**Developmental Disability WA, Online Course:**

**Supported Decision Making**

**Module Two: Planning**

**Video Transcript**

This resource is about decision making for people with an intellectual disability. The information in this resource is for supporters. Supporters may include parents, friends, family members, support workers, team leaders, coordinators and allied health professionals. The resource provides general information to guide the process of supporting decision making for the person you support. It is recommended to progress through both modules starting at module one.

Module two. Planning for supported decision making.

At the completion of the planning module, you will be able to answer:

What do we need to consider when thinking about who will support the decision?

What do we need to know about a person to effectively support them to make decisions?

And what steps are part of the decision making process?

After module one, hopefully now you're on board with being involved as a possible support person in the supportive decision making process. Planning is a very important module, as there are so many things to consider when doing supported decision making. We don't just want to support decisions, but we want to do it well and feel confident in the process. We can keep improving as we go, keep learning, and keep reflecting.

One consideration is who will be involved? We have established that supporters are needed for supported decision making to work. These supporters need to believe the person with a disability can be involved, and they have the expectation for them to express a preference. A commitment to the rights of the person, and being responsive to their preferences, are very important for good practice when providing support throughout the decision making process.

The attitudes and perceptions of the supporters have been shown in research studies to be important in supported decision making. A support network is even better. We might even have different people who we seek different advice or support from. For example, we may have some people who we prefer to discuss romantic advice, and other people we would prefer to discuss financial advice.

Also, consider if there is any conflict of interest, or bias. Consider your own values and attitudes and how this may influence options which are explored in the decision making process. Consider the right person or people to be involved. In some cases, we may even want an independent person with special skills to help out. A person may not wish to draw support from their friends or family, sometimes they may draw support from someone they already have an established relationship with. Sometimes people prefer an independent person with specialist skills.

Several people can be involved in supporting a person with a disability to make a decision. The decision maker is always at the center of the process, and can also choose who is involved.

An understanding of who the person is, their history, character and culture is often considered important before you can support a person to make decisions. In the past, a support network may have made decisions on behalf of someone with an understanding of their interests, and strengths.

Some research has found that decision making is impacted by the quality of the relationship between the supporter and decision maker and not if the support was paid versus unpaid. Considerations about the individual may also consider what is important for this person, and what is important to this person. This information is valuable to support the decision making process. Ideally, we would like to achieve a balance between important to and important for.

For example, if it is important to Belinda that she eats dessert, but it's important for Belinda to maintain a healthy weight, what balance can be achieved? Should Belinda have dessert planned for some days during the week? Can healthier dessert options be considered?

It is important to keep in mind that sometimes what is important for us is not always important to us. The focus isn't also not on the cognitive prerequisites for making a decision, but on the quality of support available to help the person make a decision. There is no single way to give support as each person requires individualized support, and each decision may require different types of support.

We need to consider the person and their factors such as who they are, what's important to them, what's important for them, and focus on the quality of the support, not cognitive requirements. Research literature reflects a strong value in supporters having a positive perception of the ability of those whom they support to lead a self directed life. There is a positive correlation in recognizing a person's rights and their engagement in supported decision making. Sometimes people may need experience with making smaller decisions before they're ready to make bigger decisions that may have bigger outcomes. A person can be supported to develop confidence capacity and their ability to convey their decision. This can help build the expectation of the individual to be a decision maker.

We need to know how the person understands information and expresses themselves. An understanding of how a person expresses their feelings and preferences is required. This can be with facial expression, gestures, eye pointing, touch, speech, sign, written text, pictures, photos, or using an aided communication system.

For some people it may be more difficult to easily determine their preferences, and a support person may need to help interpret their communication. Joanne Watson explains how people who have a severe or profound intellectual disability and may communicate with facial expression, vocalization, eye gaze and touch, may be supported with making decisions.

Communication partners acknowledge these forms of communication and observe these as expressions of preference, thus assigning meaning to them, and then act on the meaning. Expression of preference and interpretation of preference can be subjective and may require focused effort. Supporters just need to make sure that they're not assigning meaning to help shape the decision in the direction that they would like.

