

## Transcription:

### Talking disability, the NDIS and life as a self-advocate

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**Hanaa:**

*My name is Hanaa and I am from the Multicultural Communities Council of South Australia.*

*Before we get started I would like to acknowledge the traditional owners of country throughout of Australia and their continuing connection to land, sea and community. I would like to pay my respects to their elders, past, present and emerging.*

*I am very delighted for Janet to be talking to me today about herself, the National Disability Insurance Scheme or NDIS, and the importance of self-advocacy.*

**Janet:**

**Thank you for having me and hello South Australia! My name is Janet Curtain as Hanaa said and I have cerebral palsy. So, cerebral palsy means for me that I can't walk and I do things a bit slowly. I use a mobility scooter; I speak a bit high or low. But that doesn't stop me from doing things! I am also a mother of two children, Poppy and Olive, and I also work as a disability support worker for Uniting Vic/Tas. I also am a self-advocate and that is what we are talking about today.**

**Hanaa:**

*Janet, would you like to tell us a little bit about your background? Where are you from and where were you born?*

**Janet:**

**So, I was born in Singapore. Singapore was a stop to Australia. I came here when I was three years old and some people might even say I am the youngest refugee to ever come to Australia, because my mum didn't want to miss her plane from Vietnam. So I am Chinese, but we lived in Vietnam, or my mum did and her family.**

**Hanaa:**

*Janet, in your life, have you come across people from different cultures with disability or those caring for a person with disability, who felt a little bit uncomfortable to talk openly about it?*

**Janet:**

**Well, disability is seen in different ways in different cultures. In some cultures, it is seen as a sickness or a burden to bare, or even a curse. That is why it is important to overcome the stigma**

and the shame around disabilities and especially in multicultural communities. And having those attitudes means that there is a low expectation for the person with the disability, so they are not expected to go to school, or they are not expected to excel in their goals or even obtain employment, or have children. So, their goal setting is even a challenge in itself.

**Hanaa:**

*Janet, would you like to talk a little bit more about what a self-advocate is and what his or her characteristics are?*

**Janet:**

This is a profile of a self-advocate. Every self-advocate needs to know their rights and they need to know that it is okay to speak up and explain your thoughts and feelings and don't be afraid of losing their services or disappointing other people.

Value equality and equity and be proud of the person you are and that means being proud of having a disability cause people with disabilities add value. And that's the attitude that PCE has.

Network, know your community. So, what that means, know whom to talk to to get what you want. Know whom to talk to to complain if things go wrong. And also, know your community so you can change attitudes about disability. So, community is a lot to do with self-advocacy.

Along with speaking up, you have to be a good listener. So, people with disabilities need to listen to each other, so you can work together to change policies, attitudes and organisational cultures.

Another one that is really important is don't be afraid to ask for help. So, self-advocacy means to speak up for yourself and to be self-directed but that doesn't mean that you don't need support doing that.

Call out racism and discrimination. When we are working with people with disability, they've got two things to deal with like when we are talking about barriers to employment, to getting your services. And that would be disability discrimination and that would also be racism. And PCE would argue that you need to tackle both to have a holistic approach to self-advocacy and a good service provision. And just good attitudes towards people with disability.

And we have to keep organisations and services accountable. And that means calling it out when they do the wrong things. Self-advocacy is the action. It's not just talking, it's the action, making things happen. Nothing happens, if the person with disability doesn't say anything.

**Hanaa:**

*What impact does self-advocacy have in your life?*

**Janet:**

Well, it has had a big impact. As I said in my introduction, I have done a lot in my life. I've got a job and I have children, I have a mortgage, I work as a self-advocate. And that is because of self-advocacy. So all the people before me that fought for their rights as people with disabilities, they made it easier, they paved the way, so I can live as a valued citizen of the community. And I think there is more to go, so with each generation it gets better, it gets easier but all of us have a responsibility. And I think in the CaLD community it is particularly difficult to get people with a disability to speak out because of what we spoke about, about the stigma.

And just about educating mainstream organisations to support self-advocacy, to support choice and control, that is where we are heading. We are heading into the right direction folks, we are!

**Hanaa:**

*Janet, what role does self-advocacy have when accessing the NDIS?*

**Janet:**

Self-advocacy is the backbone of the NDIS. The NDIS is all about choice of control, I am sure you guys have heard about that term. And choice and control is what self-advocacy is about. So you use self-advocacy as a tool to create your NDIS plan. With self-determination you determine what your goals are in your NDIS plan. You also have to make choice about your services. What I always say is you don't know what you don't know. So, self-advocacy helps you research what you need to know to get what you want.

**Hanaa:**

*Janet, tell me about Power in Culture and Ethnicity. Who are the people behind the organisation and what is it that you do?*

**Janet:**

PCE was founded last year in about April, so we are brand new, and we were founded with two women, one of them being me but the other one being Effie Meehan. And we were both self-advocates and were kind of disillusioned that there wasn't any sort of person-led organisation that spoke up for people from non-English speaking backgrounds with a disability, wanting to tackle the hard issues, like racism and discrimination together. And in this day and age as a multicultural Australia I think it is very relevant, we thought it was important.

So, this is our postcard. We stand up for people with disability from an ethnic background. We want everyone to have equal rights. We say no to discrimination and racism. We are proud of who we are and we want people with a disability from an ethnic background to be proud too. We think that is very important.

We want to change attitudes and be the connectors in communities.

**So that is why I am talking to you today because I think Adelaide is so rich in their multiculturalism and they are so progressive and I would love to work together.**

**Hanaa:**

*Janet, how can culturally and linguistically diverse communities support self-advocacy and self-advocates?*

**Janet:**

**Well, it is about a systemic approach. The organisations reaching out to the people with disability. And it is also about the disability sector reaching out into ethnic and multicultural communities. It is also about education around how to be culturally sensitive and aware and that makes for a more holistic approach to people with disability from a CaLD background. Because traditionally, it's like you go into a service and you are serviced as a person with a disability or you are going to another service and you are put into the CaLD basket. How we thought that the best practice is to support self-advocacy is to address both, as a whole person. To have not one or the other but both, the intersect of that. And to actually talk about rights, talk about services, talk about inclusion and have mentors, so people with disability talking about the services that they use and the strategies they use in their life to enrich their life and to achieve their goals. And also, making educated decisions about your life. And it is about having education around the choices that you have because you are only empowered by knowledge and if you don't have that knowledge you don't have power.**

**Hanaa:**

*Thank you for sharing your experience with us. Do you have any final words you would like to share?*

**Janet:**

**Well, thank you for asking us to come today. I would like to recognise the members of self-advocacy groups who have worked tirelessly over the years for the right to live in the community and for equality and human rights for all.**