

---

EVENT: NDSCC 2011  
SPEAKER: DR MAREE DYSON  
DATE: 02/05/2011

COMMENTS: LIVE CAPTIONING TRANSCRIPT  
Produced from LIVE captions on the day\*

For information on all our solutions see  
[www.ai-media.tv](http://www.ai-media.tv)

Access Innovation Media Pty Limited  
5 Thomas Holt Drive  
North Ryde NSW 2113  
Tel: +61 2 9813 6780  
Email: [info@ai-media.tv](mailto:info@ai-media.tv)

\*Disclaimer: This LIVE transcript produced by Access Innovation Media has not been checked to tape and cannot be relied upon as a matter of record without verification.

---

MAREE DYSON:

Thank you very much, Rhonda. I would say that I have more experience than any other Australian been working with disabilities in an insurance model. I've worked intensively with the TAC and setting up the scheme in New Zealand. The learnings from the insurance sector are transferable to what is being proposed in the disability here. At a conference last year I shared some of those learnings, this time I want to focus on the implications of the reform.

Sorry I can't see the PowerPoint in front of me, I can't see it at all! Do I have a screen in front of me? One second. Talk quietly amongst yourself for one second. This is the stuff that the 4 AM where made of.

I would like to commend the Australian Productivity Commission. These guys work with a lot of policies and in a short space of time they come out with a quality product that shows depth of understanding of the sector. I would like to commend John Walsh, I met him in 1995 and he was working from an actuarial perspective on how these things for achievable. In 2000 he was behind some seminal COAG papers.

Can I have the PowerPoint presentation, please? My presentation depends on this. Thank you. I can be very pushy, too.

(Laughter)

This is what the Productivity Commission was asked to do. I would like to say a serious congratulations to the Productivity Commission for what it has achieved. The biggest implication of this is that we are looking for dignified, sustainable support. I use the word sustainable, but we are not talking about a change for this year or next year, we're talking about the change for our grandchildren and great-grandchildren. Why do we need this change? As Patricia said yesterday, individuals and families raise an uncertain future. In setting up the scheme we owe a certain future for not just Australians today that those of tomorrow. To realise this vision we need to refine this proposal. We need to turn it into something that looks like this.

To get to this space we need to focus what it is we have in common, and not our differences. We need to move away from thinking about diagnosis. We need to think about the fact that we were once topless, now adults, some of us are parents. We have been school children and teenagers. Some of us are creative and artistic and some of us are sports people and lots of us are workers. We need to focus on that. Beyond that, we need to focus on what our abilities are and what support I needed to sustain us in this life rolls. We need to unite as Australian. I was taken with Simon's approach this morning about being an Australian. We must not let our state politicians turn this into an opportunity for political grandstanding around state rights. I don't know about the rest of you, but I am an Australian and I'd like to think we can go forward on that basis.

There is a slight missing, I will go back. It keeps popping up, good. Lovely.

In uniting Australian surveying this is a wonderful report there are some issues. The sector has responded to a series of issues in their comments back to the Productivity Commission. Today I could have spoken about a number of concerns, and I would like to acknowledge some of them. I could have spoken about my concerned that in order to pull it a beer in this state you need to have a responsible service of alcohol certificate. I will need no such qualification to work with these young men. I understand where people can direct their own care or damage you can direct care are coming from on this agenda on that that person is more important than the technical skills. But I think we need to look at the qualifications are protections of everyone.

I am concerned it is a bit thin on what the work agenda looks like, and opportunities for employment for

---

people in this country. We are looking at tens of thousands of new jobs over the next year. I would like to see a lot of those going to people with disabilities and driven by the sort of reforms the commission is talking about. I would have liked to have seen more in the report about the infrastructure, the research agenda, building community capacity. I think we had an eloquent speech of a morning tea about inclusion and community capacity so I would like to see those things fleshed out.