Marley continues to share her story about supporting Matt, her brother, make decisions. We asked Marley, how does Matt communicate?

Marley says- Matt mainly communicates through body language. So when he is giving a positive response, you'll see him smiling, you’ll see him clapping his hands, and he'll even maybe high five. He’ll laugh and you can even see that he's at ease, interacting and interested with what you've said. If he's not interested or he doesn't like what you've asked to do, he'll maybe hit himself or hit his head. He'll point away. Like, go away. And sometimes he may even lash out and hit another person. (End of Marley Talking)

Even when supporters understand some of the person's communication, why is understanding supportive decision making principles still important?

Marley says- In the past, Matt mainly made decisions, through gestures. So he would do a nod of the head, or a shake of the head, to let us know if that was something that he wanted. He would also bring us objects, for example, if he wanted to go for a swim. He would go into the cupboard, grab his bathers, and then bring it to us and show it to us, and obviously straightaway we would say you’re ready for a swim, do you want to go for a swim? But I did find looking back that a lot of his decisions were us basically talking at Matt and really not giving him, maybe one or two options, but there was no explanation for him to go further with that. (End of Marley talking)

Sometimes people who do not use speech in everyday interactions may benefit from augmentative and alternative communication, or AAC. AAC means to enable greater participation for individuals where they can communicate as efficiently, independently, and in a socially valued manner. There are two main types of AAC. Unaided and aided. Unaided AAC includes facial expression, gestures and sign. Aided AAC includes low tech, or non electronic tools such as alphabet boards and picture cards. Also, Aided Language displays, or communication books and high tech or electronic tools such as speech generating communication devices.

People can be candidates for AAC depending on their communication needs and is not based upon their skills or capacities. In fact, some people may not be able to show us what they know without an opportunity to learn how to communicate or a means to communicate. AAC may facilitate their comprehension skills, or how well somebody understands. We need to give the person the opportunity to receive information in a language or a manner that they can understand. This may include weighing up the pros and cons and options to help them make a decision.

How did Matt’s supporters use his communication system to get more information about what he wanted?

Marley speaking- We used the pod to be able to ask Matt for his opinion for the name of his Microboard by working across the top, looking at places that he likes to go. And as we went down the list, beach got a really positive response so that was good, we knew it had to be something about the beach. We then moved across, and to the question, what things do you like?

And as we worked our way through the column food, we got a positive response too. That was a bit tricky, there was lots involved there. But then as we went down further then we hit the nail on the head with beer, and we got a really good response from that, so then he had indicated to us that the name needed to have something to do with beach, beer and food. (End of Marley speaking)

What difference did introducing a communication book, make to Matt's decision making?

Marley speaking- I've learned so much being part of this project. And I think the most important thing that I've learned is how to use the pod as a way of communicating with my brother, rather than just having a yes, no conversation. It's given me the opportunity to be able to actually have a conversation with him that is two way. Of me being able to ask questions of him and him being able to tell me, and just give me information, and at the end of it for him to be able to make a decision. And I think that's the most important thing. (End of Marley speaking)

It is important to remember that the process of how each person is supported to make decisions is individualised. There is no one size fits all approach.

A supporter said, “It's about implementing the practice of decision making. It's about stopping and thinking about how we give Sam information to make decisions that are informed. It's a very disciplined practice”.

Firstly, let's look at the decision making process. We may start with considering what is the decision. And then who will be involved. How does the information need to be presented. What is the information. The pros, the cons and possible consequences of each outcome. How will the decision be communicated. Then, the person may need support to implement this decision. And then we can reflect and review and consider how he went, and if there's anything we could do to improve for next time.

We asked Marley what decisions did Matt want to make?

Marley speaking- So we had two questions that we wanted to ask Matt. First question was, did he actually want a Microboard? And then the second question was, what he wanted his Microboard to be named?

What is a Microboard?

We decided that it would be beneficial to create a Microborard, which is a support network of people that know Matt, and who has his best interests at heart. And the purpose of the Microboard is to support Matt, to make decisions for him to have the best life that he wants to live.

How did you know that he wanted to explore these decisions?

