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TRANSCRIPT OF PROCEEDINGS

PRODUCTIVITY COMMISSION

INQUIRY INTO DISABILITY CARE AND SUPPORT

MS P. SCOTT, Presiding Commissioner
MR D. KALISCH, Commissioner
MR J. WALSH, Commissioner

TRANSCRIPT OF PROCEEDINGS

AT ADELAIDE ON WEDNESDAY, 16 JUNE 2010, AT 9.03 AM

Continued from 9/6/10 at Melbourne

INDEX

NICK RUSHWORTH

MS SCOTT: Good morning. Welcome to the public hearings for the Productivity Commission inquiry into disability care and support. This is our fourth day of public hearings. Thank you for attending today. My name is Patricia Scott and I'm the presiding commissioner on this inquiry. My fellow commissioners are David Kalisch and John Walsh, and John is joining us by Skype today.

The inquiry started in April with a reference from the Treasurer. The Australian government has asked the Productivity Commission to examine the feasibility, costs and benefits of a national disability scheme that would provide long-term essential care and support; manage the cost of long-term care, replace the existing funding for those people covered by the scheme; take account of the desired and potential outcomes of each person over a lifetime with a focus on early intervention; provide a range of coordinated support options, including accommodation, aids and appliances, respite, transport, day programs and community participation; assist people with disabilities to make decisions about their support; provide for people to participate in education, training and employment where possible.

The Australian government has asked the commission to consider how a national disability scheme could be designed, administered, financed and implemented. This includes consideration of a variety of options, including a no-fault social insurance model and approaches used in other countries. We have already talked to a range of organisations and individuals with an interest in the issues and submissions have been coming in to the inquiry following the release of an issues paper in May.

We are grateful for the submissions already received, and submissions can be downloaded from our web site at www.pc.gov.au. While we would like to get submissions as early as possible, in view of concerns raised by some participants, the commission has extended the due date for initial submissions to Monday, 16 August 2010. The commission also welcomes second or third or fourth submissions - feel free to put in as many as you like - after the due date of initial submissions.

These submissions may include additional points you wish to make, comments on other submissions and the results of community consultations. The purpose of these hearings is to provide an opportunity for interested parties to discuss their submissions and their views on the public record. It is also an opportunity for the commissioners to ask questions of those presenting material. Hearings will be held in all capital cities, depending on demand. We will then be working towards completing a draft report in February next year for public comment and we will then invite participation at another round of hearings after interested parties have had time to read the report.

We like to conduct all our hearings in a reasonably informal manner, but I do remind participants that a full transcript is being taken. For this reason, comments from the floor cannot be taken. But at the end of the day I will provide an opportunity for anyone who wishes to do so to make a brief presentation or comment. So if you have sat there all day and feel that you really do need to say something, we'll invite you to come forward. Participants are not required to take an oath but are required, under the Productivity Commission Act, to be truthful in their remarks.

Participants are welcome to comment on the issues raised in other submissions. Certainly in Melbourne a number of people presenting to us commented, either favourably or not, on the earlier evidence they had heard. You are certainly free to come and go during the day as you wish. Transcripts will be made available from the commission's web site following the hearings. This is a good time for you to think about turning your mobile phone to silent or off, because you wouldn't want to interrupt someone's evidence by having a phone buzz away. Are there any media representatives in the audience? Okay.

Safety. To comply with the requirements of the Commonwealth occupational health and safety legislation, you're advised that, in the unlikely event of an emergency requiring the evacuation of this building, to please follow the instructions of the hotel staff. If you require assistance, please speak to Dominique. I think Dominique has probably spoken to most of you on the phone already or welcomed you here today.

Just a reminder, if you do wish to say something at the end of the day, even if you have indicated that you weren't going to be giving evidence, you will get an opportunity if you'd like to make a brief comment or remark at the end of the day. I now invite Robbi Williams to come forward. Hi, Robbi. Robbi, just for the record, will you give your full name and the organisation you represent, Then would you like to make an opening statement?

MR WILLIAMS (JFA): Yes, I have got a very long statement actually.

MS SCOTT: Okay, well, you have got 30 minutes, and we have got a few questions for you, so you might just want to leave five or so minutes towards the end for us to ask a few quiz questions.

MR WILLIAMS (JFA): Understood. My name is Robbi Williams. I'm chief executive with the Julia Farr Association. Just briefly around our association's work, we're a non-government not-for-profit entity. With the latest in a series of entities, they have had a 130-year history with the disability community of South Australia. We are not a service provider now, we undertake research and policy development work.

The bulk of that work is fuelled by our activities and research and dialogue with people living with disability, their families, supporters and other people with a stake in the disability support sector. I'm grateful for the opportunity to present at this hearing today and we'll be following this up with a more comprehensive written submission in due course.

MS SCOTT: Thank you.

MR WILLIAMS (JFA): I have got 11 main points to make. I'll just say, these represent the highlights of a more extensive submission that we will file in due course. The first point is support for a no-fault social insurance scheme, or, as has been termed, a national disability insurance scheme. Our support is on the basis of one big condition, which is that any such scheme in its design and implementation is an entitlement based model of individualised or self-directed funding.

In other words, if we look to the best practice elements of individualised or self-directed funding as is practised in various jurisdictions around the world we notice a number of important features that contribute to its success. In no particular order, these include a very clear resource allocation mechanism, which includes good actuarial analysis and the application of public policy salience; a simple assessment mechanism, which includes the person living with a disability's central involvement in that process, so it has all the features of a self-assessment tool, that is then reviewed in collaboration with a government officer.

Also, genuine choice and control with the person living the disability and their family, if their family is present in their life; with full flexibility on how to use the funds, and assistance, if required, with envisaging a good life and planning for it. This is particularly important because the experience of many people of service recipiency can result in somewhat reduced horizons as people get wounded by years of well-intentioned but misdirected service provision.

Many people with disability, in our experience, have had their horizons shrink to the number of showers they're about to achieve in a week, whether their equipment can be replaced in due course, and these limited horizon markers block the view of what should be for every citizen in Australia the goal of an ordinary valid life with full participation in the economy, a rich range of relationships and freely-given associations, and many of these ordinary life features are currently denied people living with disability.

A further feature would be a range of options of how the funds can be managed on behalf of the person, and without burdensome bureaucracy. Many people make the mistake with individualised funding models that it means that the person or their family have to take complete control of the funds and their administration and manage all the bureaucracy requirements therein.

This is not true. Such arrangements are more correctly described as direct payment arrangements. Individualised funding in its best practice form provides a range of options for how funds can be technically managed on behalf of the person. These will include indeed self-management, by the person or the significant other in their life; it can include management by a trust or a microboard arrangement on behalf of the person or the family; it can include technical management by a independent third party agency; it can include a collaborative arrangement with a preferred service provider, who receives the funds directly; or it can include an appropriate government officer, such as a case worker or a case manager who manages the fund on behalf of the person, and therefore the state as well.

The final feature I think that characterises best practice individualised funding arrangements is the focus on outcomes or impact on the person living with a disability’s life. There is a tendency in service funding to focus on, at best, outputs, such as hours of respite provided, day places provided; but there appears to be little or no focus in current funding and contractual arrangements around the impact of those services on the life of the person living with a disability as a citizen.

That's the first point I wish to make, which is our conditional support for a no-fault social insurance scheme on the condition that it's an entitlement based model of individualised or self-directed funding. The second point I'd like to make is to point out what we believe is the critical difference in meaning between insurance and assurance.

In talking about a no-fault social insurance scheme, the word "insurance" features and in the mindset of most people insurance is where you pay a premium to cover for the consequences of something that might happen in the future, so you cover risk; whereas, for many people living with disability, who will need to have access to such a scheme, they already have their disability - because they might have been born with it or have acquired it before the scheme kicked in, and so the scheme should provide for those people. However, in the minds of the wider population of Australia that will be a somewhat curious notion. It's a bit like seeking insurance on your house once the roof has caved in.

People would find it difficult to understand the idea of insurance for something that has already happened. So our view is that a more appropriate term for what is being proposed is "assurance", on the basis that through an appropriate revenue-generation mechanism people living with disability and their families can be assured of a robust and fair line of funding to support them to get to a level playing field alongside other citizens. The next point I'd like to make is around the terms of reference themselves. We have a concern that the terms of reference, and I appreciate that the Productivity Commission may have limited or no room for manoeuvre on change in the terms of reference.

But we feel it's important to point out that several of the elements of the scope of the inquiry present a somewhat limiting service based horizon when thinking about the potential of people living with disability. I'd like to just give an example. Under the scope of the review there's a series of bullet points. Six bullet points in reads, "includes a coordinated package of care services which could include accommodation support, aids and equipment, respite, transport and a range of community participation and day programs available for a person's lifetime". A very noble well-intentioned statement, but it tends to reinforce the notion that people living with disability are service recipients and not citizens.

Similarly, two bullet points further on, it reads, "provides support for people to participate in employment, where possible". It's a fabulous statement apart from the last two words where it says "where possible". I think that, regardless of the extent of someone's disability, the assumption should be made that the people have potential to participate in a wide range of ways in the lives of our community and in our economy, and where we include phrases like "where possible" we effectively create the opportunity at the start to assume that some people will not be able to participate in certain aspects of citizenhood, and we don't think that's particularly helpful.

I also notice on the fifth bullet point in it reads, "ensure a range of support options is available, including individualised approaches". Our view would be that if a no-fault social insurance mechanism is an entitlement based model of individualised funding then basically every approach therein is individualised. If people choose then to take their approach and combine it with some common interests of other parties - to form a shared living arrangement, for example - then that's their choice. But our view would be that individualised approaches is the context, not necessarily an option.

The next point I'd like to make is around the importance that the weight of funding that's available through a no-fault social insurance mechanism be on the front foot in people's lives. I'll explain what I mean by that. By the way, my own background includes working in a range of human services in a range of jurisdictions in New Zealand, the United Kingdom, the Netherlands and certain other countries, on a consulting basis, as well as of course Australia, and my experience extends to services for older people, people living with disability, kids at risk and mental health services.

What we tend to find in human service provision is that there's a tendency for public funding to be weighted towards what I call back foot services. In other words, we wait for people to find themselves in situations of crisis before we release funding and service, which presents a number of problems.

First of all, it keeps people in patterns of dependency, because by acting in response to crisis situations in effect what we're doing is supporting people to survive rather than to thrive; whereas front foot investment, where we don't wait for people to enter into crisis - and some people would describe this as early intervention - but where early on we invest in people's lives, that investment gives people the opportunity and the system the opportunity to focus on a person's aspirations, a person's rightful place as a citizen in their community, their potential.

Regardless of the extent of someone's disability or the drama of their circumstances, the fact is that every person has potential to the day they die, and that front foot planning and investment recognises this potential and builds towards this. So just summarising that point, we believe that the weight of funding that's available through a no-fault social insurance scheme should be invested in ways that put people on the front foot in their lives and result in capacity-building.

The next point I'd like to make is around New Zealand's ACC no-fault arrangements. Being a New Zealand citizen, I have had something to do with the mechanism not only as a contributor through my taxes in New Zealand but also for a period of time I was a consultant to the department of labour during the work of two successive New Zealand governments in reviewing arrangements for workplace insurance, which gave me some insight into the way the ACC mechanisms work. I subsequently worked as the CEO of a large non-government disability service provider called CCS and realised that whilst a no-fault accident insurance mechanism has many merits there was one particular problem with it as far as the disability community is concerned, in fact it really created two types of disabled citizens.

There was the citizen living with disability who acquired the disability through an accident and so received a robust line of funding through the ACC mechanism, and then there was everybody else living with a disability who either had the disability from birth or acquired the disability through a stroke or other illness or a neurological disorder like multiple sclerosis or motor neurone disease who had to compete for a finite and limited pool of funding, in similar ways to the expenses of people living with disability in Australia, and this created two classes of citizens living with disability and created some tensions within the disability community.

