

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Bendigo — 12 August 2015

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Professor Teresa Iacono, Professor of Rural and Regional Allied Health, Researcher, Living with Disability Research Centre.

The CHAIR — I would like to welcome Teresa Iacono, professor of rural and regional allied health, and researcher, Living with Disability Research Centre. Before we hear from you, I would just like to caution you that all evidence taken is protected by parliamentary privilege, as provided by the Constitution Act 1975, and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege. Today's evidence is being recorded. You will be provided with a proof version of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee's website. We have allowed half an hour for our session this afternoon. We would again like to thank you for your preparedness to appear before the committee, and invite you to make an opening statement. Thereafter the committee will have questions.

Prof. IACONO — Thank you very much. I would like to draw the committee's attention to a particularly vulnerable group — that is, people with intellectual and developmental disabilities. My comments relate to my experience in terms of working clinically but probably more so in terms of research and looking at access to healthcare systems broadly, but uncovering information that is very directly relevant to end-of-life choices.

Across mainstream systems — I include health here, but it is not particular to health — I refer to the needs of people with intellectual and developmental disabilities. I should clarify that I am talking about people with development disabilities, such as intellectual disabilities, cerebral palsy and autism, the lifelong disabilities that occur during the developmental period. Their needs in mainstream systems are often overlooked; they are excluded from the same level of care and services that are afforded to or are available to the rest of the community. We know from my research, from international research, that amongst healthcare professionals there is a mistaken belief that there is some system out there, a disability system, that takes care of all the needs of people with IDD, which harks back to the days of institutions where health services were delivered within those institutions. Thank God we have moved beyond that.

Those systems are not there, and people with IDD depend on mainstream systems across the spectrum, including in terms of their end-of-life care. Strengthening these mainstream systems to provide reasonable adjustments to the needs of people with disability broadly is a target of the current Australian policy reform of the national disability insurance scheme, so I see this focus as part of that reform. We know from international literature, including Australian and my own research, that people experience poor services, discrimination, diagnostic overshadowing — whereby all symptoms are attributed to the primary disability and therefore preclude the regular investigations that usually occur — and they experience poor outcomes from primary health care and hospital services.

Fortunately — and we are starting to document this — there are exceptions, and at the research centre that I am a part of, the Living with Disability Research Centre, we are seeking to document those exceptions and to note how systems are already providing those adjustments, and how we can make those more systematic and embed them in policy and practice. The good news is that people with IDD are living longer, at least those with mild forms of disability, and they are reaching life expectancy that approximates that of the rest of the population. But the situation is different for those with more severe disabilities; they die at much higher rates than the general community. There was a recent study conducted in New South Wales through Data Linkage by colleagues at the University of New South Wales that showed that people with IDD aged from 5 to 69 years died at a rate of 2.5 times greater than that of the rest of the population.

International research — and we tend to reflect the same findings in Australia — shows that the causes of death are often those that could be prevented or delayed through good quality care. So my point is I would really like people to get to the point where they can make decisions about their end of life, rather than having them occur much more prematurely than occurs for most people in the community.

Where are they dying and what choices do they have at the end of their life? From our research it is evident that people with IDD are dying in hospitals, at home, in aged care or in disability supported accommodation. Some may be experiencing palliative care, but that is more through luck than good planning. Few are offered choices or supported to make choices, even about their everyday life — who they live with, what they eat, let alone how they are going to die or where they are going to die. They may be in aged care at the end of their lives because usually there is no other place suitable for them — and well before they should be in aged care. That is because they or their families are not provided with appropriate options.

