# Closed Captions – Colleen Pearce

*12 September 2017*

**COLLEEN PEARCE:**  Good afternoon.  If I could begin by paying my respects to the owners of the lands on which we meet, the Wurundjeri people, of the Kulin nation and their elders, past present and future and any elders here today.  I would like to acknowledge the care they have taken of the land for more than 60,000 years.

When I was asked to speak on the topic I was a bit puzzled.  As you aware, in Victoria we have laws and policies that brings safeguarding principles to life and serve as the foundation.  These safeguards apply, as they should, equally, to those individuals who do and who don't have a guardian.  Perhaps then the more relevant question is how do we find the balance between one's right to make their own decisions, equal recognition before the law, and one's right to be free from exploitation, violence and abuse.  There is a continuum of safeguards in the context of decision making with, by and for people with cognitive impairment.  However, in order to ensure appropriate safeguards are in place, we must understand safeguard capacity and its dynamic nature to ensure an individual exercises capacity.  How do I get this to work? Thank you.

So I wanted to start with just very briefly, you have had a lot of talk about safeguarding today, but I wanted to talk about the principles of individual safeguarding.  And to start with the first and most important place to start is with self-determination.  As far as possible, individuals are fully involved in the consideration and determination of their own safeguards to the extent of their capacity.  So this is a very much an empowerment model and putting the person with the disability at the centre of decision-making.  Individualised, I think that is a bit of a no-brainer, that consideration and determination of safeguards is relevant to an individual's circumstances and proportionate to their level of vulnerability and risk.  They must be individualised.  Safeguards should be responsive.  To circumstances of an individual and at a particular time and may need to change over time as individual's circumstances change.

We start with the assumption of capacity.  The starting point, as I said, is capacity that all individuals have capacity to make decisions and exercise choice, regardless of their disability, unless proven otherwise for a specific decision.  Capacity is decision-specific.  Individuals who require support to make decisions and exercise choice should have access to the supports that they need.

Minimum restrictions.  Safeguarding enhances an individual's and the community member's safety and wellbeing and while imposing the least possible restrictions on an individual and their choices.  Individual safeguards are an ongoing consideration requiring regular review to make sure they remain responsive to an individual's circumstances which may change over time.

I wanted to use a case study, one that is probably going to be very familiar to many of you here.  Because it's a situation that I see in my office all of the time.  A Jane has an intellectual disability and she lives in a group home and has lived there for nearly 20 years.  Community visitors have reported ongoing resident-to-resident violence in the house and in one case, Jane needed 8 stitches in her leg.  Jane was the victim of repeated physical and verbal abuse.  The staff in the group home feel that the best way to protect Jane from violence and abuse is to move her to a new house.  Who should make that decision? Now, I have used this case study but I want to say a couple of things about the case study in the first instance.  Jane has lived in the house for nearly 20 years and one of the principles in family violence it is the perpetrator who should be moved, not the victim.  I know in some cases where there is violence between residents in the house, it isn't always clear but in this case it is very clear Jane is the victim and she has been very happy in her house for a very long time.  So it is what we were talking about earlier, about bringing the principles in from elsewhere.

I have also done a lot of work with the judicial college and magistrates where I have argued strongly with magistrates, where a person comes before them seeking an intervention order where the person is considered lacking capacity they should be granting that, because another principle of family violence is the importance of intervention orders.  I know they are not always effective but sometimes it is the last resort and the only thing that can be done to get the house to recognise that the violence can't continue.

Having put those around it just for the sake of the argument, the decision is who should make this decision? Does Jane have the capacity to make the decision to move to a new group home? Can Jane be supported to make the decision about where she might live? Does Jane need a guardian to make that decision?

The starting point in understanding how we might go about looking at this particular situation has to be the UN convention on the rights of people with a disability and particularly article 12, which is equal recognition before the law.  I am just going to read you article 12, which is, it obliges parties to the convention to recognise and ensure that persons with disabilities have the right to recognition as persons before the law.  Persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life, appropriate measures are taken to provide access by persons with disabilities to the support they may require in exercising their legal capacity.  Measures relating to the exercise of legal capacity respect the rights, will and preferences of persons are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, applying for the shortest possible time and are subject to regular review by a competent, independent and impartial body.

When I read that, I think what does it mean? What does it mean to you in practice? But it is the fundamental principle which guides our work in safeguarding.  Last year, the Australian Law Reform Commission produced a work on capacity.  They tried to operationalise Australia's commitment under article 12.  They had four principles.  So the four principles are the equal right to make decisions.  All adults have equal rights to make decisions. Two, support.  Persons who require support in decision-making must be provided with access to the support necessary to make them - sorry, for them to make communicate, and participate in decisions that affect their lives.  3, will and preferences.  The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.  Laws and legal frameworks.  Must contain appropriate and effective safeguards in relation to interventions for person who may require decision-making support, including preventing abuse and undue influence.  I have gone the wrong way.