On the basis that people can't necessarily choose how they get their disability, it seems unfair to introduce a mechanism that basically favours a particular demographic within the disability community based on how they got their disability in the first place. So our view would be that if there is going to be a no-fault social insurance mechanism that's designed to have a positive impact on the disability community it has to be designed and implemented in a way that covers everyone living with disability, both those in the future who might get a disability and those currently living with a disability.

The next point is around eligibility criteria. We're a little troubled by diagnostic based criteria and also age-related thresholds - in other words, under the age of 65 or over the age of 65 - because this presents and continues some of the interface problems that we have in Australia at the moment between sources of funding and the age people are at when they get their disability.

I'll give you a personal example. I have got a close member in my family who has age-related macular degeneration and she is now blind. The nature of her disability is that it impacts on all aspects of her lifestyle because she is now blind. The fact that she happens to be over the age of 65 is neither here nor there; the fact is that she now has a set of functional support needs to which we as a society hopefully can respond in a way that's fair and equitable.

An eligibility criterion that's based on a diagnostic notion of disability and excludes people over a certain age will present interface issues that are going to be unhelpful and will also exclude some people who I think will have a fair and reasonable claim on the funding sources that are available, and it presents problems not only with issues like macular degeneration but also of course with other types of impairment that emerge with what might be regarded as the natural processes of ageing, such as arthritis.

Many people in Australia live with varying degrees of debilitation because of arthritis, and if we have a criterion based on age 65 then people who develop severe arthritis after that age and whose functional support needs would be no different to somebody else living with disability will be excluded from a mechanism that sets that age-related threshold.   So concluding that point, we believe that an eligibility criterion should be based on the degree of somebody's functional support need rather than their diagnostic category or the age at which they acquired that function support need.

The next point we'd like to make is around assessment tools. We are aware that there are a number of assessment tools that are either currently available or in development in Australia, including I-CAN, coming out of New South Wales, and D-START in South Australia.

I speak with a background in psychology, I have some professional familiarity with the process of designing and running assessment tools, having designed an assessment tool myself a few years back. The issue with assessment tools, particularly in relation to looking at a no-fault social insurance mechanism is the importance of the need to avoid over-engineering the assessment tool. If the primary reason of an assessment tool is to determine the extent of someone's eligibility for a quantum of public funding, then it's our view that tools such as D-START and I-CAN are over-engineered, because they ask far too many questions for the purpose of testing eligibility and extent of the funding allocations made available.

The example I would use would be of some of the local authorities in the United Kingdom, who of course are operating within a national mandated funding mechanism that's moving towards individualised budgets. I believe the target is that least 30 per cent of adults receiving social care in the United Kingdom will be in receipt of an individualised budget by next year. We are finding that in some of the local authorities there are now successfully identifying the extent of people's eligibility for a quantum of public funding on the basis of very brief assessment tools, which include a self-assessment dimension to them.

Some of these tools run as little as nine questions to determine not just people's eligibility in terms of in or out but also the extent of eligibility in terms of a price point. So someone produces a score on the assessment tool and that relates to a quantum of public funding. We like this mechanism because it's simple and it quite rightly and properly involves the person living with a disability and their family in that process of assessment, because they are partners in the running of the tool. I know there will be some anxieties that you might get - what you called in the document "needs inflation". But we think that needs inflation can be avoided. I won't go into the details about how, but we'll put that into our written submission. We think needs inflation can be controlled, like any other inflation.

What is important is the participation of the person and their family, if their family is present in their life, in that process of understanding the extent of the person's support needs. Fortunately, the more multi-layered professionally-designed the tools the nature and design of those tools means that it's only professionals who can conduct them, which right from the outset is disempowering to people living with disability and their families. So concluding that point, our view is that an assessment tool for entry into funding for a no-fault social insurance scheme should be simple and should have the capacity for the person and their family to be partners in its completion. The next point is that there needs to be a coherent contextual framework for a national disability insurance scheme mechanism.

What I mean by that is that a lot of the dialogue around disability support funding is based on the idea of how much money is available to provide people with supports, in terms of equipment or respite or day places and so on. What we don't have though is a vision, a coherent contextual framework that says, "These are the outcomes we seek to pursue by apportioning these public funds to the disability community." Our view is that that there needs to be a clear, coherent contextual framework that talks about the place of people living with disability in our communities as citizens. We will be in our written submission putting forward our own model, which is called the Model of Citizen Support, which sets out five key domains that we think public funding should be targeting that in and of themselves and in their interrelationships will build a platform for people living with disability to access an ordinary, varied life as valid citizens in their communities.

The next point is around the need to ensure parallel investment in community awareness and community development. Funding doesn't buy everything for a good life and, whilst the attention to adequate levels of funding, whether it's for the current mechanisms or for a new no-fault social insurance scheme, is important, because it's important to get the funding levels right and get the actuarial analysis right, the fact is that funding in and of itself doesn't buy everything that a person needs for a good life; you can't buy love. So there's important needs to ensure parallel investment and community awareness and community development.

If funding is more robust for the disability community it doesn't necessarily create welcoming local communities. If you look back at the last thousand years, particularly based on the analysis of people like Wolf Wolfensberger from the United States, what we see is a 1000-year history where we have trained our communities and our wider citizenry to believe that people living with disability are catered for somewhere else, with money. What we have done is systematically dismantled our communities' orientation to people living with disability as valued members of their communities.

We have trained our communities to believe that people living with disability are catered for through quantums of money and that they are supported in congruent arrangements often separate from the main community. So we believe that there needs to be parallel investment in community development, in intentional community development, so that we build welcoming communities that value diversity, and communities that see the potential that people with a disability have and not the burden that they believe to be the case.

The penultimate point we'd like to make, for the purpose of this verbal submission, is the need to provide for the activities that lie in the space between formal employment and freely-given assistance. We know that there's all sorts of concerns generally in the disability industry around work rates, industrial awards and so on, and that for the industry and for the government officers working the industry there are often concerns around tax obligations, around certain types of payments.

Unfortunately, what this can do is not help the natural, organic development of freely-given associations in people's lives. Having an all or nothing approach, to the extent to which people are paid for service, basically means that some people aren't supported to become involved in people's lives, for want of a little bit of gift money or honorarium money or money for help with transport or whatever, to give their time as a friend. We know there's a lot of financial transactions take place in our communities already that really represent neighbourliness and community. For example, payments to teenagers to babysit young kids. These are cash-in-hand payments that reinforce a sense of goodwill between families and friends and neighbours; same thing with gardening, lift money.

Again another member of my close family provides assistance to a person living with a disability and that relationship is based firstly and foremost on a sense of neighbourliness and acquaintanceship, but some money changes hands to pay for petrol and inconvenience. So our concern would be that a no-fault social insurance scheme needs to ensure that its financial regulatory framework doesn't exclude the potential for funding to be used for those small payments that help facilitate the natural associations in people's lives.

MS SCOTT: I am just conscious we are running out of time. So if you could wrap it up maybe in just two minutes.

MR WILLIAMS (JFA): Indeed. I will make our very last point. By the way, I don't have a disability myself, so I'm just speaking verbatim from what has been said to me over the last 25 years of my career by people living with disability. On the basis of "Nothing about us without us," it's really important that people living with disability have a significant formal role in the governance of the social insurance arrangements, or whatever scheme emerges. We don't believe it should be an advisory role or a steering role or a consultative role; it should be a governance role involving people living with disability as formal leaders in the system.

MS SCOTT: Thank you. John, can you hear us okay?

MR WALSH: Thanks, Patricia. I don't have any real questions, but I'm interested in a lot of the things that you have put forward, Robbi. You have mentioned a number of schemes that you have worked in: the Netherlands, British, I think you said Denmark, and New Zealand.

MR WILLIAMS (JFA): Not Denmark.

MR WALSH: If you have any information on any of those, I think it would be really useful, particularly the way in which the British local authorities assessment tool works, the quantum of funds that are available and the nine categories of assessment. That would be really useful.

MR WILLIAMS (JFA): Yes. Very happy to oblige.

MS SCOTT: David?

MR KALISCH: Just one question mainly from me, Robbi, although I'd be interested in some further information that you could provide around early intervention in your submission and the success that it has had. It has certainly been a recurring theme.

I suppose the other aspect that we'd be looking for in the submission is any information about whether you still believe a scheme should cover dementia, because I mean that has a real challenge for the fiscal sustainability of a scheme if it does actually have no limits. My question is actually on the simple assessment tool, and certainly simplicity and engagement of the person with a disability in the assessment process is something that we have heard a number of times.

I am just sort of wondering if you're aware of any evidence or benchmarking of using different assessment tools in a similar context. Is there any evidence that you're aware of that actually tests assessment tools, rather than that just utilises them in different circumstances? We're aware of them being used in different environments but not necessarily aware of any tests or any evidence about which one works best, which one has the most reliability, which one produces the best outcomes over a longer term.

MR WILLIAMS (JFA):   No, I'm not aware of it, but we're an agency that gets itself involved in research, so we'll probably go and find out for you.

MR KALISCH: Yes. I mean, if you can find something, that would be great.

MS SCOTT: Robbi, I've got a series of quick questions. I'll start with one of the simpler questions first. The gift money idea, I can understand how that works and so on, but if we go to a model of individualised care where one of the options available to someone is to have the money paid directly to them and they then can choose how the money is disbursed, why wouldn't that solve the issue of the person having to hand money to someone for petrol to get around, and so on? You're talking about a model where you've got five or six options. Doesn't that naturally solve the gift moneys?

MR WILLIAMS (JFA):   Yes, one would hope so. It just depends on what regulations are put in place. Again, we know that some of the better practice mechanisms in places like the United Kingdom really only set three main constraints on how people can use their personalised budget, being nothing illegal; nothing directly associated with gambling; and thirdly, which is my favourite, that it has got to be demonstrably useful to the person, in terms of the support needs that were identified, and of course the person tends to be the best expert on that.

MS SCOTT: Yes. Maybe for your submission, because I think it would be too hard a question to answer and do it justice here, the community development idea, the idea of an all-inclusive community, who is going to say that's a bad idea? But I guess to tell us what it actually is in concrete form, what are the actual mechanisms to achieve it and how much it has cost, because at the end of the day we need to look at the feasibility of a proposal and not just the lofty rhetoric. So I'd be very keen to get concrete examples there, if there are again examples which you can point to, either in the states of Australia or overseas, I'd be happy to hear on that. My last question is on boundaries. David has sort of referred to this already, with dementia. But any scheme, no matter when it is or what it is, has boundaries at some point.

The government has very clearly suggested to us that one of the boundaries should be age. Now, you think that's a mistake, I understand that, but all schemes have boundaries, and I'm interested in your outlining, if age is not a boundary, where the other boundaries are, because when this proposal goes forward there will be a lot of accountants and economists and so on who will want to know whether or not it’s fiscally sustainable. So you have removed one of the boundaries. I'd like to know the other boundaries you see would be in place.

MR WILLIAMS (JFA):   Do you want me to reply now or put it in the submission?

MS SCOTT: To do it justice, you might want to put in your submission. But if you have got a quick answer - I'll take a minute answer, or two.

MR WILLIAMS (JFA):   I think it comes down to a functional support need assessment, or, as the criterion for extensive access to the funds, because essentially that's what the funds are designed to provide a response to; a bit like Centrelink payments at the moment, it's an assessment of people's need for financial support because of their circumstances. In the same way, a funding mechanism that looks at people's functional support needs. It feels a much more sensible and natural way of approaching the challenge.

As I say, you can have a threshold where up to a certain point there may be no funding available. You can also apply other elements to the way that mechanism works to take account of the potential for co-contributions, as they do in the UK, and also the potential for social capital in people's lives, because there are some people who, in addition to living with disability, also have a very impoverished social network or social capital in their lives, and so you'd like to think that a mechanism would cater for people with that sort of priority need.

MS SCOTT: John, are you okay?

MR WALSH: No, I'm okay, Patricia. I look forward to your submission, Robbi.

MR WILLIAMS (JFA):   Thanks very much. Thanks for the opportunity.