In moving forward there are issues to address. I would like to talk about sustainable enduring and dignified support. I should declare my colours at having worked in the insurance sector where it is very well funded. I believe in these schemes, but dignified support they offer people but that does not mean I am blind to how they gained OK shaped. The TAC and the ACC have faced significant financial problems in trying to manage this small cohort of clients with brain injuries. I am a believer. Some people will have seen this before, but I will speak recently about what sustainable means. It means like our household budgets we have an income that we spend on today's things, and we save some of it and then we have our extra. We get too excited about what we spend today, it erodes, and then we find ourselves in the space of pennypinching.

It needs to put money aside for the future. Inflation can erode that money. We need to be saving for the future so we can manage inflation and restore the dignified support that we want. I will come back to the theme of enduring, for any commission to address this notion of enduring. If the dollar start work and sustainability becomes a problem for government that can only do two things. They can increase taxes, or they can reduce services. There are only two alternatives. These are the constraints of government and assist them on the sustainability agenda.

What then affects the sustainability? Sustainability is affected by who receives funded support. I am not talking about other people with disabilities who might receive information and referral services, that is as small component of any schemes costs. I am talking about who receives the funded support. The other component of the debate is what is funded? Is it the walker in the back of the car will stop is at the accommodations in the back of the car to accommodate the walker, or is it the purchase of the car itself?

I could talk quite a lot about individualised planning an interface with statistical models. That is not for today. That is for another time. I need to focus on the issues of who and what. Who receives support? The commission have proposed people with disabilities and software, intellectual disability, early intervention groups, larger identifiable benefits groups. Patricia spoke about what these groups are aiming to achieve. I want to focus on intellectual disability.

I want to talk about why they are unnamed group. There is a vast amount of research showing that people with intellectual disabilities live with vast disadvantage in their day-to-day lives. Other people live with

[Lindsay.Captioner is Live]

it and then we have our extra. We get too excited about what we spend today, it erodes, and then we find ourselves in the space of pennypinching.

It needs to put money aside for the future. Inflation can erode that money. We need to be saving for the future so we can manage inflation and restore the dignified support that we want. I will come back to the theme of enduring, for any commission to address this notion of enduring. If the dollar start work and sustainability becomes a problem for government that can only do two things. They can increase taxes, or they can reduce services. There are only two alternatives. These are the constraints of government and assist them on the sustainability agenda.

What then affects the sustainability? Sustainability is affected by who receives funded support. I am not talking about other people with disabilities who might receive information and referral services, that is as small component of any schemes costs. I am talking about who receives the funded support. The other

---

component of the debate is what is funded? Is it the walker in the back of the car will stop is at the accommodations in the back of the car to accommodate the walker, or is it the purchase of the car itself?

I could talk quite a lot about individualised planning an interface with statistical models. That is not for today. That is for another time. I need to focus on the issues of who and what. Who receives support? The commission have proposed people with disabilities and software, intellectual disability, early intervention groups, larger identifiable benefits groups. Patricia spoke about what these groups are aiming to achieve. I want to focus on intellectual disability.

I want to talk about why they are unnamed group. There is a vast amount of research showing that people with intellectual disabilities live with vast disadvantage in their day-to-day lives. Other people live with this disadvantage because they have a primary brain injury. It is a reflection of the size of the group? Or is a reflection of the true difference? This is what I want to explore. I want to explore it because it seems to me that for some people the barriers to entering the scheme are high. If the naming of one group a reflection on the size of the group and the amount of research that has been done? Or is it a reflection of the true difference? This is what I want to explore. It seems to me that for some people the barriers to entry for the scheme are quite high. You have to have a significant impairment, mobility or communication and so on.

For others, the barriers are relatively low. It is all people diverse as having an intellectual disability. In practice, what does this mean? We have 2 16-year-old people looking to transition from school. One has a diagnosis of cerebral palsy and they need to demonstrate their need the services and support. We have another 16-year-old person with very mild disability. So let me get a bit theoretical and unpack a little bit more of what I see happening as a result of a naming of a diagnostic group.

The World Health Organization has a model that talks to us about body function, body structure, activities and participation and the effect on our lives and environment. It also then sees when some sort of injury, disease, whatever you call it, interferes with those things. There can be impairment-based outcomes, they can relate to activity and participation restrictions, traditionally called disability, and in the environment can become a significant facilitator or barrier to the sort of lives people lead. At no point does the world health organisation talk about diagnosis. They talk only about the consequences of the insult that has occurred. I want to look then at what our brains do in the insult that can happen. They can affect our feelings, how we think, our muscle tone, how we communicate with other people, how we get around, how we can plan, balance, how we see the world.

