poorly on standardised measures of shared decision-making behaviours.²⁸⁻³⁰ No studies have systematically measured the extent to which young people diagnosed with mental health disorders receive a shared decision-making approach.

Shared decision making - it's worth the effort

Every young person has the right to be consulted and involved in decisions about their own care. It is what young people desire, and is likely to lead to better engagement, adherence to treatment and therefore better outcomes. Shared decision making provides a structured way of achieving this involvement, but lip-service to 'collaboration' by service providers and clinical staff is not enough; incorporating shared decision making into clinical practice requires commitment from both services and clinicians to making it a routine and valued part of practice. Although a structured shared decision-making process might require learning new skills and a change in practice, these are worthwhile investments in young people's care.

“ It's very important to make sure [young people] are making informed decisions about their own healthcare; shared decision making ensures a better consumer experience.

Youth peer worker

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