MS SCOTT: Thanks for attending.

MS SCOTT: I call forward David Holst. Welcome to our hearing, David. Could you identify yourself for the transcript, and the organisation you're representing?

MR HOLST (IDASA): Good morning. My name is David Holst. I'm a parent of a 25-year-old daughter with a severe intellectual disability and I, like many in the disability community, wear a number of hats, including one as the chair of the Intellectual Disability Association of South Australia. In my other life I am also the director of a publicly-listed company, we sell cars, and as such I have a key role in an organisation that turns over $750 million a year. We work on a 2 per cent estimated profit margin, so lean and mean, or whatever you want to call it, is part of what we do all day every day, which has strong similarities with the disability sector.

I have made a submission, and I apologise that mine will not be as eloquent as others you will receive, but I guess it comes from the context of a parent and someone who is involved in the disability sector, in a way that impacts on their family but also which is extremely interesting when I put on my business hat. In the end, I think there are four key areas into which almost everything falls that you can talk about to do with disability: (1) the quantum of services that are available; (2) the quality of services that are available; (3) the flexibility of services that are available; (4) the priority of the sector to outside decision-makers.

In my submission - because I'm a two-finger typist - I tried not to regurgitate all the information about how poor the sector is, but one of the points I made is that the quantum of services is so manifestly inadequately that there is effectively no genuine service delivery option or future plan that I can see in this state. I should also add, and I made the point in my submission, that in our state a lot of good things have happened in the last three, four or five years in terms of restructuring and reorganising. It's a bit like having a sports car; you could build a model, but without an engine, wheels and fuel it won't move.

That's a little bit what seems to be happening; we are building a model that encompasses much good in disability strategic direction, but at this stage there is no traction. One of the reasons for that is that I think the funding by the federal government is not equitable. In some ways the disability sector has contributed to that, because too often discussion in the disability sector is about people's priorities or philosophies, to the detriment of the greater good.

Robbi mentioned before a saying, "Not about us without us," which personally I find interesting, because, as a representative of people with an intellectual disability, largely they are ostracised or excluded from high-level disability policy input at the moment, for the simple reason that by the very nature of their disability they are unable to talk and represent themselves. How you can have a structure where people who are the largest consumer group can be excluded from the process without an acknowledgment of the ipso facto right of their voice to be heard totally befuddles me.

One of the things that I'm interested in, certainly when I listen to Robbi Williams speak, I am always in awe of his knowledge and information and the holistic way in which he approaches things. I'm forced by my employer to be pragmatic, but the building that I would like to build for my business, which my clients would like, I can't afford to pay the rent on. So pragmatism and commonsense and commercial reality are important in the way we go forward I think.

That makes the disability sector no different from other major community services in the country. Children obviously go to school, but they have no right to a new desk, a new computer and an airconditioned classroom with state-of-the-art technology. Children with illnesses commonly are put on short-term waiting lists that in a pure world would not be acceptable. However, in the real world in which we live there has to be some compromise.

I recently had the pleasure of attending a lunch with Tony Abbott and at that lunch, when we were discussing the priority of disability, I asked him if he wished to be prime minister of a country in which people regularly kill their disabled children for lack of service, and he indicated he didn't. But that's the reality of the depths of crisis of disability support when compared with other community services around the country. There are a couple of other things that I find really strange about the disability sector.

I have never had anyone suggest to me they want to leave a service provider provided by an NGO and move to a service provided by a state government; the opposite happens all the time. People are saying that if they could get out of a state government service provision scheme and move to one provided by a quality NGO, they feel they would be better off. I have never had it suggested to me the other way. Why state governments persist in being service providers, I don't quite understand, because in our business model we have all hired specialists; we don't run our own major IT department, we contract it in.

We seek expert advice as we need it from specialist people, but in government that is not the case. I am deeply concerned that so much of what has happened in the last 20 years in the disability sector has strangely been based on research and academic theory. It was commonplace in years gone by that women - and with respect to the chair, Patricia - were not seen as being able to have high level positions, that children were removed from Aboriginal parents, that left-handed schoolchildren were caned, that homosexuals were electrocuted, and all that was done under the guise of academic research and theory.

In my business life we consult our clients and the clients who we would like to attract regularly, daily, often and always and any suggestion - and there are many academic theories about the business world and how it should operate - we clearly listen to them, we take note of them and we acknowledge them, but fundamentally we're drawn by the consumers who we wish to engage with. The information that we glean from people who have interacted with our business and left with dissatisfaction is often more important to us than the information we get from people who actually signed on with us.

When you go into the disability community there is no doubt that person-centred planning and self-managed funding, individualised funding are all key parts of the solution going forward. There is also no doubt that none of them on their own - and the chair made a comment earlier about if we move to a model of individualised care I personally would be horrified. I think it should be one of a range of a menu of options that are available to consumers of disability of service, that they should have a choice of service style, service provision and where they sourced and actuated their services without being put in a position where one size fits all. Sometimes in the heat of the debate I think that goes by the way.

In our state, and credit to our minister and our previous minister, they have actually done some very good things in the last three or four years. They've closed some dysfunctional government service delivery units like IDSC and they've actually compiled a single state-based waiting list register. They tried to implement a priority sorting matrix based on need. They've actually appointed non-traditional disability experts or executives to run their departments with a charter of consultation and choice. They've consulted widely. They've developed a new strategic plan that focuses on flexibility and choice. They have rolled out pilot plans like self-managed funding which is in its early days and still has a long way to go, and it's important it succeeds. They have recognised that clients with intellectual disability need equitable representation and they're also now working on alternate and cost-effective specialist models, accommodation and services which is a system that's been stifled for the last 20 years nationally in the disability sector.

In the end I think they've responded to community pressure and been accessible but, unfortunately, at this point in time the waiting list for services grow. We tragically had a fatality in our state in the last 12 months where a parent allegedly murdered their child and there is, as I made the point at the start, nothing that I can see that looks like a genuine plan going forward that's going to address the issue.

MS SCOTT: Thank you. David, do you want to lead off.

MR KALISCH: I was really interested, I suppose, in the concept you're introducing around how to give a voice to people with intellectual disabilities and I'm just wondering whether you can expand a little bit on that from your experience, David. Are there particular mechanisms - and Robbi raised the issue of governance as well.

MR HOLST (IDASA): David, I find it strange that the powers that be, be they state and federal, have actually embraced a system that is so obviously fundamentally flawed and in management today the person in charge is largely empowered with the responsibility to consult widely and to ensure that you have broad representation in the submissions, whatever the area of management you're talking, whether you're talking about business, private and even to the point where in my household my teenage children believe they have some right to have a very large say on how our family runs its life. So that the concept of inclusiveness is not a difficult one.

The structure that exists in the disability sector today - I can't believe it's got to the position it's got to. In the early days when I first became involved in advocacy, which was only seven or eight years ago - so I'm not a long-term expert on this, I'm a person who has come to it, I think, without a history and trying to look at it - I was shocked to be told of disputes between people with different types of disability largely scrambling for positions of power in policy and development and direction and it horrified me. One of the things that I'm proudest of in the last six or eight years is that in our state now amongst our leading advocacy groups we have people who represent the physical disability associations, the intellectual disability associations and plethora of other groups who actually sit down at the same table and talk about the same issues rationally, logically and with commonsense.

We have, as you would be aware - and I assume she will be speaking later - an MP who has a physical disability whose adviser is a carer. Now, it's not hard to do but I don't understand why anyone would allow it to get to the position it has but that's where it is and it needs to be changed. The structuring of some sort of national disability advisory system whereby there is balanced and equitable representation - and he who hold the dollars has the control, I think is how the saying goes, and many of these organisations rely on funding from federal - not so much state because our state funds very little advocacy. It is not hard to develop a charter that insists that equitable representation is fundamental in that process and without the funding is not available and people would change their minds very quickly.

So it has driven a culture that has been divisive. It has driven a culture where people such as yourself will receive mixed messages and the message of appropriateness will not necessarily be what's right or wrong, it will be who comes from the best funded or the most powerful organisation and largely that hasn't been people with intellectual disability who have largely been ostracised from the process in recent times.

MR KALISCH: Just one more question, picking up on one of the aspects that you raised about one of the key deficiencies in current arrangements and that's around the quality of services.

MR HOLST (IDASA): Yes.

MR KALISCH: We have certainly heard a lot around the quantum of services and that seems to be largely because of limited funding. But in terms of quality, obviously the extent to which the person with the disability and/or what arrangements they have for using that funding might actually introduce some more quality control themselves. But one other aspect that's been raised with us, and I wouldn't mind your views on it from your business background, is whether there needs to be an external evaluation monitoring accreditation process, whether that would be of some merit.

MR HOLST (IDASA): I don't think there's any doubt there needs to be some sort of external evaluation monitoring process. In my world and if I was Prime Minister for a day - a lot of things would change - I think the federal government should control the funding streams and that doesn't necessarily mean they supply them all. I think the state government's role should be to get out of service delivery and to get into service management and service supervision and those type of situations. I think it should be the role of other programs to then deliver the services, be they managed self-managed services, be they NGO service, be they a plethora of choice. In any effective model you need an audit, a supervision-type situation and without it you are doomed to failure.

It would be fair to say that much of the debate about quality of service probably, in my opinion, stems back to two things: one is that quality has deteriorated as funding has become impossible to get. The second stage is that the management models that are established - in our business environments we tend to believe small is good and we tend to believe stakeholders should have a say. One of the things the Intellectual Disability Association has done is put a submission to our state government whereby in a partnership between a major NGO with a family management committee, so you get the probity coverage from the NGO and you also get access to trained staff and some of those things you need, but with a heavily reliant family management structure we think you'll improve the quality of service. As the numbers run, it tends to indicate that we can do that in a way that's about 30, 35 per cent more cost effective than the traditional model that the state government uses today.

At this point in time that model is bouncing around somewhere in someone's office and we'll keep pursuing it. But the idea of flexibility, the idea of different stakeholders being more involved in the management, that's where I think one of the big outcomes comes in improvement in quality.

MS SCOTT: That 35 per cent figure, is that documented somewhere?

MR HOLST (IDASA): Yes, it is. We call the model Kardinya, it's been summarised, so it means the sun's coming up hopefully.

MS SCOTT: Okay. I have read your submission and I know you make reference to Kardinya, it's towards the back, but I don't recall that figure being in here.

MR HOLST (IDASA): I could forward that as an additional submission.

MS SCOTT: You can imagine that's very interesting to us.

MR HOLST (IDASA): But one of the things that really I find quite disturbing is, if you like, and for very good reasons in the 80s, the concept of people being disinstutionalised and moved into the community was embraced. But with it came all sorts of traps and shortfalls and we could argue for a long time whether that overrides people's right to choose and at the same time as we have been on a plan in a disability direction, the rest of the world has chosen to go in a different direction and gated and ungated communities, seaside living, you name it. One of the key drivers of all of that, putting aside the quality of life, the social interaction, being where the action is, has been there are financial benefits of it. So the model that has been propagated is very expensive and because it's very expensive then it's cut the service and then the quality deteriorates. I was reading some comments on an online blog this morning from a Victorian Auditor-General or someone's report talking about poor quality outcomes.

Without innovation, without a focus on appropriate management and financial outcomes in the long term the federal government can't afford to just keep putting the amount of money in that's going to be needed to cover disability support. If you look at health care - and I'm not a student of it so I can't - but I know they talk about community clinics and I'm aware years ago they started dental therapists in schools who could do minor work on children's teeth and the dentists were offended by that. There needs to be a commercial pragmatism driven by key stakeholders with flexibility and with financial commonsense as an outcome. That has been nonexistent in the last 20 years in the disability sector. If the federal government came out now and said, "We have X amount of money and we went to major NGOs and can you help us alleviate the bottleneck and the crisis, they could help you."

MS SCOTT: Okay. David, I've got a few questions. John, would you like to go before me though? I've got about five or six questions I wouldn't mind exploring with David.