So, once we'd worked out the areas that Matt was interested in. We then asked him using the pod, whether or not he would like help, if he would like us to help him to actually name his Microboard, and we got a very positive response to that, and it was a definite yes.

What were the steps of supporting Matt's decisions?

It was important to have this happen at his home, where he felt safe and familiar. And next, then we had a series of photos that have been taken of each member of the Microboard and mom had popped that up on the wall, and so Matt was introduced to each of the Microboard members via photo image as well as in person.

Then a Microboard reader had been devised and for the Microboard reader was a single photo, a very clear photo, and very simple text that explained each of the part of what a Microboard meant. And this was read to Matt several times for him to have some comprehension and understanding of what the background behind what the decision that he was going to be making was. (End of Marley speaking)

Matt’s supporters helped to come up with some ideas for names and discarded the ones that Matt didn't like. What did they do once they were down to three possibilities?

Marley says- We then came up as a group with three names for Matt’s Microboard. One was eliminated very quickly, and so that left us two options. So, we then put the two pieces of paper in front of Matt.

Once they were down to two options which Matt liked. What did Matt supporters do?

Marley says- So I just re-drew a picture based on his interests with the new title and we put them both in front of him. For him to decide.

What was Matt’s final decision, and how did you know?

Marley says- We placed two options in front of Matt, and the one that we called the Pub Grub Beach Club was by far the winner. And when each of those words in the title were mentioned his hands went up, massive smile, clapped, and we knew that that was the one that was going to be the name of his Microboard.

How did the supportive decision making steps help?

Marley says- following the steps that we did, we were able to work through a process to help Matt to make his own decision on the name of his Microboard. (end of Marley speaking)

Another supporter said, “through the process, It's his decision. I've learned a lot. It's not just a yes or no. But if he does say yes, you feel confident as you know what he wants”.

What difference has supported decision making made to Matt, and his sister Marley?

It's mainly about supporting Matt to make decisions. It’s that I now know and have a process that I can go through with to help me. And I now know I won't make an assumption on what I think he wants. He can now actually tell me what he wants. And he can make his own decision.

Being involved in the supported decision making process, and just this whole experience has been such an aha moment for me, actually even to the point of slightly life changing. Because the night that Matt made his decision on the name of his Microboard was absolutely amazing. And he was so happy that he had come to that decision. I was absolutely gobsmacked that we were able to get to that point. And I think that what totally amazed me was that he was so persistent. He didn't leave that table until we had got a name that he was completely happy with.

 And I was, I remember I was flagging. I was tired, and we gave him the option to come back to decide this at a later date. And he didn't, and he just stayed at the table. And when we came up with the final name, the Pub Grub Beach Club, and he was so happy. And I just thought you've made this on your own. This is your voice. And I was so proud of him and it just made me realize how resilient he is, how intelligent, he is. And the pod has given us the ability and the opportunity to be able to communicate and have a conversation, which all my life I haven't actually had that with him. So, yes he's my brother. But I really felt like I had an insight into who he is and his personality. (End of Marley speaking)

Module 2. Planning

Quiz

Question One. Who can be involved to support a person to make decisions?

A. Parent

B. A friend

C. Support Worker

D. Coordinator

E. My physiotherapist, occupational therapist or speech pathologist.

F. Any of the above.

Answer is, F. Any of the above.

Question two. What qualities does a supporter, need to have?

A. Enthusiasm.

B. A sense of humour.

C. Disinterest in the outcome of the decision.

D. Put personal bias aside.

E. Reflect on who might be the best person to make the decision.

Answer is E. Reflect on who might be the best person to support the decision.

Question Three. What do we need to know about the person to be good at supporting their decisions?

A. Their history.

B. Previous experiences.

C. Preferences, likes and dislikes.

D. How they communicate.

E. All of the above.

Answer is, E. All of the above.

Question Four. What are the steps to going about supporting decision making?

A. Decide who is involved.

B. Clarify the decision.

C. Recording information about the person's communication.

D. Ask the person a question.

E. It can be different for each person, and each decision.

Answer is E. It can be different for each person and decision.

End of transcript for module two.