

Inform Podcast
Episode 11: Supported Decision Making

Dr Jo Watson

I think probably the key message is that we need to make the assumption that everyone can communicate and everyone can make decisions, and that it shouldn't be a test of capacity. It should be a test of, perhaps if we're going to test anything, the support that is involved in, that is around someone so that's where the onus needs to be not on the individual's cognitive capacity to make decisions, but the amount and type of support they need to ensure their will and preference is reflected in decisions that are made about their lives.

Dr Jo Watson

My name is Dr Jo Watson and I'm a senior lecturer at Deakin University. I'm a speech pathologist by background., and I engage in research doing a number of things. But my real focus is around supported decision making for people with severe intellectual disability.

Kirby Fenwick

Hello and welcome to Inform, a podcast where you'll be hearing from people with disabilities, as well as industry experts, on a range of topics. I'm your host, Kirby Fenwick.

In this episode of Inform, we'll be discussing supported decision making.

At the start of this episode, you heard from Dr Jo Watson.

Today, Dr Watson will provide us with some background to supported decision making, information about the process including the value of circles of support and she'll give us some tips on how to support a friend or family member to make their own decisions.

So, what exactly is supported decision making?

Dr Jo Watson

So many people ask that question, what is supported decision making? What are the mechanics?

So, supported decision making is a very broad term. And I think it's generally, it's about supporting people to have their will and preference heard within decisions that are made about their lives, giving people that autonomy and self-determination and empowerment.

We all seek support from people in our lives to help us with decisions. Whether that be a financial advisor whether that be our GP there's, there's many of us who are very lucky to have an intimate and a close circle of support of people that know and

love us. And they're the people we turn to when we want support to make a decision.

So, I think what happens is for people with intellectual disability, we forget that we all need support to make decisions. And we tend to present as an independent decision maker. But that's far from the truth. I'm not an independent decision maker, nor are people with an intellectual disability, we all need support.

Dr Jo Watson

Okay, so supported decision making, I think, is really important. Because perhaps in the 70s and the 80s, even the 90s we started to see within the intellectual disability arena, we started to see a real focus on empowerment and self-determination for people with disabilities generally, and also for people with intellectual disability

And I worked in the US in the 90s and was very much a part of of that process. But what I saw was the people that I supported as a speech pathologist, people who communicated, not in an intentional way, not in a formal way, they really weren't being invited to this party. They were not on this empowerment boat.

Mainly because of their complex communication needs. So, they communicate, they may communicate informally, which means that they're not using speech to communicate. And they're not using symbols, but they might be using facial expression, they might be using eye contact, sometimes behaviours that that challenge some of us and all of that is communication.

When we think about human communication, we can think about it along a continuum. So you and I are having a conversation now Kirby around using symbols, so we're using words to communicate. So that, that if we wanted to label our communication type, we would say we're symbolic communications, all right, and we're communicating in an intentional way. We understand that I'm sending you a message and that message will have an impact on you in some way. So, I understand the power of communication. Then if we go along that continuum a little bit further, people might communicate in an informal way, okay. So not using symbols, so not using words, not using sign language, not using text. Okay. And they may, as you say, use facial expression, body language, eye contact, even very subtle communication systems like the pace of our breathing.

We all communicate in many, many ways. And speech is just one very effective way of communicating. however, we all communicate very subtlety, informally and sometimes unintentionally. And this, for people with severe and profound intellectual disability, the focus just needs to be a little bit more on that other communication.

Dr Jo Watson

So, when, at the turn of the century, when supported decision making started to be talked about, and then formalized within the United Nations Convention on the

Rights of Persons with Disabilities. I could see that as a mechanism that just might help us support this group of people.

So, that's where my interest came from. And then my PhD which I began in 2011 was to really explore what this supported decision making mechanism could look like for this group of people. And what we came up with were lots of great examples of how supported decision making and its principles can be applied in the lives of people with more severe and profound intellectual disability, and how then they can start to be living a more autonomous life.

Because autonomy is such an important part about being human. It really defines our personhood. And it always has, you know, that's something that has always been a very important part of being human. So therefore, everyone should have access to that autonomous life.

Kirby Fenwick

The United Nations Convention on the Rights of Persons with Disabilities that Dr Watson mentioned, was ratified in 2008. The first human rights treaty of the twenty-first century, this convention served as a catalyst for a global movement to view people with disabilities as full and equal members of society with human rights.

Signatories to the Convention are required to ensure that people with disabilities enjoy those human rights and that they are recognised and receive full equality under the law.