MR WALSH: Yes, David, I'd like - again if you become Prime Minister for another day - and when you paint a picture of a system that's pretty dysfunctional, inadequate funding, poor quality, cannibalistic service network and inappropriate community living arrangements, assuming that we recommend a different system, just putting a bucket of money in would be probably the worse thing you could do, all it would do is cause inflation. Again, thinking about it with your business hat on, if you released the money supply, the cost of cars would go up obviously because there would be more money to spend on them. So as well as putting more money into the system, what would you do to get it moving? What are the steps you would take immediately to build a transition plan to change the system?

MR HOLST (IDASA):   If you're talking immediately as in over a six or 12-month run - - -

MR WALSH: More like over, I think, three to five-years.

MR HOLST (IDASA):   The biggest fundamental change I think is that the money has to get to the service recipients or the service providers more directly and faster and that there is less scope on the way through for other organisations - and particularly for the government department, that is Disability SA, and I can only largely speak for our state - the federal government as part of the national disability agreement I believe gave $72.8 million to the state government in January 08 or thereabouts. Four Corners recently said not a single bed has been opened in South Australia with that money in two years. If you gave that $72.8 million to non-government organisations with a charter to interact with their clients and, as Robbi rightly pushed the point, on an outcome base, you would have opened hundreds of beds by now.

We all know, and the federal government may choose to argue, but the recent situation with the Building Australia in the school situation that's been well documented that state schools have got allegedly somewhere between 50 and 70 per cent of the bang for their buck than the private schools is probably an example that would confirm what I feel and think and I see in the disability sector every day. In the future - and the future needs to be soon because the crisis is so strong. In our local area we've got a proposal from the state government for another inquiry that has not been widely supported and it's not been widely supported because we believe there is a need for some crisis management. The current system of federal, state, NGO, client doesn't work. It simply doesn't work.

I think that is the biggest change that needs to be made and made quickly and it should be made - our state government, if I was premier for the day - that would be another interesting position - the state governments with appropriate transfer of funding could transfer their service provision responsibilities to appropriate NGOs in our state and be out of the service provision business within 12 months. If they transferred, the client, the funding, the responsibility, they could be out of that service provision in the time it takes for the NGOs to build the infrastructure they need - they could even take over the infrastructure that currently exists, no matter how bad it is. The duplication is absorbing funding at a frightening rate and the efficiency that's involved is just alarming.

MR WALSH: Are you confident that the existing NGOs that we have have the capacity, capability and innovation to be able to deliver on all of the new models that you've been talking about and Robbi's been talking about?

MR HOLST (IDASA): John, in South Australia, the last time I checked there was about 145 NGOs and one of those NGOs had one client which is interesting but everyone was happy with that. There is no question that not all NGOs have that competence but there is also no doubt that many do. When you talk about self-managed funding, if I was running as an NGO, I would see that as a great opportunity that if I could provide great services effectively and efficiently, people who were in control of their individualised funding would actually be rushing to my door and saying, "We want the services you've got because of the way you deliver them." If you move to that model some NGOs will fail to keep up with it, others will prosper, new ones will come into the market and that dynamic service delivery is what we have in the rest of our life in all the other services we use. We don't have it in the disability sector and you don't have it because philosophy and policy has constrained it to a one-dimensional concept that simply we can't afford and doesn't work.

MR WALSH: Thank you.

MS SCOTT: David, I just want to clarify something because it seems to me like you actually do support the concept of funding coming, in some cases, direct to the individual or their family if they need support or whatever.

MR HOLST (IDASA): Absolutely.

MS SCOTT: I just want to check your version of the model. So you'd have assessment based on the individual needs?

MR HOLST (IDASA): Absolutely.

MS SCOTT: The government would go away, allocate some money, for example, for your daughter.

MR HOLST (IDASA): Yes.

MS SCOTT: In a case where maybe your daughter can't make decisions alone she'd have support of other people or maybe have - - -

MR HOLST (IDASA): My 25-year-old daughter's favourite video is Humphrey Bear.

MS SCOTT: Okay. So it might be the case that the family or someone else manages the funding, but that money would go to the service provider that most likely in the decision-maker's mind to provide the best services.

MR HOLST (IDASA): Yes.

MS SCOTT: The reason why I'm clarifying that is just because you're not really thinking necessarily that you want the dollars to go straight to the service provider unless you've nominated that service provider.

MR HOLST (IDASA): Unless we've nominated that.

MS SCOTT: Okay, I've got that. In your submission you've indicated that you'd like it to be regionally managed and locally delivered.

MR HOLST (IDASA): Yes.

MS SCOTT: So regional management you've got obviously some governance structure you've got in mind.

MR HOLST (IDASA): Absolutely.

MS SCOTT: We've got federal, we've got state, we've got local but it sounds like you want to jump over the states and go to some sort of regional - - -

MR HOLST (IDASA): I'm not fond of the state.

MS SCOTT: Right. Could you talk a little bit about how this regional operation would work, just for a minute or two because I've got some other questions, David.

MR HOLST (IDASA): Again, I'm not an expert on it and I don't know that we need to reinvent the wheel with disability. I don't see disability in the forward structure as being a whole lot different to Medicare and the health provision services, I don't seen it being significantly different to education. The structure that appears to me that works reasonably well when it comes to regional management is to do with Centrelink and unemployment and where the federal government has decentralised the responsibility for supervision of those sort of programs and they're not supervised by the state government but they are supervised by people working within appropriate guidelines at appropriate levels and my experience - in my business experience, we're a big employer, we have 900 people - my opinion is that they seem to work relatively effectively. They may not be perfect, but effect.

MS SCOTT: Okay, that's good. I want to come back a bit more to your commentary about potential economies and choice and also about general community living. One of the themes in your paper is that - and you said it also the morning - there has been this trend to take people out of congregate living and to put them in individualised arrangements but in fact the general communities in fact are moving from the suburbs into the city and so on.

MR HOLST (IDASA): Yes.

MS SCOTT: Could you just explain a little bit more about that and I also would like to know what you think is the right size and why that model has attractions and I guess I'd like you to think about what the critics would say about that model and how you would address their criticisms.

MR HOLST (IDASA): Yes, okay. A couple of points. First of all, if you just go back to self-managed funding and whether I support it or not. I absolutely totally believe it should be an option of choice for people.

MS SCOTT: Yes.

MR HOLST (IDASA): I would not choose it for our daughter because whatever arrangements my wife and I put in place are only sustainable as long as my wife and I are around. So if tomorrow we are the victims of a car accident or I'm a victim of my unhealthy lifestyle, that arrangement does not cover the question that many people with an intellectual disability and their family and carers have of, "What happens when I die?" So we wouldn't sign up for it, because no matter how well I think I could run it and what benefits I could get out of it, I want a system that is going to postdate me.

Going back to the other concepts you were talking about. My position, and it's unchanged for eight years, is that the choice of the consumers or ipso facto the person who is acting on their behalf should drive the outcome. My comment on the size of a model would simply be that is to the choice of the people that are involved. If they choose to live on their own, so be it. If they choose to live in a high-rise apartment with 140 other units, so be it. It is not my right to stipulate how, when or where they should choose to live. In regards to the critics of those choices, there are two issues that I think come out of that: one is I think those people should be embarrassed that they think they have some God-given right to tell other people how they should live their lives, regardless of what it is based on. I think they should be ashamed of that position and to do it based on research or something like that - I'm assuming most of the people in room eat ice-cream and I think if we followed academic theory ice-cream would be banned because it has no nutritional value.

The second one and most importantly is that unless you let people have those choices, you are fundamentally building where it is "you get what I say you can have" and no-one has the right to do that. It doesn't work anywhere else in the community. No normal person would accept for one second being told how to live, where to live and who to live with. Whilst the theory has been pushed - and it has been pushed for good intention, we understand that, and it's also been pushed because many of those organisations in the past have been very poorly managed. If tomorrow any of us in the room elect to - and I would, but my wife wouldn't - go and live in an aggregate living situation, she prefers the garden. I would happily go and live in a congregate living situation and who knows where that will end up and when I finish work and I'm home all the time, I've got not a clue.

But the situation with many of those organisations that have failed in the past is they've been poorly resourced, they've been poorly structured, they've been poorly supervised. Now, if I go and tell my boss, "This business is no good," he will simply go, "I pay you to fix that. Don't tell me what's wrong with it, fix it." Now, because you've given up on something and closed it, at the same time as the disability community has closed down a concept of living, the rest of Australia has embraced it. The rest of the world has embraced it and they have done it by doing - they have local management committees of people who sit there and talk about what community exercises they should have, what community programs.

The criticism - is it a criticism of the structure or is it a criticism of the management? Much of it to me appears to be a criticism of the management and there are thousands of examples of communities around the world now where people live close to the action, and close to the action, close to the socialisations, close to the networking seems to be the driver of what most people want in their life. Robbi made the point, it's not all about money, you know, "He who does with the most doesn't have the happiest life." So you've got to be going, "Hey, are we doing something?" Now, am I suggesting for one second that people should live in an aggregate style? Absolutely not, unless they choose to.

MS SCOTT: Okay. I got that, that's good. John, shall we wrap up now?

MR WALSH: Yes, thank you, David.

MS SCOTT: All right. Thank you very much, David.

MR HOLST (IDASA): Thank you.

MS SCOTT: I think we can anticipate a second submission - even if it's a short one - about that 35 per cent figure you referred to.

MR HOLST (IDASA): Yes.

MS SCOTT: Thank you.

MS SCOTT: Harold Rush. Harold, for the purpose of the transcript, could you just identify yourself, and I understand you're speaking on behalf of yourself and your family.

MR RUSH: Yes, my name's Harold Rush. I live in Campbelltown, South Australia, and I've come here this morning to speak about carer issues. I have a profoundly disabled son, his name is Ashley. He's now 19, he's a young man. My wife and I are both getting on, I'm now 60, my wife is 57, and we are concerned about Ashley's future, but we're equally concerned about our own future. No disrespect to the disabled, I'm here today to talk about carer issues. There are a lot of areas I could talk on but there are three that I'd like to talk about this morning. First and foremost and I think the most important I desperately - now when I say "I" I'm speaking personally, but there are many people in the same or very similar situations - I desperately need a Health Care Card. I have half my teeth, I cannot afford plates. I have been like this for nine years. No teeth. Can't afford to do anything about it. I wear glasses, I can only afford to buy a new pair of glasses about every five years, or if I break them, then I have no option. I'm fortunate in that generally my health is robust, but health is a major issue.

First and foremost, carers can't afford to be ill. But when you are ill and you actually acknowledge the fact that you are ill, you are seriously ill, usually. Secondly, we can't afford private hospitals and things like that. We have private health cover for the family, but we cannot afford to use things like private hospitals and things like that, we have to use the public system and make do, like the vast majority of people in our situation. A Health Care Card is an imperative. If your carer gets sick, someone else then has to step in as the carer, and we all know that preventative health is better than retroactive health.

My next point is the issue of superannuation. I am a man of 60 years of age. I hold four trade certificates. I have been a taxi owner-driver. I have been quite a few things in my life. I quite routinely have worked 80-plus hours a week most of my working life, I am that kind of person, I work; not for the money, I do it because it's also the right thing to do. I used to do community service, things like meals on wheels and things like that, where I was actually helping out others. All that came to a screeching halt when our son was born, because we knew straightaway - he has severe cerebral palsy. He is one of the most profoundly disabled children in the state. He is totally dependent on others in absolutely every respect.

Now, for 10 and a half years I brought no income, not one cent of income into our house, because I was totally devoted to looking after Ashley. My wife and I are together; we have managed to stay together through all of this. It wasn't through a lack of trying to get work. To get work that would fit in with the hours that I had available was impossible. I eventually got part-time work, I work 20 hours a week in a specialty model railway shop, and I got that job simply because I took model railways up as a hobby, for my own sanity, when all this started. I joined a club and I have been a committee member on the club now for nearly 15 years, and it's a great activity and a good group of people.