In a recent study that I conducted here in Bendigo I recorded the story of an elderly parent of a man in his late 40s who had lived at home all of his life, had worked and was relatively independent. He developed Parkinson's disease and as the disease progressed and his health and mental health needs became greater his mother was no longer able to provide care. She met with a total lack of assistance from the disability care system. Fortunately through crisis intervention and local healthcare professionals who got to know her and realised that this just could not go on, they managed to find a place for him in an aged-care service. He was very lonely and distressed in that service. The mother and sister did all they could to try to see him regularly; the mother was there every day, but he was still very distressed. He got sick; he developed pneumonia. It had nothing to do with his Parkinson's disease. For some reason the aged-care staff delayed calling an ambulance. They finally did when the family arrived and wondered why this had not occurred. He got to hospital and very shortly after admission they were informed by the attending doctor that he was dying. He died within a couple of days. The family received no palliative care support or advice. Whether his death was premature is difficult to know.

People with IDD are also dying in disability support accommodation cared for by staff who have goodwill but who lack experience and skill in supporting older people with IDD, let alone those who may have a terminal illness. We are seeing a greater and greater incidence of people with an intellectual disability with dementia, particularly people with Down syndrome for whom dementia occurs much earlier than the rest of the population. We are directly researching that area.

Disability staff are often distrustful of mainstream systems, including palliative care. They feel that these services, or the people who work in them, lack an understanding of IDD — and they are probably right — or they do not understand their particular needs. In a study into dementia in people with IDD we found the disability staff, through their distrust of aged care, delayed transition. Staff had experienced clients dying soon after they moved to aged care. We suspect their deaths related to having delayed a transition to late dementia care until the point at which the staff could no longer provide the level of care that was required. These staff have no medical training; in fact they have very little formal training. They may have a certificate III or certificate IV.

Hence the clients' transitions have been triggered by crisis, and we see this again and again. They occur through crisis rather than by careful planning that would afford them and their families the opportunity to participate in advance care planning and end-of-life choices through a process of supported decision-making. There is a belief that people with IDD cannot participate in decisions. We know they can. They may not have the capacity for informed consent in terms of conventional definitions, but they certainly are able to contribute to decisions.

There are currently two studies addressing the nexus between disability services and palliative care. There is a submission to the inquiry about this by Dr Rumbold from La Trobe University, and another study is being conducted in New South Wales.

Overall, I ask the inquiry to consider the special needs of people with IDD, including to strengthen palliative care services to meet their needs and those of people who provide them with care. We need that through a systematic approach rather than ad hoc processes. We need to reduce the siloing of services across the healthcare spectrum, where one system thinks the other system has the responsibility. They exclude people with IDD from their service through problematic policies, lack of knowledge or discrimination. We need to build a strong nexus between disability services, aged care, dementia care and palliative care to address support for people with IDD who are ageing or seriously or terminally ill and, finally, to build an understanding of supported decision-making for these people so as to educate and guide families, disability support staff, advocacy workers and mainstream services in the process and to include people in decisions about the end of their lives.

The CHAIR — Thank you very much for that evidence. It brings to light, as you said, a very vulnerable cohort in a way that has not been brought before us before. I know it is still early days and this region is not part of the trial site, but could you talk to what the NDIS may do in this space to help this vulnerable cohort that you are talking about?

Prof. IACONO — Absolutely. One of the tiers is focused on trying to shift people from a reliance on disability services to supporting quality care throughout all our other services. Whether it is the forensic system, the primary healthcare system, the hospital system or the education system, the way we can best serve the needs of people is through shifting that expertise around disability and understanding diverse needs to those systems.

The NDIS is looking for models, and I guess that is where our research is coming in. We are trying to look at not turning a mainstream system into a disability system. What we are finding is that these needs are not peculiar to disability. Overshadowing, for example, will occur wherever there is an underlying disability. Someone who goes into hospital and happens to have Parkinson's disease may not have their symptoms adequately addressed because people put everything down to the Parkinson's disease. The NDIS really is trying to get those mainstream systems to think more diversely, to not see the typical patient but to understand that a symptom is a symptom is a symptom, regardless of who it is who is communicating it, and that the way that you communicate those symptoms will vary according to your cognitive needs. It usually relates to people who lack the cognitive capacity to self-report or self-advocate. They are reliant on people in those systems to be able to read their signals and to work with people who know them well to understand what is going on.