Capacities.  So, what gives the person the capacity to make decisions, and we will find this definition in various laws, but simply, it is a person is seen to have capacity if they understand the relevant information, if they retain or remember relevant information, weigh up the relevant information and communicate the decision in words, gestures or by other means.  So that is the definition of capacity that we have in law.  For you, as many of you I am assuming are disability workers, then how do we then take those and really try and operationalise it further down? I want to quickly take you through a framework for capacity and this is called the PEACE framework.  If you can remember PEACE you might be able to remember this, people have the right to make their own decisions, this theme comes up time and time again, in the United Nations convection, in the ALR report and here again, people have the right to make their own decisions.  Everyone needs time and support when making important decisions.  A person's capacity to make their own decisions should be assumed.  Capacity is decision-specific and can vary over time.  Every reasonable effort should be made to support a person to make their own decisions.  So the themes that we are seeing again and again are around the right to make decisions, capacity being decision-specific and efforts should be made to support a person to make their own decisions.

What does that mean for Jane, if I could just go back to Jane and that decision.  Well, in Jane's case, Jane expresses herself using some words, facial expressions and body language.  She finds it difficult to discuss abstract ideas or things she hasn't experienced.  But an advocate was asked to support Jane in making this decision.  The advocate spent time with her in different environments and got specialist advice on the best way to communicate with Jane, used pictures, symbols and structured language familiar to Jane in order to find out the things that were important to her.  The advocate spoke to people who knew her and visited homes with her.  When some suitable places were identified, they took photos of the houses to help Jane distinguish between them and support Jane to work out which house she prefers.  During this process, it became clear that with the right communication, Jane was able to move, able to comprehend of idea of moving and to tell it was she wanted, where she wanted to move and why.  People can be supported, even in situations where you think they can't be.  In Jane's case, she was provided with the right support, the right communication tools to enable her to make a decision.  It wasn't necessary to move towards a more restrictive model such as the appointment of a guardian.

I wanted to just talk about the role of providers and frontline workers to applying these principles, the PEACE principles, to support people with disability to exercise their capacity.  In the context of decision-making, OPA's view it should be seen as a spectrum and decision-specific with complete autonomy on the one hand being presumed capacity and at the other, substitute decision making.  Between advocacy and supported decision-making can assist a person to make decisions and to implement their wishes and to safeguard them from abuse, neglect and exploitation.  The ideal is, of course, for individuals to make their own decisions and to put into effect or be assisted to put those decisions into effect.

I listened to the earlier speaker and we talked about empowering models.  Empowering models of support identified within the disability community involve a long-term relationship of trust, unpaid support, usually drawn from friends, family and community.  Flexibility to respond to varying needs at different times, agreement by all involved to support the person in reaching and expressing his or her decisions, agreement about types of decisions that will be made through supported decision-making, provision of information and explanations in plain language.  And individuals should be involved as far as possible to the extent of their capacity in consideration and determination of their own safeguards as an authority of thane own lives.

Now, I don't think I have got time to go through this case study, because - but what I wanted to do is say okay, we had Jane, now we have got Max.  Max has higher levels of risk here.  Max has a - is depressed, he has made a number of attempts on his own life for which he has been hospitalised.  But he is exhibiting high-risk behaviours.  And as such, Max is in danger of becoming involved in the criminal justice system, a system that will not meet his own needs.  So I don't have time today, I don't think, to work through this with you, but if you look at the principles that we raised, I raised under the PEACE concept, then perhaps you can start thinking this through and think through with other people that you see in your services, is it necessary for a guardian, in fact to be appointed.

I wanted to just take you now to guardianship, which, of course is the most - sorry about this - guardianship is when VCAT can appoint a guardian when they are satisfied the person is 18 years and over, has a disability, cannot make reasonable judgments because of that disability, needs a decision to be made and there is no less restrictive, it means the appointment of a guardian or administrator and someone is needed to act in their best interests.

I just wanted to say that sometimes applications are put before VCAT and therefore situations where a family member is involved with a person and with the person with the disability residing in a group home.  And the service provider and the family aren't getting on.  I have to say, that is the least likely scenario for VCAT to appoint a guardian.  Because the service provider isn't getting on with the family member, VCAT would be very reluctant to appoint a guardian, so I am going to actively discourage you in those circumstances to apply to VCAT because it is unlikely you will get that.  It is the responsibility of the service provider to work out with the person and their family members what the issues and to resolve them and if there is a complaint to perhaps take it to the DSC if that is relevant but not to get a guardian and have the greatest level of restriction imposed on that person.

A guardian? What is a guardian? A court-appointed substitute decision-maker.  Guardians are appointed for a limited amount of time with regards to a specific decision.  What is the decision that will need to be made? A guardian will be appointed to make decisions such as an accommodation decision, where should the person live; access to persons, who can the person see? That often involves families in conflict where, perhaps, the guardian has to make decisions about times when access can occur. Sometimes it is access to travel and passports and most commonly, it is around healthcare decision-making.  Guardians must act in the person's best interest, take into account a person's wishes and make decisions that are least restrictive of the person's freedom of decision and action and substitute decision-making should be used only as a last resort when no least restrictive alternative is available.

As frontline workers, perhaps the most important way you can contribute to safeguarding the rights of your client is to build and maintain a positive culture around your work, creating a culture in which rights are not only protected and upheld but are promoted.  In practice, this means how you support people with disability to make decisions about things that affect them, the way in which you maintain good relationships with your clients, the effort you put into gaining true and clear understanding of your client's support needs.

This will be ever more important in the context of NDIS where regulations and obligations might diminish, where safeguarding will rely on a complaints-based system and consequently be stronger for those individuals who are able to make complaints. In this context, I believe the more interesting question to ask is how do you make safeguarding an integral part of your daily work? How can you work in a way that is empowering and rights-enhancing? Thank you.