For the last nine years I have been paying superannuation, even though I only work part-time. I earn $20 an hour as a sales assistant. I put $50 a week in out of my own pocket to bolster the employer's contribution. Even so, I will have effectively nothing when I stop work. My wife is on the verge of retirement right now. Carers shoulder their responsibilities in the community. The government has responsibilities to the disabled. It also has responsibilities to the carers. We are citizens, we work, we pay tax.

I should have a carer's pension, but, because the cut-off level for the carer's pension is so ridiculously low, we can't get it. Even when my wife retires, I probably still won't be able to get a pension. That's a great thank you for doing the right thing by the community and your son and your family and shouldering your responsibilities. I'm an invisible person, I'm a ghost; as far as the state and federal government is concerned, I do not exist other than as a taxpayer, and I don't appreciate that position. On the subject of means-testing, one of the first things that the Howard government did when they came into power was introduce a carer's pension for carers of the most profoundly disabled people in the community under 16 years of age.

Up to that point there had been no support. They laid out five medical criteria, which were quite stiff, and a means test. To get that pension you had to meet any three of the five medical requirements, and the means test. I understand several hundred people across Australia actually got a pension out of it. Good luck to them. The trouble for us was our son exceeded all five of the medical requirements and we were means-tested out, because the cut-off level was $21,600. So basically what the federal government does is abandons the carers, even though we're doing the right thing. We are doing specifically what the government has said, we have shouldered our responsibility. Most people, when a disabled child is born, will walk away at the hospital.

There's many here, I'm sure, that have been supported well all their lives by loving families. Their parents and supporters and carers have been through the same as what we're going through now, and the situation doesn't get any better the older you get. They're my three primary concerns. They're not just my concerns, they're concerns of probably everybody who is in a similar position. I can't stress enough, I find it really offensive that I find myself in this position, because we did the right thing and shouldered our responsibility. We could have walked away, like so many do, and got on with our lives and got over it, and I wouldn't be sitting here talking to you today.

But we chose to do the right thing. Our son had to have his chance; that was the bottom line. He survived birth, he survived the neonatal unit. He was born 17 weeks premature, he weighed a kilogram. You could hold him in one hand when he was born. You could hold him up to the window and you could see through him. There's something you never forget. If you've ever had the opportunity to do it, do it, it is mind-boggling. But from there it has all been downhill. Just quickly on the issue of government funding, I, for one, am getting to the point where I actually hope - it sounds ridiculous - that the government doesn't make any more changes or allocate any more funds, because, from the coalface, I can tell you that every time they improve the system we lose out; we lose services, we lose funding, we lose all sorts of things, the net result is we always lose out at the end of the day.

That sounds an absurd thing to say, but it's true, and I'm sure you can find many people that will say exactly the same thing, because they have lost services and funding as well through so-called improvements to the system. Anyway, look, that's my statement. That's my concerns.

MS SCOTT: Thank you very much. John, do you have any questions for Harold?

MR WALSH: Harold, thanks very much for telling us your story. It must have been very difficult for you over these years. What I'd like to explore a little bit is how it could have been different if a system had been in place to provide more support for your son and yourself. Did you explore what services were available to provide the support that you and your wife have obviously provided over all these years.

MR RUSH: My wife, Jill, is in middle level public service in Centrelink. We claim every benefit and service we can legally and legitimately claim for our son. She knows the system, she works in the system eight hours a day. So we are in a much better position overall than most people in our situation. Try finding out what is available to you, that's a hard part in itself. In that respect we're fortunate, because Jill works in the system.

MR WALSH: What supports, in terms of - - -

MR RUSH: The additional supports. As far as support for my son goes, I have never been critical of the state or federal government other than issues of funding. It takes such an incredibly long time to get funding allocated. The needs are quickly identified, the equipment is sorted out quickly, but then you go on hold until the funding arrives; and that can be years sometimes, depending on what the need is and how you fall in the system, and sometimes, I'm convinced, just how lucky you are, as to how long it takes. The big thing for me is staring at old age, that bothers me. My health worries me, and staring at old age. My wife has worked full-time. When our son was born I was a taxi owner-driver, my wife was a middle-level public servant.

We made a very easy, quick decision: she was netting one-third more than I was, so I sold my taxi, we paid all our bills off, the only thing we were left with was a very small mortgage.

That's the only reason we have survived as well as we have up to now, because we started out from day one with effectively no debt and deliberately lived our lives so we didn't put ourselves into huge debt. It's as much a psychological thing as a financial support thing, the superannuation issue. I sit here today and all I can see is a future where I'm going to be - not just me, my wife and my son and my daughter also are going to be worse off in our old because of the lost opportunities over the last 15, 18 years while we have had Ashley, from the lack of paying superannuation.

I have had work opportunities made to me that I've had to pass up, simply because they'd take me away from home; things like this, it just goes on and on. I sit here today, I have got $70 in the bank, and I don't mind telling you that. The wife is the financial manager of the house. I'm not good with money' I don't have that much, so I can't squander much either.

MS SCOTT: Harold, I have got your three points. You have been very clear on what you are particularly keen to see the commission think about and then, over time, the government consider. I wouldn't mind exploring something else you said - I have got those three points, so I don't want you to think I've forgotten the three points - and that is your concern about Ashley's future as you go on. Could you talk a little bit about that, if you feel comfortable about it.

MR RUSH: We're very concerned for Ashley's future, as is anybody in our situation; it's the eternal thing, "Who is going to look after him?" We had a very traumatic time about 18 months ago when my daughter, Yvonne, who is 17 - she is perfectly healthy, there's no disability there, a bright, young lass - came to me in tears and said to me, "Daddy, am I going to have to look after Ashley when you die?" I absolutely reassured her, "No way," that she had no responsibility in it. She was really distraught about the thought that she may be saddled with Ashley when we died. Siblings are a whole other issue again; and unless you want to go down a whole separate interview on the siblings side of things, we'll stay away from that.

Yes, we're very concerned about what's going to become of Ashley. Fortunately, both of us come from very long-lived families. But I have health issues, I have a crook liver; my wife has health issues. We are doing okay, but what happens when we go? As David Holst said, I could walk out of here today and have a car accident driving home. We don't know. At this stage we're looking into things like day care. One of the problems with Ashley, because he is very profoundly at risk, is that we have only ever used respite once in the last 19 years, and that was a fiasco that ended up with a hospital stay.

Our biggest fear is that Ashley will be dead within 12 months of us being dead, not through negligence but through the extremely high level of care that's required on a day-to-day basis. We live with it, we know it, we do it. For someone else to come in, they could not step in and do it as well as well do. That's no offence to the carers and the support workers, or anything like that; it's the simple fact that we live it 24-7. I might add too, if I'm lucky, I get five hours' sleep a night, and it has been that way since Ashley was born. He has to be turned regularly. When I had my taxi I was a night-shift taxi-driver, which in this situation was fortuitous, because I stay up till 2 o'clock every morning, turn Ashley last thing before I go to bed. Jill is up at 6.00, turns him again, and then gets him up at 7.00. I sleep normally till 7.45; she leaves me in peace till then.

Now, if I get to bed at 2.00 and get to sleep quickly it's five and three-quarter hours. If I'm a bit slow getting to sleep, if it has been a hard day or something like that I might be awake for another hour or so. If something happens in the morning, if there's a bit of a minor drama, I'll wake up. Try surviving on five hours' sleep a night for 20 years and see what that does to your disposition and perspective of life; it doesn't help. But that's our problem. That's not a carer problem, that's not a government problem; that's our problem.

MR KALISCH: I just have a question, Harold, around the Health Care Card. If you could just sort of elaborate for us what you think that Health Care Card would deliver for you.

MR RUSH: When I say Health Care Card, in fact it should be more like a Seniors Health Card; the main thing would be to give us access to things like dental plates and glasses and things like that, that we don't really have. I mean, the avenues are open there of course, but when you haven't got money to pay for services, in a western society, you either grin and bear it or you go and commit crime. Well, I'm not a criminal, so I grin and bear it.

I haven't had a steak in about 10 years; you know, a nice, medium rare steak, I'd love to kill one, but I can't. You lose the simple pleasures like that. From a health perspective, it's not an issue, because I've altered my diet accordingly, so I can live with it. But it doesn't change the fact that you miss things like the odd nice piece of meat and things like that that I just can't have any more.

Any optometrist will tell you that you should have new lenses in your glasses at least every 12 months, I just simply can't afford that, I'm sorry. The private health cover for optics particularly is so low in this day and age, because that hasn't been boosted in well over a decade, I believe. At one time with private health cover I could get two pair of glasses a year, these days I cannot get one. So new glasses are out of the question too.

Everything has got to be budgeted for. I wear cheap $15 shoes, because they're cheap; wear them out, throw them away and buy another pair, I can't afford shoe repair. I've got a beautiful pair of R.M. Williams boots at home, they're worth about $250, I only wear them when I go out, and that's rarely, simply because I can't afford to wear them out, and yet there's a good sturdy, solid set of leather boots that I'd love to be wearing today.

MR KALISCH: Just on the health care dimension, a little bit tangential to that, in terms of access for health care for Ashley, do you have difficulty accessing health care or do you have one practitioner?

MR RUSH: I have got to say and I have always maintained that when it comes to Ashley's needs, especially the medical needs, we have never found the system wanting. The quality of some individuals within the system is an entirely different issue, we do strike the odd deadhead, but as far as access to medical support, surgery, pharmaceuticals, everything we need like that, Ashley is very well supported. I do give it to both the state and federal governments that by and large Ashley is very well supported. I have always said that and I will always maintain that. But the one big issue there is funding for equipment and things like that; that is where the system, for us, falls down so badly.

MR KALISCH: That was where you talked about sort of having assessments done and then waiting years for - - -

MR RUSH: You have the assessment, the equipment needs are identified, and then you just put your life on hold until the funding comes; that's it, that's where it all goes pear-shaped. Kelly Vincent, our disabled member of parliament - and it still boggles my mind - was stuck in the same wheelchair for 11 years and grew from a child to an adult in the same wheelchair. I cannot believe the failure of a system that would allow that to happen. Now, I grant you I'm a pushy person, so is my wife, and we're not backward about coming forward and forcing public servants to do their job. We do it a lot. I spend a lot of my time chasing public servants and yes, I'll take issues to the ministers. But it really jerks my chain when people that are very well paid for their positions basically will not respond to the people that they've got to deal with in an appropriate and timely manner; and believe me, there is no shortage of them. People at the coalface, the workers, the support workers and that, you couldn't ask for a better crew.

Administration. One of the biggest single issues as far as I'm concerned in the entire disability sector is the whole thing is so bloody top heavy with administration gobbling up the funds that are supposed to be going for things like equipment I find it offensive and I think personally that it borders on criminal neglect. I seem to have a voice of agreement over there somewhere. Good on you, mate, you know what I'm talking about, don't you?

MS SCOTT: Okay.

MR KALISCH: Yes, thank you.

MS SCOTT: John, any further questions for Harold?

MR WALSH: No, thank you, Harold.

MR KALISCH: Thank you.

MS SCOTT: Harold, thank you very much for coming along today.

MR RUSH: Thank you for the time to just come and have a talk about all of this. I appreciate it.

MS SCOTT: Thank you.

MR RUSH: When you're an invisible person it's nice to be heard.

MS SCOTT: Thank you for coming.

MR RUSH: Thank you. Thank you, John.

MS SCOTT: Okay, well, we're scheduled to have a break now for morning tea. So we'll come back. We might come back a little bit earlier Dom, if you don't mind. We might give people 15 minutes for morning tea and that would probably have us back then about 5 to 11. Thank you.

MS SCOTT: Well, welcome back. For people who have joined us we've got John Walsh coming through by Skype and David Kalisch and myself. We're the commissioners and Dominique Lowe is from the commission. We're going to have lunch - well, that got everyone quiet. The lunch break is at 12.45, so it's a bit of a session to go through now. If anyone needs assistance at lunchtime David and I and Dom are available and some of the hotel staff, so just give us a hoy if we have can assist in any way.