Ms PATTEN — Thank you for that. It is really interesting. You mentioned supported decision-making, and obviously when we have been talking about advance care planning and those areas, we want to be able to provide people with intellectual disabilities the same access. Have you got any examples of where supported decision-making works well and how it could possibly move into this area?

Prof. IACONO — I do not think we are at the point yet where there is a whole system where it works well, but we certainly have examples of where it is working, and that may be where you can bring together a group of people who know an individual who perhaps has a very severe intellectual disability or who has suffered a traumatic brain injury and lacks certain aspects of cognitive capacity; where you have got family, perhaps friends or perhaps professionals, who have worked with that individual, who come around to a decision that needs to be made, who share information about the individual, who take on board each other's perspectives, who take on board their understanding of the person's preferences, who include the person as much as is possible and who are willing to, I guess, test out a hypothesis if you like — that is probably the best way of describing it — where any decision may not necessarily be the final decision. The group of people feel that this is the most appropriate decision — for example, where the person may live or who they may live with. Then they find, by watching the person and talking to the people they are with, that maybe this person is not enjoying this experience, that they read the situation wrong or maybe the person would have made that decision, but as we all know we all sometimes make decisions and decide maybe it was not the best. We are allowed to make those errors, to re-evaluate and to have the opportunity to change things.

We do not have good examples in a systematic way yet but we are starting to see research — —

Ms PATTEN — That is what it looks like.

Prof. IACONO — Yes, and there are different models. There are some really interesting models in Canada but very little research around them, where there is a committee that makes a decision which kind of formalises it a little bit more than I would feel comfortable with. Or there is an individual who takes on that responsibility. There are lots of models but not too many — actually probably none — with really good evidence about how they are panning out.

Ms SPRINGLE — You talked about clients transitioning from more independent living into facilities, often triggered through crisis, and I am curious to know how you think that can be addressed?

Prof. IACONO — Sorry, the issue is that the crisis triggers the transition?

Ms SPRINGLE — That is right. Yes. How do you think that can be addressed and by whom?

Prof. IACONO — In that situation I can talk about it through example. We know that for people who develop dementia and who are in supported accommodation support workers will often opt to take on the responsibility for caring for that person and want to care for that person at home for as long as possible, but what they need is education and support to understand the dementia process to be able to observe that individual and know the point at which they are not going to be able to support the care for that person at home, considering also the needs of the other people who live in that house. So you put in place a process of future planning where they develop a relationship with the place that this person will transition to, so that by the time they are at that point they know where they are going to go, the support workers know where they are going to go and there is some communication. There is a transition process rather than saying, 'Day one, you are in your group home, and tomorrow you are in an aged-care facility that you do not know, you have never been to and with people who do not know you'. It is a matter of planning.

Ms SPRINGLE — Just so that I have it clear in my head, are we talking about professional carers or are we talking about family carers?

Prof. IACONO — It could be either. In disability supported accommodation at the moment — and this is before we move to the NDIS with individualised packages, and then it could look like anything — our disability support workers in group homes are very rarely qualified. You may get somebody who happens to have a nursing background or who is studying an allied health area, but largely they are people who maybe do a certificate III or IV at TAFE, which does not prepare them — —

Ms SPRINGLE — But they are not family members?

Prof. IACONO — They are not family. But a lot of people with intellectual disabilities or developmental disabilities are living with family, so we need to cater to both.

Ms SPRINGLE — Right.

Prof. IACONO — And the issues that happen for families, the crisis can be either with the offspring with disability or it can be with the family member. As people with IDD hit their 40s and 50s, they have got parents in their 70s and 80s. Now we have had a situation where parents in their 80s were searching for dementia care for their 50-year-old daughter with Down syndrome, who moved house to try to find accommodation, an aged-care facility, that suited her and understood her needs or at least was open to learning about her needs.