However, it's specifically Article 12 within that convention which Dr Watson believes is a 'vehicle that can be used to have everyone's voices heard in the self-determination movement.

Dr Jo Watson

So, what article 12 said is that everyone, or says, is that everyone has the right to have their will and preference heard within decisions that are made about them, that everyone has the right to make their own decisions. Now, we've had United Nations treaties or mechanisms in the past that have talked about this right to self-determination. So, it's not it wasn't something that was new. What was new in the United Nations Convention on the Rights of Persons with Disabilities, what was new is that article 12 said not only has everyone got the right to make decisions, make their own decisions, but really importantly, they have the right to be supported to make their own decisions. So, the emphasis then was taken away from the onus being on the individual. And the emphasis was on, more on the support that is required to have their will and preference heard.

Kirby Fenwick

So, Supported Decision Making is a mechanism for supporting people with disabilities who may have complex communication needs and be unable to make their will and preference clearly known, to make decisions about their lives and live

autonomously. So how does the process of supported decision making work? Dr Watson takes us through it.

Dr Jo Watson

So out of my research, I have come up with a model of supported decision making. This framework is a step-by-step approach, where a group of people, a circle of support, will come together around a person and go through five phases. Now in my PhD research, I worked with five people and their support network over a period of two years. So, it takes a long time to work through these phases properly. But first of all, we need to identify that a decision even needs to be made.

I'll give you an example as I'm going through those steps to just to tell you about how we have used this process in the, in the in the real world. A man that I've worked with for a long time has a wonderful circle of support. He doesn't use speech to communicate, he is an informal communicator, but he has a lot to say. A lot to say. So, one of the decisions that it was identified that he was, he was faced with and he had this, some money hanging around that needed to be used and he looked really, really bored on the weekend. So, he was living in a residential unit. And so, we came together and put the decision on the table, perhaps we need to help Tom make a decision about what he does on the weekends. He's got some money to spend. So, let's, let's help him make that decision.

So, the next step in that process once we've identified that decision, was to spend some time listening. Listening to Tom's smiles, listening to his body language, listening to even his behaviours that are challenging sometimes, listening to him. And that takes a lot of time. And the really important part of that is to do it collaboratively. Really important to do it collaboratively. Because we all have different, we all know Tom very differently. Okay. So Tom, for me, I may have a perception of his will and preference that is very differently to say his mum. So we came together, and we came up with some of the things that we thought he was telling us about that decision.

Kirby Fenwick

Dr Watson explains that on a hot Melbourne day, she went for a walk with Tom and one of his support workers and discovered something

Dr Jo Watson

We were at an athletics track and on that athletics track there was a corrugated iron shed. Very hot Melbourne day. And you know those, how they can get very, very hot. He kept going up to this shed and, and touching the shed and running his hands along the corrugated iron. I was very concerned because I thought he's gonna burn himself. It's very hot. And his support worker assured me that this was something that he did every day.

What we did in that time because this was a phase where we were exploring what he was telling us about how he might spend his money. We used a lot of video, we use a lot of video in this exploration phase. So, we took a video of that we took it

back to the circle of support. And we said, what do you think this means to you? And people agreed, yes, he really loves that texture, doesn't he? There's something about the texture on there, and the warmth that makes him happy. And when we looked at the video, we could see him smiling. We could see there's something about that texture. So, we explored what we could do with that. And that led us into the next phase.

So we came together and we came up with some activities that we thought he might enjoy. Now the corrugated iron, the shed issue we thought how could he, how could we think about these and build this into a decision about how he might spend his money. So on another Saturday, he went off to Bunnings. And to cut a very long story short came out with his own shed that is now in his backyard. He spends a lot of time feeling that and you know, spending, spends a lot of time touching it and that's, that's his happy place.

So we explored lots of options, we use a lot of video, we come back together. And then we document these decisions. Because-we need to make very clear recommendations as to why that's really important to him to achieve his goal of living a good life. So documentation is really important. And as I said, we decide together, but what we also do is close that loop. We're constantly going back to that decision. You know, maybe the shed isn't for him in a year's time. Maybe he'll move on to something else that he really enjoys. So we're constantly, it's very fluid, we're constantly supporting him to have his will and preference realised

Dr Jo Watson

So, some of the driving principles around supported decision making are obviously, autonomy that, you know, humans are autonomous beings. But on the other hand, we are also relational beings, that we all seek support from each other, that we're social beings. And that's really important.