Well, I'm welcoming to the table Ross Womersley. Ross, could you identify your organisation, please, for the transcript and would you like to make an opening statement?

MR WOMERSLEY (SACOSS): Sure, thank you. So I'm here today representing the South Australian Council of Social Service. The South Australian Council is one of a network of other councils of social service that exist around the country. We've had a long-standing interest in the issues confronting people who live with disability and the people who love and care for them and indeed, have a continuing interest in many of the organisations who in fact work to support people to enable them to continue to live good lives in their local community. So we're pleased for the opportunity to speak to you today. I think you might have received a few brief notes about some considerations.

MS SCOTT: Yes.

MR WOMERSLEY (SACOSS): Of course one of the observations that we would make at the outset is that this is an inquiry that has a great breadth to it. We are of the view - we note that there is a question in the inquiry, an opening question, which is about whether there in fact is a substantial amount of evidence around what might be desirable or helpful for people in their lives. We believe that there is a huge body of evidence that speaks to both the problems that people have experienced for many generations and indeed there's a body of evidence around what we think might be more helpful. So we'd be pleased to - certainly in the context of our submission to the inquiry will speak to some of that, but I'm sure that you have at your fingertips already a whole raft of that kind of stuff.

I guess the thing that we would be particularly keen to try to frame for the inquiry is that we think that there are probably three very important issues to conceptualise when we're talking about people's long-term care needs. The first relates to a question about what might constitute a life that is good. It's our view that the aspirations of our community ought to be about supporting all the members of our community to have access to a good life. That in many instances we recognise that disability provides a whole series of challenges and barriers to potentially having access to a good life. We think and believe that a good life for people with disabilities is the very same good life that most of us would look forward to enjoying, and that in that context we have a responsibility as a community to ensure that we support people in ways that mean that they do have access to the good things in life in much the same way that most other people do.

We would argue that that means that there needs to be some work at the level of individual support. There needs to be some work at the level of community and indeed there needs to be work at the level of the service system that we construct in order to support people. We think that our community continues to be a place where in many instances people with disabilities are not made welcome. We note that that starts from a very early point in people's lives and is reflected in the difficulties that people have in getting access to very ordinary early developmental experiences like access to ordinary childcare or access to the local school.

We note that from a very early age people seem to be streamed. As a result of your disability you end up being positioned somewhere different from everybody else, often positioned with other people with disabilities or other kids with disabilities, and that in a sense what many young people experiencing disability grow up learning about is that they learn a lot about what it is to be somebody who lives with a disability and often miss out on a whole lot of those typical experiences that are about the ordinary things in life. So some of our challenge as a community is, from that very early point in people's lives, to ensure that we make available to people the very opportunities that the rest of us take for granted.

I suppose we notice that as a result of that our community learns some things as well, not the least of which is that people with disabilities must belong somewhere else or maybe need to belong somewhere else because they obviously aren't with us, they are somewhere else. I continue to see examples where we watch the young people with disabilities in the special unit at the local school being watched by the other kids across whatever boundary it is, sometimes even a fence. You can only imagine what that does in the minds of those children in terms of setting up that great division, that great divide.

So we would argue that our community needs to do a whole lot of work at that level around ensuring that people belong - from the very moment they belong. We believe that there's sufficient evidence around to point to the capacity for schools to include kids well. We think that if we can begin that process at schools and even preschool, then in fact we will begin the process of changing the place of people with disabilities in our community; because we will help a whole bunch of new generation kids grow up being able to see that people with disabilities are just like them.

We think that that needs to happen beyond the schools to our community more generally. So the local clubs and the local opportunities that are available for most kids - clubs need support in order to make themselves accessible to people; accessible not just in a physical context but accessible in a meaningful, emotional context as well. So not setting up yet another separate club for people with disabilities. While there is a body of evidence that speaks to the possibility, we don't believe that we've practised that nearly as much as we've practised the art of segregating and congregating people with disabilities together.

Therefore what we think probably happens in most instances for most community members is that they assume that the situations where people are segregated and congregated together must be good for them or they must be the right place for people with disabilities. Indeed then when you come to a point of wanting to challenge that, even to the point of somebody living with disability wanting to challenge the mere accessibility of a property, people find themselves confronted by angry reactions from the owners of properties who say, "Well, why should I make provisions for you?" Now, we think that they're the very provisions that people ought to be making in all aspects of our community, so ranging from school to every other element in our community.

We think that that effort needs to go on outside of any of the direct effort that might be required for people's personal care. So in a sense we conceptualise the issues as having at least two elements: one element that relates to building the capacity of our community to include and incorporate and attract and invite people with disabilities to be participants. On the other hand there is another area of work which relates to the personal care and support that people might need in order to do some of the basic elements of life, and of course depending on your disability will influence very significantly the type of support that one might require; ranging from, in some instances, what might seem quite ordinary through to quite intense personal, intimate care.

We see those things as needing to co-exist, in a sense. We need to put the effort into the capacity of our community to include people as well as putting the effort into the capacity of providing personal support in a manner that befits the person. So we would be arguing very strongly that as we pursue a personal support system that we seek to create a system that in fact reflects as closely as possible the needs and interests of that person, so that in fact it is that person who sits at the heart of the personal support and personal assistance that's provided to them and as much as possible that they exercise as much authority over that as they possibly can. We see that there's many good reasons for that, and again we will speak to that in terms of our submission.

We think probably at the heart of this is a question about where we think and where we decide as a community we want people with disabilities to be, and that if our decision as a community is that people with disabilities belong at the very heart of our community we're going to have to bend over backwards to make that possible, because we've practised a long time and I listened to Harold's presentation before and I'm sure that - in the afternoon I note that there's a number of other people making individual presentations. There's a huge body of evidence that speaks to the impact and the influence that our existing system has on people.

So we join with the commission in seeking a way forward and we do think that the imperative is for us to - and we conclude that people belong at the heart. That is where people need to be and it's our job as a community to make that happen. It needs to happen both with the assistance of specialist assistance but it also needs to happen with the assistance of our community opening itself to making people - inviting people to be present. Is that enough for a start?

MS SCOTT: Yes, thank you. I might lead off, if that's all right. You've talked about the role that we need to play, and I take that to mean society in general. What role do you see community groups playing or what role have you seen community groups playing or your own group playing in order to bring about this change in societal views? I mean you see a distinct role for government, and a lot of people will tell us about the role of government, but you and a number of other speakers have highlighted the role the community can play. What can you do to that - what have you done or what can you do as an organisation to further this ambition?

MR WOMERSLEY (SACOSS):   I think all of us have a - you know, and SACOSS is one of those vehicles - have a capacity to raise this issue with the community and to provide assistance to people to think through how they might or might not be able to include people well. I think that we can play a role in helping people understand the exclusion and what the impact of exclusion is. We can certainly invite our members and challenge our members to make their own - you know, the various services that they run and the very community that they live in - much more accessible to people with disabilities. So I think that in a sense it's a responsibility we all have to use our civil responsibilities to say if we believe that people with disabilities belong at the heart of things then we ought to be saying - making demands on our community to make allowances and to include people.

MS SCOTT: Okay.

MR WOMERSLEY (SACOSS):   That might mean that we actually need to provide some support to community groups to actually think their way through some of these issues. Sometimes it's not straightforward in terms of how to incorporate somebody who, for example, has a very significant intellectual disability, might have trouble with their communication, may in fact present a range of challenges to a community group in terms of thinking about well, how could we structure what we do in a way that makes sure that that person has a good experience of participating with us. We think that some of the capacity-building that needs to go on - and we think that we can position groups and organisations to do that work if we support them well.

MS SCOTT: Have you had experience in that work yourself or your organisation in terms of positioning organisations?

MR WOMERSLEY (SACOSS): Yes, certainly in terms of a previous role that I filled. I filled a role with an organisation called The Community Living Project for over 25 years and we worked extremely hard at supporting community and supporting people with disabilities to find their way into community life. Certainly we were confronted by all those challenges around how do you (a) open the door, how do you help people not be anxious about - and our experience was that in most instances people were anxious about two things. One was that the person not have a bad experience. So there was a desire to try to ensure that the people experienced whatever it was that they were doing positively. Or there was a set of assumptions about the person's disinterest, likely disinterest or incapacity to participate. So some of the work that you needed to do was to both reassure and support people to think their way through some of those issues.

MS SCOTT: I'm interested in, Ross, your response to a story we were told by one of the senior state officials that we met with in part of our consultation. He was saying that his state was trialing individualised packages and seeking to see more engagement and social participation and so on. One of his workers had gone out and met with someone who was looking for better social engagement and said, "Well, what do you like doing," and they wanted to go fishing. The official had come back and worked out that this was the cost of a trailer, this was the cost of a boat, this was the cost of a fishing rod and proceeded to send it up the line. The very senior official said, "Did you try a fishing club," and then went back and the person engaged with a fishing club and had a wow of a time. It was actually what they wanted, whereas the boat, the trailer, the car to go with the trailer, the complicated arrangement was going to gobble up every bit of resource that this person was going to get in an individualised package. But it did require the fishing club to take on a new approach.

MR WOMERSLEY (SACOSS): Yes.

MS SCOTT: I guess what I'm interested in is that's a great anecdote for us to have in the back of our mind but I guess I'm after practical experience and lessons that we can learn from, you know, what works and what doesn't, because I guess I'm always concerned about lofty words if I can't see the - - -

MR WOMERSLEY (SACOSS): The practical implications, yes.

MS SCOTT: - - - practical thing. So will it be the case that your submission could give us some actual examples where community groups have had a more - - -

MR WOMERSLEY (SACOSS): Absolutely.

MS SCOTT: - - - socially-inclusive approach?

MR WOMERSLEY (SACOSS): Yes.

MS SCOTT: And what works. Can they do it on their own volition? You'd like to think they would but, you know, what encouragement does need to be given, what structures - if you think they're appropriate or not. I mean I imagine a hell of a lot of this happens just naturally, you don't need to have organisations assist, but if you could tell us your experience that would be great.

MR WOMERSLEY (SACOSS): I think, just quickly, we'll certainly speak to that in our submission. One of the things I'm struck by is that sometimes these things are so ordinary, you know, it is - and yet sometimes what we do in the system is, confronted with the needs and interests of somebody with a disability we suddenly believe that you can't use the ordinary. I think your anecdote just illustrates the power of how a set of almost systemic thought emerges around what it needs to include somebody with a disability when in fact what it actually might need is just an invitation or just an opportunity down at the local fishing club rather than - you don't have to construct, necessarily, this vast special system in order to do it. Yet so often what I think our system currently does is it tends to think that that is the way forward.

Of course what happens with those examples is that whenever we invest that much we have to defend them. So we then begin finding evidence that supports why we did that. In many instances we may invent even examples of why that was so effective for people. I hear that talked about in terms of often times people will talk about the importance of people being with other people with disabilities because they will be safer there or they will like those other people. Yet I know - across my lifetime I think I've met thousands of people who live with disability and I do know that some of those people actually like each other but there are many of those people who don't like each other at all in much the same way that any other person forms relationships across time. People with disabilities are no different.

MS SCOTT: Okay. John, you've got a question for Ross?

MR WALSH: Yes, my questions are along the same lines as yours, Patricia. Ross, whilst this community engagement, community opportunity is critically important and the way you've presented it is very compelling but I also - I mean if it was going to happen just through ordinary things happening, it would have happened already. So while the way to do it is through ordinary things some stimulus is going to be required to make those ordinary things happen.

MR WOMERSLEY (SACOSS): Yes.

MR WALSH: I'm interested in your thinking about how a national insurance or support scheme might contribute to making those ordinary things happen. In my mind it seems to require people that are prepared to think outside of those systemic approaches. How do we give those people the opportunity to trigger what's required?

