Practical exercises for having discussion with people with an intellectual disability

Talking about the desire to have a child

Toolkit
Talking about children
Familiarizing yourself with the desire to have a child

Stand by people with an intellectual disability: try to stay positive

Offer space and explore

First ask then contribute

How can you engage in a conversation with someone with an intellectual disability as openly and neutrally possible?

Practice a discussion about the desire to have a child

Annexes:

• Five case examples
• Observation list
• Evaluation questions
Familiarizing yourself with the desire to have a child

Professional care workers and family members become aware of the desire to have a child of someone with an intellectual disability in different ways.

It may be that the client talks about it straightforwardly. For example: ‘I want a child because my sister also has one.’ Or: ‘we live together now, so now we also want a child.’ It may also be expressed more indirectly. You notice that they express much interest in matters concerning babies: they pay a lot of attention to baby clothes, are always looking in baby strollers, or they look fondly at young children around them. You might also suddenly be faced with a fait accompli that someone with an intellectual disability is already pregnant.

What do you do when the topic of wanting to have a child suddenly comes up in a discussion? What do you do when a client explicitly expresses a desire to have a child? What about when you suspect that your client wants to have a child? What do you do when you suspect or have just heard that a client is pregnant?

How do you bring this topic up?
What are the important issues it involves?
What is your attitude?
What skills do you require?

What do you do when a person with an intellectual disability expresses a desire to have a child?
Stand by people with intellectual disability: try to stay positive

In actual practice we still see that the moment someone with an intellectual disability expresses a desire to have a child, or when there is suspicion of their desire to have a child, all sorts of alarm bells go off immediately.

Doubts about parental competence and concerns about the development and well-being of the child often result in professional care workers engaging in the topic with a sense of anxiety. There is an almost automatic control mechanism that kicks in, and either consciously or unconsciously we convey: ‘Don’t do it!’

In any case, these are not the thoughts that would help us provide appropriate support. Preemptively placing a risk label on the issue may result in the potential future parents turning away from us rather than having us actually assist them.

That is why you should try to engage with people who have an intellectual disability as positively as possible and listen to what they have to say.
The most important thing you can do is let the ‘desire to have a child’ be there. That is not the same as approving or encouraging that a child arrives.

It is, however, important that the client tell her or his story without any external interpretations or prejudices. You will notice that taking this position creates the space necessary for discussion about the desire to have a child.

The next step is to explore what the significance is of the client's desire to have a child. Take some time to think about the following questions with the client: Why do you want a child? Is it so that you think you’ll be like everyone else? Is it so that you'll have something to cuddle? Is it because you get so much in return? Above all, find out if the desire to have a child also means the person wants to be a parent. Does this person really want to be a mother or father?

You can have sessions with both partners or individual sessions with each partner separately. If the desire to have a child comes from a single female client, the discussion should turn to why she is choosing to have a child on her own, and if it is a realistic option.

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**Offer space and explore**

*Take some time to think about the following question with the client: Why do you want a child?*
First ask
then contribute

In order to be able to hear what a client says, you also have to listen carefully. This means that the client is able to tell her/his story without well-intentioned interference beforehand, because you anticipate what will be said.

For the discussion about a desire to have a child with a client, among the things that apply are the following interview skills: Listening! Restrict yourself to listening and suppress the tendency to convey a value judgment either verbally or non-verbally. There is no right or wrong. Active listening: this means that you ask and inquire further, without immediately trying to find a solution or give advice.

Many things can be discovered by giving client space:
- What exactly is the client’s question?
- What is the client’s experience regarding the desire to have a child?
- What ideas does the client have about this topic?
- What does the client know about children and raising children?

In a first session, it is mainly about providing the client the opportunity to express herself/himself. Try to keep an open and neutral position. Make sure that what you say is in accordance with what your body language is expressing.
How can you engage in a conversation with someone with an intellectual disability as openly and neutrally possible?

- Follow the client using her/his words.
- Ask questions for clarification when you do not understand something.
- Ask open questions (who, what, where, when and how).
- Support the client's feelings.
- Constantly summarize and organize the information the client provides.
- Check to see you that understand the client correctly (‘Am I saying that right?’).
- Be aware of your non-verbal body language. Avoid saying that ‘the desire to have a child’ may be there, while at the same time there is a stamp of disapproval on your forehead.
**Practice a discussion about the desire to have a child**

A desire to have a child is not the easiest topic to discuss with people with an intellectual disability. It therefore requires some practice to have such a discussion.

