**TRANSCRIPT**

INTERVIEWER: There has been so much in the news lately about Stevie Payne, strapper to the Melbourne Cup winning horse, Prince of Penzance, who also has downs syndrome, Stevie Payne. And that has really struck people in the downs syndrome community, like myself, because it’s really quite rare to see people with intellectual disability represented in the media, especially when they are allowed to speak for themselves. So how far have we come with making opportunities for people with intellectual disabilities really take part in the world?

Professor Chris Bigby is the Director of La Trobe University’s Living with Disability Research Centre and the co-ordinator of the 50th annual conference of the Australasian Society of Intellectual Disability, which has just wrapped up. Good morning Chris. That’s an impressive CV right there and it’s interesting that there’s been 50 years of the Australasian Society of Intellectual Disability. How much has changed over that time?

CHRIS BIGBY: Well, things have changed very significantly in that period of time. 50 years ago we used to call people with intellectual disabilities a whole range of derogatory names, they were completely excluded from society. Often they weren’t even present amongst us, they were shut away in institutions and or shut away from families.

INTERVIEWER: From childhood on?

CHRIS BIGBY: Yes. And there’s a whole cohort of people who have moved out of institutions in Victoria and are now living in small group homes in the community. But I think we still have a long long way to go in terms of building relationships between those people and community members. But, I must just correct you, the co-ordinator of the conference was an amazing young woman called Alice Nicholls. I co-ordinated the scientific program.

INTERVIEWER: OK, good, well I’m glad we clarified that. I’m wondering how much of a cycle it is – like the more that people with intellectual disability are allowed to be out in the world, the more people get used to them as being part of the range of *normal* people and the more accepting they are. Is that how it works?

CHRIS BIGBY: I think it works when you actually build social connections on a one to one basis between an individual with an intellectual disability and somebody else in the community. When you have a presence of groups of people, 4 or 6 people all going to the shopping centre as a group, they often actually, there’s a big barrier, a bubble around them and people don’t make contact with them. So it’s how we support people to be out in the community that’s really important. And we, our world isn’t very well adapted to people with intellectual disabilities – we go at a very fast pace, we rely on words, and people communicate in different ways and most people in the community don’t know how to communicate with someone that doesn’t use words, so they need that exposure on a one to one basis and need some help to do it.

INTERVIEWER: Yes, and it’s interesting, as you say, we are very fast paced and we use words and we are very interested in intellect and performance and that kind of drive to succeed in a very particular way which is perhaps not the way that someone with intellectual disability has experienced the world. That’s a massive change though, how do we go about chipping away at that?

CHRIS BIGBY: Well I think if you think about the conference that we’ve just run, we actually had a sort of microcosm of the world there and we tried to make it inclusive for a whole range of people with intellectual disabilities. So there was an older man actually with downs syndrome, who was the guy who took the microphone to all the people who wanted to ask questions, and that was a task he could do really well, so it was including him in a way that he could be included, and he talked to people along the way and it was a really good experience for him and for the other people at the conference. But there were also people there with some much more serious and profound intellectual disabilities and those people were supported in a very individual way to still play a part in the conference. So one lady helped to stuff things into the satchel to give them to people as they came through, using a method that was developed in the UK called active support – enabling people to just do the things they can do and taking the opportunity every moment in their lives to be engaged. So I think there’s many ways you can include people – you have to stand back and think, how do we do it for this particular individual? And it’s much more complicated that lifts and ramps and guide dogs and braille. You know for people with intellectual disabilities, they are a very diverse group and we can adapt the world to them but they need really skilled individual support as well.

INTERVIEWER: Where does the dividing line fall between active support like hand on hand guidance for someone, for example, to help perform a task, and doing that thing for them? And I guess in a whole range of different ways, how do you help someone communicate without communicating for them.

CHRIS BIGBY: Often it’s a shared communication. There are some people with very severe and profound intellectual disabilities who really aren’t even intentional communicators but if you get to know them really well then you can have a sense of what they might like and dislike. But for somebody with a mild intellectual disability, you just need to give them some time. To listen, you might need to give them some prompts, you might need to find a picture or an object and help them talk around that, rather than going fast and saying ‘what do you think about this, tell me’ and not giving them time to stand back, so there’s a whole range of sort of technology and easy things that people can use as props for that sort of communication.

INTERVIEWER: And talk about some of the technological techniques that you used in the conference to help people take part in for examples polls or conference interaction.

CHRIS BIGBY: So for instance, one of the things we did was actually do quite a lot of pre-recording because many people really don’t do well with crowds and things like that and wouldn’t be able to stand up in front of a group of people and speak, so some of the people from our inclusion committee did some filming of people in their own environments and enabled them to talk about their lives and to show things they wanted others to think about and we showed captions of that in the main sessions and we had some very simple polls which people could be supported to understand and you had to press yes or no. And we also had a lot of drama and music and movement, so we had a stream which was inclusive of everybody, it wasn’t just a stream for people with intellectual disabilities, but it was a stream that they would be able to understand. There was a group of schoolchildren from Ballarat that came and did a performance, there was a very skilled academic from the UK, Wendy Key Bright, that did some music and movement work – back to back theatre. And speakers not only gave their very good keynotes but they then had a session in the plain English session, that was a much slower pace, that was more informal and that enabled both people with intellectual disabilities and other people to have more of a conversation with them. So it’s sortof changing the pace and the tone in which you do things and I think it was a real success. Everybody said, this is a really good scientific conference but it is also a really good model of inclusion.