So, a concept called relational autonomy is something that I like to talk about within the context of supported decision making, because it's about being empowered, having my will and preference at the centre, but within the context of my relationships, okay, so we can be empowered with support from people around us. So that idea of relational closeness is very much a driving principle.

I think a presumption of decision making and communication capacity is really important. That that's where we begin, we begin, we don't start with a question of someone's decision making capacity, but rather, we start with an acknowledgement that all people communicate, whether that be through speech, or facial expression, body language, auslan. There is many different ways of communicating. And that communication can be, we can express our will and preference through that communication. And that will and preference can be built into choices and those into decisions. So, what's really important and another driving principle here is that this should happen with support. So, it's that supported part of it, what's really important is that support rather than questions of decision making capacity.

Kirby Fenwick

Dr Watson says that alongside these steps, there are some key ingredients to ensure that the process of supported decision making runs smoothly and successfully.

Dr Jo Watson

Now a really important part of this whole process which is what my research has been looking at is some of the key ingredients of this process, what makes it really work. And I think that there's some really key, key ingredients of supported decision

Collaboration. So, having a group rather than just one person supporting someone and that group, interestingly, what we've seen in our research is that group needs to get along. There's often a lot of conflict within circles of support because we're human, and we all most people in that circle are there, because they don't care about the person. So, we all have different agendas. So that's really important that that circle of support works hard to be collaborative, to listen and respect each other. So, collaboration is really important.

Another important aspect is an assumption that someone can communicate, whether that be informally or formally, intentionally or unintentionally. And they can, they can make a decision with support. Okay, so that responsiveness is really, really important and what we know about that responsiveness from my research is that it's very dependent on assuming that someone is able to make a decision, and someone is able to communicate.

The other really important part of this supported decision making process is relational closeness. And that really shouldn't surprise us. The closer someone is to someone, the more likely they are to understand their true will and preference. Understand who this person, who the person is. So that's really important that relational closeness is a very, very important aspect of being able to hear someone's will and preference and then support them to have that will and preference incorporated into decisions about their lives.

Kirby Fenwick

Alongside these important ingredients, Dr Watson says the circles of support that exist at the heart of the supported decision making are really really important

Dr Jo Watson

A circle of support is a term that is getting more and more traction, I guess, over the over the years. And I think that, that's because what we see through the research for people with intellectual disability is that circles of support are really important in people's lives, whether that be paid or unpaid.

So a circle of support can take many different forms. It can be a very formal process. So there's all kinds of models throughout the world. There's some great work being done in British Columbia in Canada, where the circle of support is corporated and,

and formalized. So, people come together with very clear agenda around supporting that person.

So, a circle of support can be very formal. It also could be very informal. So it could be someone's brother or sister or the guy in the milk bar down the road. It's really, it's a very organic process and very individualized, you know, there's not one, one size fits all. And I think that that's really important that we don't get stuck on a circle of support needs to look like this. Because humans are diverse, and we all, our relationships are diverse. And so that's the same for everyone. So I think that we need to be very careful that we don't become too academic about that process of developing circles of support, and really embrace that organic nature of human relationships.

Kirby Fenwick

If you'd like to pursue supported decision making for yourself or for someone in your life or if you'd just like some more information, Dr Watson has some resources that can be useful.

Dr Jo Watson

For people who are interested in exploring supported decision making with someone they support, whether that be in a paid or unpaid role, there is a growing number of resources and supports out there. When I was working at Scope, we developed a resource called 'listening to those rarely heard'. There's a lovely video online if you're interested in that. There are also a number of resources, paper based resources that you can find online.

Dr Jo Watson

But I think it's really important that we acknowledge the organic nature of decision making support. And that that is that it's very individual. So if you were thinking if anyone out there is thinking about embarking on a process of supported decision making, what's really, really important is that circle of support, that there are enough people in that circle of support that allow for brainstorming and a collective understanding of that person. So a circle of support is really, really important. And also, a presumption that person can make a decision and can communicate is also very, very important. Time. And that's something that's where, you know, we're really struggling with in all aspects of our lives at the moment.

So it's really important that we think creatively and organically about how the a circle of support can be developed, but also how we can create time in people's lives. Because what we know is that this does take time. It's not an easy fix. And we just need to keep working at this, We need to keep having these conversations. And I think that that's really important. People need to tell their stories. Stories are really important.

Kirby Fenwick

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You'll find links to the resources mentioned by Dr Watson in the show notes at informonline.org.au

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