You can do this in your own team, during an intervision or theme meeting, during training or work supervision, with colleagues, managers, experts, and possibly also with parents and/or family members.

The case examples included here may be of some assistance with this. Of course, you can also take a case from your own practical experience. Jointly decide on a case and decide on who plays which role. One person takes the role of the client, and the other takes the role of the professional care worker. The third person (or the rest of the group) functions as an observer.

The case examples are described on separate cards. The general description is read aloud for everyone to hear. The cards contain additional information. There is one card for the one who plays the role of the client, and one card for the 'care worker.' They do not exactly know what the assignment is. They begin the discussion. The task of the observer is watch closely and keep track of a number of items (see the Observation list on page 15). Keep a notepad nearby to make notes.

After the exercise, the discussion is examined collectively using a few questions (see page 16).

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**A desire to have a child is not the easiest topic to discuss with people with an intellectual disability.**
Annexes

Case example 1: Kimberley

Case example 2: Janette

Case example 3: Wilma

Case example 4: Nell

Case example 5: Saroya

Observation list

Evaluation questions
Case example 1

Theme: discussion of a plan for the future

Kimberley

General description
Kimberley is 15 years old. She is in vocational training and does not yet know what she wants to do when she finishes with school. Kimberley still lives with her parents. She has a 21-year-old boyfriend who is a groundskeeper. Kimberley loves children.

Role of the client
You do not yet know what you will do when you finish with school. You would like to do something with children. Would a degree course that prepares you to work with children be an option? Perhaps you would also like to have your own child. You will have a meeting with your professional care worker in a little while. Together the two of you are going to make a plan for the future. What would your ideal future look like?

Role of the professional care worker
You are Kimberley’s professional care worker. Today you have an appointment to discuss her future. Think about which topics should be addressed if you and Kimberley want to make a plan for her future.
Case example 2

Theme: the desire to have a child is expressed directly/arises during a discussion

Janette

General description
Janette is a 26-year-old woman with an IQ of 59. She lives alone and receives three hours of supportive care per week. She does not have a partner and works in a sheltered workplace. Janette is able to maintain her home independently. Her professional care worker has tried to teach her how to cook, but that has been unsuccessful. She now eats already prepared convenience foods almost exclusively. Janette has a sister with three children. She sometimes babysits for her sister. She goes to the clubhouse around the corner every day of the weekend. She line dances and is very fanatic about it.

Role of the client
You are absolutely crazy for your sister’s children. She has six-month-old twins and a three-year-old toddler. You were there this week. You think that your sister really likes it when you go there to help her. She often says that you do everything very well. Now you also want your own child. Your professional care worker is coming by today. During your discussion, you try to express for the first time that you want to have a child.

Role of the professional care worker
You are Janette’s regular professional care worker. During your weekly house visit at Janette’s, as usual, she talks about how she is doing and how things are at the moment. Of course, you also ask about the kinds of things she did during the past week.
Case example 3

Theme: there is suspicion of a desire to have a child

Wilma

General description
Wilma is a 28-year-old woman. She has an IQ of 68 and works in the cafeteria in a community centre. Wilma has one brief relationship after another. She cannot seem to keep a steady relationship for a long time. Wilma can take care of herself reasonably well. However, she has depressive periods. In those times, she does not take very good care of herself. She has a dog and three cats. When you go to Wilma’s house, it does not always smell very pleasant. Wilma uses the pill, but she thinks it is making her too fat. That is the reason why she has stopped using it.

Role of the client
You are not feeling very well. You have periods when you are somewhat depressive. You are looking for what you should do with your life. All of your friends have a boyfriend or are married. A few of them have children. You would also like to have one. Only, you cannot seem to keep a steady partner. They always leave you. At any rate, you want to have a baby, either with or without a partner. Maybe that will happen if you stop with the pill…?