MR WOMERSLEY (SACOSS): Yes, John, I think you're absolutely right. I think that it does require a different way of thinking about the issues to the way that we've typically come to think about them and it will require a new group of enablers, if you like, or some sort of - and historically we saw roles of - we've seen roles in many systems that have been about care coordination. In Western Australia they have a set of roles that are called local area coordinators of which, I suspect, if you're not familiar already you're going to become a bit more familiar.

But the critical thing about those roles is that in fact part of those people's jobs is to help open some of those doors and to assist not only the person with the disability but to assist the community group or the place that the person is trying to access to problem-solve how they're going to enable the person to do that. So in a sense for me it's a part of what role the system plays and what role we as workers see ourselves as playing and that if there are workers in the system who are good at opening doors or facilitating relationships then they're the roles that we actually need to give voice to and make allowances for in addition to the roles that might be involved in much more direct, immediate personal care support.

In some instances we might also need to go to the heart of what constitutes a good support worker, because one of the temptations over many years is for support workers to imagine that their job is to be that support to the person. In fact in many instances they become a major barrier to the person's inclusion because we see members of the community actually interacting with the support worker rather than interacting with the person who has a disability; in part because sometimes support workers get a bit confused about what their job is, and often very unconsciously. So not necessarily in any conscious attempt to undermine the person but often unconsciously simply step into a role that means that the person who has the disability starts to find themselves behind rather than in front. So the best support will always be support that can be as invisible as possible.

In some instances, if I go back to the issues of special education, one of the things that has happened in education around some people who have a disability is that they've acquired personal assistance or support aids, I can't remember what the technical term is in the Education Department at the moment. But in many instances those people almost wear the person with the disability like a human backpack. You know, wherever the person goes this adult - and this is one of the experiences of some kids in that system - this adult follows. Of course the kids, the other kids in the playground, aren't drawn to interact with the person with the disability because they've got this bloody adult with them all the time. Of course they don't want to deal with the adult, they're dealing with teachers and adults all of the time.

Now, a clever school would actually see some of those things and would then begin some work at trying to undo that so that in fact there was a capacity to create a different relationship. But then we hear schools getting tied up in, "Well, what's our duty of care and what if something was to happen? What happens around the other kids? What if one of the other kids did something that hurt the person?" All of those things, all of the typical things that happen in school playgrounds every day. But because it's a person with a disability we suddenly surround them with some sort of extra due care and we don't use commonsense.

I think that in a sense some of what we - we over-manage, we over-develop, we over-specialise and the cost of that is a very major cost to the person with a disability. Of course the community - sorry, John, I can see you're anxious to say something - but the community learns again that the person needs someone with them and they can't simply interact in and of their own right.

MR WALSH: Yes, look, we've heard a number of submissions about this issue of the nature of personal support or personal care. I guess what you're saying is that the support worker needs to be a facilitator rather than an imposer. I'm interested - I mean if you look at what we require at the moment in organisations, certificate III, certificate IV and so on, which are very prescriptive. You know, "I know how to put on a leg bag and I know how to put someone's jumper on," stuff like that. So are we looking at a different set of enablers for support workers to be able to produce this sort of system?

MR WOMERSLEY (SACOSS):   Yes. Look, in some instances some of those skills will be really important. So in a sense that facilitator role probably fits with a certain group of people and a certain group of support work roles. There are some support work roles that are simply concerned with - you know, for example, if your support work role is helping someone get up and out of bed and ready for the day, then in fact you're actually working in a very intimate sphere with somebody. If they're living, for example, in a home with other members of their family, you might have to be very mindful about supporting the person without impacting on the rest of the family. In that sense you might have a facilitation role. But in lots of ways your role is actually quite invisible in that context. It's where we're supporting people to access and supporting people to be present in their community that the role of facilitation becomes a much more significant and important quality that we actually need to build in. There is absolutely no doubt in my mind that (a) that's a sophisticated set of skills of which we have limited experience at the moment, and (b) we don't teach those things to people in our current education regime.

MS SCOTT: John, I'm just conscious of time. Do you have any further questions?

MR WALSH: No, but I think this is an important issue.

MR KALISCH: Can I just - - -

MR WALSH: If you could explore this in your submission I think it would be a good thing, Ross.

MS SCOTT: Yes.

MR WOMERSLEY (SACOSS): Yes, be pleased to.

MR KALISCH: Not necessarily a question but just something that I would like to see in your submission is actually - one of the issues that has been raised with us is the capacity of NGOs to play a greater role in terms of providing services. But I wouldn't mind you also exploring in the submission what you see as some of the constraints or issues that need to also be dealt with in terms of improving the capability of NGOs to play that role. So not for now, because I know we're running out of time.

MR WOMERSLEY (SACOSS): Sure.

MR KALISCH: But if you could address that in your submission that would be great.

MS SCOTT: And on my wish list for your submission I'm very much after the practical examples. If you know that there are schools or organisations that have adopted an inclusive approach, that have done it on their own volition or needed a little bit of support, what worked and what didn't. Sometimes people learn from failure just as much as learning from success; so people that have had surprising barriers put in their way when they have sought to be involved in clubs, clubs that have sought to involve a more diverse group in our community and yet lo and behold it didn't work out. I'd be interested in that as well. I think this issue about place is very interesting but again, if we could have examples rather than theory and words that would be very appreciated because then people can react to it and say whether they think it was realistic or not.

MR WOMERSLEY (SACOSS): Yes.

MS SCOTT: Well, Ross, thank you very much for your time today. We appreciate it.

MR WOMERSLEY (SACOSS): Thank you. Thanks very much.

MS SCOTT: We now have two individuals presenting.

MS A: Good morning.

MS SCOTT: Welcome.

MS A: Welcome and thank you for inviting us today; a little tiny ad in the paper which I would say needed to be a little bit bigger for a bigger audience, quite honestly.

MS SCOTT: Okay.

MS A: But I would say thank you to everybody. I thank the commissioners. I thank also the old academics who have put this together. I thank the students of our society. I thank all our carers. I thank you all very much and the people I thank are the commissioners. I thank also the academics who have put this together. I thank the students of our society. I thank all our carers. I thank the lay people.

I am actually going to hand this over to my daughter, as I am actually quite nervous, ridiculously. We have planned and put this together between us and the best that we can do is to read it through. Some of our experiences have been very poor and I don't know that that is the right way to go about it. My daughter is my primary carer and has been since the age of 10; she is now 23. My concerns on the whole are what happens to the children in the future. So I am saying education is the biggest issue. All the children that are living with a disability or living with a family member who has a disability need an education.

From what I have noticed and read, it is scaled down greatly from the previous forum where promises were made to family members, to mothers, fathers, that this would be ingrained and get bigger, but it's not happening and I would like to see and understand how I can make this a better opportunity for the future children, because children will be born with disabilities forever, they have been to this date. Thank you.

MS SCOTT: Thank you.

MS B: I have prepared something that we have written out. So I will just read it. The submission I am making today is on behalf of both myself and my mother. I am 23 years old, a young carer and a full-time primary carer of my mother who suffers with neurological illness. I have been in a serious care role since the age of 10. I am also a full-time university student. I bring the perspective of what it is like to go through primary, middle and high school education as a young carer and have a good insight into the services offered for young carers during periods of education.

My mother was first diagnosed with her illness at the age of 36. Due to her illness and the support services that have been made available to her, she is unable to work. She has an extensive insight into the treatment of people with disabilities, and in particular what is it like to be a parent with a disability and her experiences as a parent in the education system and relating to support services. The issues we would like to focus on today are in regards to the alarming numbers of young carers pursuing an education and how their role and lack of support may be drastically narrowing their lifestyle choices. Lack of available services, particularly in South Australia, are possibly impending upon this.

Furthermore, we wish to discuss the requirement for government initiative in tackling this issue and the need for some form of structure within the young carers system. I would like to outline the definition of a young carer. Young carers are classed as young Australians under the age of 26 who help care in families where someone has an illness, a disability, a mental health issue or an alcohol or other drug problem.

The Carers Australia federal budget submission of 2010 states that there are more than 170,600 young carers under the age of 18 across Australia, and 348,700 under the age of 26. Of these two groups, there are 132,000 who are primary carers; that is, they provide most of the care. We are talking about a growing group of young individuals whose likelihood of reaching their full potential in both education and the workforce is at a significant risk. In fact, Carers SA 's Young Carers Updated Statistics (October 2006) states that only 4 per cent of young primary carers between the ages of 15 and 25 are still at school; this is compared to 23 per cent of the general population aged between 18 and 25.

The Carers Australia federal budget submission 2010 states that supporting young carers is particularly important as young carers are less likely to complete secondary education than their non-carer peers and have an increased likelihood of low socio-economic status over their lifetime. We make reference to these statistics as they are an indication on the identity young carers hold within our community and that identity is a reflection on the value which society places upon young carers. One of the ways we believe that support towards young carers' education can be achieved is through reinstating the Young Carers Association in South Australia.

Approximately two to three years ago the funding body of the Young Carers Association reduced the funding guidelines in an alleged bid to focus more heavily on funding young carers' education, as this was seen as a significant issue. Unfortunately, these new guidelines resulted in any young carer above the age of 18 and not studying year 12 being excluded from the program, with no forwarding organisation to assist them. Consequently, young carers aged between 18 and 25 were ineligible to receive services, including funding for respite or education, from the Young Carers Association of South Australia. University and TAFE levels of study were not recognised under the new guidelines.

What does this say about the value we place on the education of young carers and the expectation we have of young carers and their ability to complete higher education? I can say from personal experience that when I was excluded from the program, based on age, I felt degraded and undervalued. I felt as though my right to an education was not valued equally and my potential contribution as a member of society was viewed as inadequate. Since this restriction in funding, I am sad to say that the Young Carers Association has been all but dismantled.

There is no longer an office for young carers even to contact. Information on young carers and their services is largely provided by Carers SA. Staff employed, who acted as a port of call to assist young carers, were made redundant. There is no published documentation on why this occurred nor any media releases from the Department of Families and Housing, Community Services and Indigenous Affairs.

How is it that a service so vital to assisting such a vulnerable group of young Australians was allowed to disappear, seemingly, overnight. We believe that there needs to be an adequately funded young carers association that has a considerable focus on the educational needs of young carers. It is important that the organisation is inclusive of all young carers, including those aged between 18 to 25, and that they work to encourage young carers to pursue higher education.

Two years ago we attended a disability forum in which Bill Shorten, Parliamentary Secretary for Disabilities and Children's Services, answered questions for the public in regards to disabilities. The issue of young carers was mentioned, with one young man stating how he had to leave school in year 10 to care for his mother. He didn't wish to leave school and his goal was to pursue university. With a lack of government support and no family to help him, he felt there was no other option. The idea that young Australians are leaving school, particularly those in low socio-economic areas from single-parent families is not acceptable.

Young carers should not have to forgo an education due to inadequate support services provided to help them succeed. Young carers are a vulnerable group in our society and in most need of our support. As referenced in the Carers Australia federal budget submission 2010 a proposal is that young carers align with the government's Social Inclusion Agenda and that they also meet the first principle of the ALP's 2007 national platform for education, namely that all children have "the right to a higher quality education so that they can live fulfilling and rewarding lives". It is the responsibility of the government to protect that right.

An additional proposal that would aid young carers in support for education, in particular those who rely on government services, is to change the way funding applications are viewed within Disability SA in regard to educational funding.

Currently applications made for more support, on the basis of funding for education, are deemed as low priority. We believe that in the case of young carers funding applications for education should be given high priority status up to the age of below 26. As there is currently a significant absence of a government-initiated young carers' support service, this proposal is more important now than ever in South Australia. With a clear lack of research into young carers and no national database of young carers, it is very difficult to fully comprehend the enormity of this problem.

MS SCOTT: Thank you very much. John, do you have some questions, to lead off?

MR WALSH: Thanks very much. You're going to have to excuse me, I'm not familiar with the Young Carers Association. If you could just describe to me what the Young Carers Association had done before it was effectively de-funded, and what particular support they were able to give to you and what was withdrawn. Just give us a bit more detail around what the Young Carers Association was able to do.