INTERVIEWER: Well it could work for other people too, for example the push towards plain English, so it might be a problem for some of the academics wanting to keep their vocabulary count up [laughs] – it could be very handy for the rest of us who are, you know, not so au fait with that particular niche.

CHRIS BIGBY: Well I think we have found that turning things into plain English is really good for everybody. And actually, turning things into plain English is often just the first step in enabling communication – it’s a way of giving support workers the tools to start to talk through something with somebody. Often plain English and pictures on their own aren’t enough for many people with intellectual disabilities, they need that support as well.

INTERVIEWER: And the level of support I guess is something really interesting to consider now the National Disability Insurance Scheme is about to be rolled out, very slowly, across the country. What lessons can we learn from similar schemes overseas? I know there were people speaking on this from a Swedish perspective..

CHRIS BIGBY: Magnus Tideman was speaking from Sweden and they’ve had a similar right to receive services over a number of years but I think there was a number of lessons Magnus talked about – the need to still have the voice of self-advocacy groups of people with intellectual disabilities, to make sure they are involved in the design and the delivery of services so that the market and the professionals don’t take over. We need to find ways of keeping peoples voices in that bigger picture. But he also raised issues about delivering services and having individual support isn’t enough, we actually need to address inclusion in mainstream services in hospitals, in the health system, in the education system. And one of the things that’s happened in Sweden is many more people with intellectual disabilities, many more people have been identified as having an intellectual disability and because the Swedish school system has become more theoretical, much more higher status, higher demand and so it’s started to exclude those people, so getting that label of having an intellectual disability gives you more resources but puts you in a separate system. So we need to be really careful about separating and segregating people.

INTERVIEWER: Is there more suspicion and awkwardness from the general population around people with intellectual disabilities than people with physical disabilities? Or is it hard to separate those two?

CHRIS BIGBY: There is still enormous stigma around people with intellectual disabilities. The fundamental difference I think is that people with physical and sensory disabilities can speak for themselves. They can challenge those things, they can direct support workers, they can give as good as they get from the general public. For the people with intellectual disabilities it’s much, much harder to do that. And adapting the social world and adapting environments to people with intellectual disability is much more difficult, so in many ways people with intellectual disabilities are left out of some of the debates too. They are sort of the poor relation in the disability movement because as we heard of the NSW Council on Intellectual Disability, to involve people with intellectual disabilities in policy debates and things takes an enormous amount of resources and scaffolding to enable that to happen.

INTERVIEWER: And time…

CHRIS BIGBY: And time. And advocacy groups that are made up of people of a whole range of people with disabilities are really poorly resourced and find it really hard to do that because they don’t have the time. And the government, you know, puts consultation papers out and say ‘we want a response in two weeks’. You can’t do that and expect to have the voice of people with intellectual disabilities in there.

INTERVIEWER: And yet 60% of people using the NDIS will be people with intellectual disabilities.

CHRIS BIGBY: That’s right and I think that’s something – you have to give credit to the NDIS. In the last two years I think they’ve actually realised that and they’ve begun to shift and to understand some of the complexities of exercising choice and control, making decisions for that group of people and they’ve now set up a part separate group, unfortunately from the National Independent Advisory Group that’s going to advise the advisory group about issues to do with intellectual disability and I think that’s the first step. I mean, maybe down the track we’ll see some board members with intellectual disabilities and sooner or later it might become, you know an organisation that’s run by and for people with disabilities in which people with intellectual disabilities have a really strong voice. But it will take a lot of time, a lot of resources and a lot of skilled support to do that.

INTERVIEWER: Just finally Chris, when you were talking before about the relationship that needs to grow up between society and trying to support a person with intellectual disability – that person. That really raises the issue of trust but also the relationship between the caring part of the caring work and the work part of that. So either it all falls to the family, where hopefully the trust can be there and the safety can be there or it falls to a worker where they are a paid employee as well as having chosen to be in a caring role. How do we ensure that families are well resourced but also that workers are well resourced and that people with intellectual disabilities are safe in whatever context they find themselves?

CHRIS BIGBY: I think it depends on the skill of the worker, the training and support that they get and you have to build a relationship. This sort-of cold professionalism is really a thing of the past but there’s a growing body of evidence that suggests workers need good practice leadership. They can’t do it on their own. They’re often working with an individual on their own but they need to have supervision, they need to have somebody to support them, to monitor them or to coach their practice and unless we do that we’re just going to have really poor support and they won’t be safe. But the other way is that workers can enable and facilitate people to make social connections in the community, though we can break out of that distinct social space so people have got more informal support, I mean that should be the role of workers – not to be companions but to facilitate the building of social connections so that people aren’t so reliant on families and after all when people with disabilities get to be adults, they don’t want to live with their Mums and Dads and they don’t want them deciding things in their lives, they need friends like everybody else.

INTERVIEWER: Indeed they do. Thank you so much for coming in today and just dipping a toe into the waters of the debate surrounding people with intellectual disabilities. It sounds like a fascinating conference was had by all.

CHRIS BIGBY: Thank you very much for asking us.