Role of the professional care worker
You have an appointment with Wilma today. You are concerned about her. Wilma has told you that she stopped taking the pill. She says that it is making her fat, but you suspect that there is another reason. Try to talk to her and find out what she wants now and in the future.
Case example 4

Theme: there is suspicion of or it has been discovered that the client is pregnant

Nell

General description
Nell is a 17-year-old girl. She still lives with her parents and has no longer gone to school for a while (vocational training). Nell is away from the house the whole day, hanging around in the city. The police have knocked on the door a couple of times because she shoplifted. Nell's mother has little time for her. She has a large family with five children and provides the family with financial support on her own by cleaning houses. She is now very worried. Recently Nell has not gotten out of bed and does not even go to the city anymore. She is very irritable and often nauseated. Her mother thinks she is pregnant.

Role of the client
You have different boyfriends and do not get very close. You have recently had unprotected sex. You have not felt very well for a while. You wonder if you are pregnant. You do not dare tell this to your mother. She would only get incredibly angry. In a little while, your professional care worker will arrive. You have not seen her for a long time because you really have not seen much use for her. This time you want to speak with her.

Role of the professional care worker
Nell's mother calls you. She is afraid that her daughter is pregnant. Mother does not dare to have this conversation with her daughter. They would possibly have an argument that gets physical. You have not had any contact with Nell for a long time. Every time you had an appointment, she found an excuse to cancel. Mother says that Nell wants to talk with you now. Have a discussion with Nell.
Case example 5

Theme: the client already has a child and wants a second child

Saroya

General description
Saroya is a 19-year-old woman with Antillean heritage. She has a two-year-old son. Her IQ is 75 and her emotional age is 8. Saroya has three sisters and two brothers. She sees two of her sisters and her brothers regularly. The third sister turned her back to the family years ago after having a major dispute. All together Saroya has eight nephews and nieces. Her father and mother often babysit for their grandchildren, including Saroya’s son. Saroya has been living in a flat with very intensive supportive care for a year. She is reasonably competent when it comes to the physical care of her son, although he sometimes wears the same clothes several days in a row. His emotional development escapes her. She does not fully understand why he does certain things such as saying ‘no’ to everything. She says he is being quarrelsome. She sometimes finds him to be burdensome. Saroya works in a supermarket two days a week. She keeps her apartment clean and cooks every day. She has many friends and often goes out. She is crazy about babies.

Role of the client
You would like to have a second child because you are crazy about babies. You do not really like that your son is getting bigger. You also like the feeling of being pregnant. Many of your friends have two or more children. So, why not you? You do not mind that you do not have a steady partner. You have enough support from your family.

Role of the professional care worker
You are Saroya’s regular professional care worker. You suspect she wants a second child. Try to find out if you are right and if so, as further about exactly what her reasons are for why she wants to have another child. Is she aware of what a second child involves? How does she imagine that? Discuss this.
Observation list

1. What do you think the feeling was that the client and professional care worker had at the beginning the session?

2. What was the mood during the session?
   Did you sense that the session was emotionally charged in any way?
   What was it you saw to substantiate this observation?

3. What was the intonation and physical posture of both parties?
   What could this intonation and physical posture mean?

4. Does the client have room to tell her story?

5. Is there attention given to the client’s likely desire to have a child, and in what way does that happen?

6. Are there solutions and recommendations given during the session, and at what point does this happen during the session?

7. What is your opinion of the way they both experienced this session?

8. Do you have the impression that the client felt understood?
   What gives you that impression?

9. How would you characterize the professional care worker’s attitude?
   • sensitive
   • disapproving
   • neutral
   • tense
   • indifferent
   • other, specifically:

Make sure that everyone who takes the role of observer has a copy of this observation list.
Evaluation questions about the case examples

Questions for the client
Were you able to say everything that you wanted to say?
Did you feel like you were understood?
Did you feel interest or disapproval from the professional care worker?
What did you think of the questions that were asked?

Questions for the professional care worker
Have you ever carried out a session such as this in the past?
Did that session go the way this one did?
Do you think that you listened carefully to the client?
What did you think was easy and what was difficult when asking the questions?

Questions for the observer
What did you see/hear?
What observations did you document?
Compare these observations with the findings of client and the professional care worker.

General
Have a more in-depth discussion with each other and exchange any pertinent practical experiences.

Provide a copy of these questions to all participants.
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