But let me close to the things our brain can do well. I have cognitive thinking. It is about thinking. They have affect our physical abilities, sensory abilities and behavioural moderators, which is what prevented me today turning up in a little pair of tights and shorts over the top. So to a greater or lesser extent, the diagnosis intellectual disability implies some sort of disability in the areas of how we think, physical and behavioural and central disabilities. They are represented differently in different people.

Brain injury, equally, has to a greater or lesser extent, difficulties in these areas. Autism, to a greater or lesser extent, has difficulties in these four areas. Cerebral palsy, to a greater or lesser extent, difficulties in these areas. My proposition is that whatever the cause of the brain impairment, the label applied is not relevant. The areas affected are the same. Simon McCullin spoke this morning about how we should not be overly concerned about how the disability arose in the first place, and this is precisely the point I want to make.

But what will happen if we go down this path and say intellectual disability should not be a named diagnosis? And before you rise as one and shoot me, let me offer some alternatives. The outcomes of the diagnosis as I see it is, frankly, discriminatory. If you acquire the right label, you are in, if you have the wrong label, you are out. If you acquire the disability in the right way, before birth, you are in. If you acquire it as a result of landing on your head later, you are out. I think that is discrimination.

---

My second point is the other thing that will happen, and this is about market distortion. What will happen is we will simply come up with diagnoses of convenience. Autism will be batched intellectual disability, TBI will become developmental delay, CP will become intellectual disability, official alcohol syndrome. I could continue. We have seen this before. When Western Australia and Queensland introduced specialist autism funding programs, the rates of diagnosis of autism shot up. Questions were asked in the Queensland Parliament as to what hasn't. So I look to history for my evidence and factual basis for this proposition.

I have a couple of solutions and a plea to the disability sector. My first solution says tier 3 funded services should take out reference to intellectual disability and merely talk about people with large, identifiable benefits. A child with whatever he will benefit from transition services on leaving school. That is one alternative. The other option that I have is that we talk about people with a primary brain impairment. We as examples of intellectual disability, cerebral palsy, traumatic brain injury, autism and so on.

I am saying to the disability sector, will you invite other people in to the area that you have covered? The other people who have similar issues as you do. I would like us to be able to speak with this one voice that doesn't say, intellectual disability is special. I would like to speak with one voice that says brain impairment is special, because it affects all these critical areas of your life. I would like to see that going forward.

(Applause)

Thank you very much. Briefly, the question of what is funded. There goes the watch. I will be fine. This is typically what insurance sectors fund, self service and support. The productivity commission is proposing a bit of a shift from there. You can take some of these dollars and use it to buy a cinema ticket and this would be a substitute for a day. To be honest, I am not seeing how someone who is able to go to the cinema would have been in a day service in the first place. I think we have come a long way in the sector. Let's follow this through. Another example I have heard is that of a fishing rod. If this is a substitute for attending care services, this is a good investment. My question is, where does it end?" You would need a club membership. You need equipment. Now I want a boat. This may seem far-fetched to a sector that has always lived with constrained resources, but believe me, in the insurance sectors in Australia and New Zealand, this is reality. The helicopter flying lessons, the inground swimming pool connecting to the lounge room. Few people, I agree, but with enormous questions for sustainability. We need to be really, really careful about how we think this through. We need some good lines in this room to turn their heads to it.

Disability support is not income, is my position. It is about dignified care and support. Income is income. It buys us cinema tickets, holidays, restaurant dinners. We have an absolutely unique opportunity to move from beggars to cultivate this beautiful daffodil we have and grow it into something that looks like this that is enduring, that is here for our children's children, but only if we focus on refinement, not complaints. A feedback should be positive. It is for adults, teenagers, people with disabilities and people with support needs. On who we are, which is Australians. If we focus on needs and abilities and not diagnostic labels, and we focus on care and support as the function of this scheme. Thank you.

(Applause)

– END OF TRANSCRIPT