You can have someone facing their own end-of-life choices also having to think about what is going to happen to their son or daughter. For them, end-of-life choices may have to take into account what is going to happen to the person who has actually been dependent on them their whole life, and that is one of the biggest fears that older people whose children are living with them have. When we interview them and we have focus groups, that is what they talk about — what is going to happen to my son and daughter when I am gone? Who is going to know them, love them and take care of them? It is heartbreaking.

Ms SPRINGLE — Absolutely. Thank you.

Mr MELHEM — On that, how does Victoria compare to other jurisdictions in comparison, for example, in terms of end of life for people with disability?

Prof. IACONO — I can comment on people with disability. I think the situation is fairly similar throughout Australia and overseas. We see the same issues. It is really interesting. It is so entrenched that it is frightening.

In the UK, for example, they have had a number of inquiries into the hospital treatment of people with intellectual disabilities in particular. The *Death by Indifference* report that came out in 2007 basically screamed institutionalised discrimination across the hospital system. People died from horrendous — not mistreatment — but neglect in hospitals. The UK went through a number of inquiries and recommendations that were implemented to some degree, but then they just fell off.

In Australia we can see the same sorts of things happening. I know you have not asked this question, but if we are going to shift things, I think those of us in disability need to stop thinking that it only happens in disability, to be honest. We need to realise that the hospital system has its own processes and restrictions, and this is where the NDIS comes in. How does disability and mainstream work together to overcome those restrictions so that what we ask the hospital to do fits in with their own quality framework and their own targets? We are assisting them rather than damning them. To answer your question, it is very similar across the states.

Mr MELHEM — Just on that, people with disability in aged care, I met some young people with disability — that is, under the age of 65; they are considered young — and they end up being in aged care.

Prof. IACONO — They do.

Mr MELHEM — What impact will that have on them? Is it a good idea? Is it a bad idea? It is something we need to — —

Prof. IACONO — It is a horrendous idea. The example I gave is a good example — that someone in his late 40s was with elderly people, and he was lonely. Aged care is not set up to provide social inclusion for a person

with disability, and these people have lives to live. They are in aged care because there is not an appropriate accommodation service for them. Their families did the right thing — well, they felt they did the right thing — and kept them at home, but then they get to a certain age, a crisis happens and there is no disability accommodation available to them.

We have got families in Bendigo who are working to try to fund homes for people with intellectual disability. If we are not careful, they will reinvent institutions, because they have no alternative. We group people with disability and we provide them with staff. If those staff have not got the right training, we will have them in institutions, and that is what scares me. Unless we look at meeting individual choices and supporting people to live in regular accommodation, as with the rest of us, we will have institutions again.

Ms PATTEN — I just wanted to make a comment, if I may. The NDIS and that challenge of working with the mainstream, that has really struck a chord. The model you just spoke about, that decision-making model, just seems like something that disability services could bring to the mainstream, and I hope that you do.

Prof. IACONO — Yes, there is just so much grounds for cross-fertilisation. It would be a shame. That is why I talked about silos. We have got to get out of those silos.

Ms SPRINGLE — Just on that, I have heard from other regions around the NDIS — and it was from one of the pilot areas — that the funding is there, but there are no services to tap into. Do you think that would be an issue for this region?

Prof. IACONO — Yes, I do. I am from the rural health school, and we provide training for allied health, nursing, dentistry and oral health. We are working to try to at least increase awareness of disability in our students. Working in intellectual disability has never been particularly attractive — the pay has always been poor, it is sometimes seen as not as glamorous as working in a hospital — but you do get a core group of people who will end up working in disability who just find their niche, and that is where they want to be. That is part of what my remit is, I guess, in the rural health school — to try to give some value to that work, which I think has incredible value. We are chipping away slowly.

Look, the autism packages were a good lesson. People have money for autism services, and they just cannot find the therapists.

The CHAIR — Professor, thank you very much for giving us a perspective we had not heard previously and for your obvious passion for such a vulnerable group in our community. As I said, the transcript will be with you in the coming days.

Prof. IACONO — Thank you very much.

Witness withdrew.