MS B: Previously they offered funding for respite and they were also involved in organising group activities and camps and events which focused a lot more on, obviously, younger carers, and I did attend a few of those growing up. Most notably, they offered ongoing funding for educational purposes, and that was the big thing that was withdrawn when they dismantled and when we couldn't receive their services any more.

MS SCOTT: So what was the level of assistance that people were able to get?

MS B: The level of assistance wasn't great, to be honest, but it was there, it was something. It was pretty much on a needs basis. Say, you were studying year 12 and had exams coming up and you needed some funding to help study for your exams, then they would pay for someone to come in and help with respite so you could complete your studies.

MS SCOTT: Are other respite services available to you? When this one was de-funded, were you able to find alternatives?

MS B: I wasn't forwarded on to any alternatives and I was pretty much told that there's nothing they could do, as far as my age group went. However, there are different organisations, a lot of community organisations, which bear the brunt of the load for young carers, and it should be made really clear how much it is they do. There's different carers networks depending in what area you're located. I actually receive some funding from the Northern Carers Network; I think it's about six hours a month they fund so I can have some respite, which I use towards my studies.

MS SCOTT: Six hours per month.

MS B: Yes. There's also Carers SA which are very good with offering temporary funding. The biggest problem we have with education is that there's no ongoing funding available for education. Any funding that comes through for carers is always short-term and temporary. I understand the need for respite, but there needs to be some sort of package or something offered for educational purposes.

MR WALSH: Could I just try to understand the issue? Is it that because of your carer responsibilities you can't sort of have enough income support to support yourself while you're in education? Is that the issue?

MS B: It is partly the issue. There's a few issues regarding it. There's the 25-hour rule with Centrelink. I'm not sure if you're aware of that. There are a few young carers who have had to leave school so they can have the financial support and receive a full-time carer's pension; they're having to leave school, because their schooling is exceeding 25 hours a week, to receive that financial support. I'm in a position where I have needed to rely on government support to help look after my mother.

Whenever an application comes up and I say, "I need some help so I can make it to my classes and have someone in there to help throughout the day or at night-time," because it's deemed as low priority, it's pushed to the bottom of the list and it's not taken as seriously, and that is a really big issue that I have faced. Having education deemed as low priority is unacceptable. It makes things so hard; you can't leave the house to study, because there's no-one to fulfil your role if you're gone.

MR WALSH: The other point you mentioned was that when you were younger you would have some peer support type activities. Is there an issue here of emotional support or being a young person who is in a caring role?

MS B: I do think there is an issue of emotional support and the lack of it. But I do have to say that community organisations, such as even Wesley Uniting, they offer great support for carers. When it comes to respite, I personally haven't experienced too much difficulty with obtaining respite, for me it has been being able to separate and say, "I need time to do some work. I need time to study for exams. I need time to actually be able to complete a full study load," and not having that taken on the same grounds as respite and having it deemed as low priority, that has really been a big struggle for me in the pursuit of an education.

MR KALISCH: Just one aspect I wanted to raise was the way in which the education system either facilitated or itself put barriers in your path and whether there are particular strategies or arrangements that you have found helpful, or suggestions for improvement.

MS B: I had a lot of difficulty in high school with attendance. At the time we didn't receive the amount of funding that we receive now; we were on waiting lists and those sort of things, and we only had carers come into the house from Monday to Friday, 10 am till 1 pm in a three-hour block. At that point agencies wouldn't split up the hours. So I was in the position where I was getting up in the morning, helping my mother with personal care and going to school late, going at about recess, on a regular basis.

Despite the fact my mother was a parent who rang the school every day and said where I was and there was a genuine reason why I wasn't there, there's not always good communication between disabled parents and teachers; a lot of that has to do with their limited access with getting into schools. I understand teachers have a very heavy workload, but we do need to go a little bit further as far as contacting disabled parents and including them within the school community. If we don't do that, we see a breakdown that affects the young carers.

That was a huge problem for me. I had very few teachers that were aware of my situation. I went to a school which had different year-level coordinators for different years. In year 9 I had a very good year-level coordinator, who sat down and spoke to me about my role, who spoke about arranging alternative ways for assignments and submitting things, but by year 10 it was someone different and everything was out the window. My experience with university has been incredibly positive. I have meetings with my program director, they arrange extensions when necessary or alternative submission dates for my work, they have given me access to the off-campus library if I can't travel. I have to say that it's those sort of things that really allow me to succeed.

MR WALSH: Could I ask a question of Ms A? Your experience through Ms B’s school and university, how have you felt about the way in which the education system has supported you, as a disabled parent?

MS A: As a disabled parent, I was never supported through school. University, I was supported totally. During her high school years, not at all, not in any shape or form. So much so, to the point where I would ring the school and ask if someone would be able to gather the work together, for my daughter to be able to complete her work or even initiate some sort of response to the work. Never happened, never, ever happened to me. I would have to send my son to the school on some time of occasion when he had - find time or her dad would have to call him and ask for his help. We are not together, that was difficult. The teachers never, ever phoned and let me know how difficult things were for her.

My daughter was in school. I went to a parent-teacher evening. The teacher absolutely abused me and said my daughter had not presented any work, had not handed work up. I turned to them and I said, "Look, this is inappropriate. I was there when she was doing it." Fortunately computers actually date and time. I'm very lucky that I - it was the first time in my life I've ever thought a mobile phone was worthwhile. I picked up that phone. I did lose my cool, so much so that it was embarrassing; embarrassing for my daughter the next day because she was told how upset I really was with this teacher. But at the same point I was able to say, "It's been done. I sat there, watched her do it. I helped her. I can print it off the computer, it's dated. You are the one that has lost it."

In other words, I was often blamed that I was not helping her achieve where they were really saying they actually had lost the work but were not being truthful to me nor my daughter, which was very upsetting for her and myself. Didn't look at my disability, didn't see that it was a wheelchair - don't know how they missed it, quite personally. But no, there was no emotional or physical involvement whatsoever and I really think that needs to be upgraded. We know of many children that have parents that are disabled, other members in their family are disabled. This just cannot go on. We cannot go on treating the children or ignoring the teachers' needs to be able to access the parent. These people need to be - they need to be helped too, the teacher, they really do. I don't know what else to say. Thank you.

MR KALISCH: No, I've got nothing else. John, anything else?

MR WALSH: No thanks, David.

MS SCOTT: Well, thank you very much for coming.

MS A: Thank you.

MR KALISCH: Thank you.

MS SCOTT: Very good. Do we have Dell Stagg here? Great, all right, thank you. Firstly, my apologies. This is quite a noisy environment but we are trying to make sure that the volume is loud enough. Is it okay now? You can hear all right? Look, please indicate to us if - when the hoon traffic comes by if we need to increase the volume. We're trying to do our best up here but thank you for your patience. Well, Dell, welcome to the inquiry. For the record could you just state your name and the organisation you're representing and I understand you want to make an opening statement.

MS STAGG (SACID): Dell Stagg, president of the South Australian Council on Intellectual Disability. My opening statement is my reason for being the president of SACID is that I am the mother of an adult daughter who is 45 who through circumstances of family when she was seven and a half we had to relinquish her care into institutional arrangements. Who does that now? No-one, hopefully. She lived in institutional arrangements for 18 years and was, as a result of the devolution of the institution called Ru Rua Estcourt House was placed into a group home not far away from my home and enabled a lot more contact between me and her. The institution was appalling. I used to drive past it in tears and not go in because I couldn't bear it, which is why I am so passionate about institutional - not supporting institutional living.

She lived in a group house for 18 months and she became extraordinarily ill. She went from size 16-18 down to a size eight in 18 months. She slept 22 hours a day, vomited everything she ate and drank. I watched her go down to this little tiny size eight in that 18 months. I gave up my job and brought her back home. She has been living home with me for 20 years now. We have developed a model of self-managed funding. We didn't come home with any funding and it wasn't given to me freely. It was hard-fought for and many, many days and nights of angst around how I was going to support her with nothing. But over the years we have secured a level of funding which is reasonable. It still saves our government in this state $60,000 a year, but that would mean if I had all that money I'd have people in the house all the time and I couldn't bear it.

We have developed relationships with one of her support workers who have been with us for the 20 years. She started as a 19-year-old, she's now a 40-year-old with two children, built a couple of houses, has built a room onto the house that they have for Michelle. The plan is that if I die before Michelle does she will go and live with them. Now they're building a new house with an apartment underneath for Michelle so that she will stay with them. She gets paid through my management a reasonable - a good income and it has supported her to be able to not go to work and look after her kids and all that.

So it has been - the self-managed stuff, the direct payment stuff is the thing that we need to think about - has been so valuable to keeping Michelle. She is now healthy. She is beautiful. She gets her illnesses because of her profound severe and multiple disabilities. Her developmental age is under three months old, so she can't sit up, she can't talk, she's blind, she has severe epilepsy. But because I've been able to keep an eye on it all - she would have died if she had have stayed in that group home at that time because there were inappropriate health and medical supports around her. It has changed today but I have experienced through her all sorts of levels of disability support.

As I say, my passion is about people having ordinary lives in ordinary homes in ordinary streets where they can be connected with their local neighbourhood with proper and adequate supports around them, because I have seen some terrible, terrible things as I come and go from these institutions. I know of many terrible things that have occurred to people in these institutions and they still happen today. So that's my opening statement.

MS SCOTT: Okay, all right, thank you.

MR KALISCH: I'm really interested in this arrangement that you've got with the carer, and that must provide - - -

MS STAGG (SACID): We like to call them support workers.

MR KALISCH: Support workers. Apologies about the terminology.

MS STAGG (SACID): We get paid to care, that little payment, you know that pension they give us?

MR KALISCH: That obviously must give you a lot of encouragement and comfort that you've got a long-term arrangement in place. How difficult was it to find a support worker that actually met your daughter's needs and that fitted in with your family environment?

MS STAGG (SACID): In the case of Sylvia, not too difficult because she'd already had a relationship with Michelle in her day options program. When I brought Michelle home and was looking for someone I sent the word out and most of the people who worked in the program and who worked in the group house said to Sylvia, "Why are you going to work with her for, she's terrible." But Sylvia has the same philosophy as I have around Michelle's support and she said, "No, no, no. I want to be there with Michelle." Her whole - it's around Michelle and Michelle has become a part of their family, their extended family. Whatever goes on at their house Michelle is there involved in it.

So that one was easy. We've had other support workers who stayed with us for eight years and six years; seems to be around the time when after those many years everyone is getting a bit tired of each other and I'm getting a bit tired of them in my house. So there's a break. It's very difficult to find people who really match what I'm looking for in support of Michelle and I have always taken the line I'm in the bottom line. If I can't have anyone, I'll do it. Two years ago I was really, really ill and that was really difficult to manage and it frightened the daylights out of me because I was walking around on a granny cart because I could hardly walk, I'd done my knee in. I had cancer of the foot - all sorts of things happened and it really frightened the life out of me because I thought I'm going to have to sooner or later relinquish her again; but I'm better now. But it still makes me - you think that you really have to plan.

The idea of having self-managed funding and having control over the funding, it enables people to build relationships which while not freely given - I don't think I could expect anyone to freely give like Sylvia has done because she needs to go out and earn a living in some way, shape or form. But it's enabled us to maintain that really strong relationship. With the other workers that stayed six and eight years it's the same thing. When you self-manage you have to be aware of what's going on in their lives and sort of play the game a bit and give and take a bit. I gave up a promising career to bring her home but I'm not - the only thing that I'm sorry is the money, but I'm not sorry she's home. Every day I walk down the passage, I look in her bedroom when she's at home, because she spends some time at Sylvia's, and I think, "Oh, you're home, you're safe and I know what's going on."

MR KALISCH: So you're now confident that you've got an arrangement in place that will work when you're no longer around?

MS STAGG (SACID): Yes. Well, you know, depends who's in the chair at the time, which government is doing what and which department is doing what. But the plan is that Sylvia will take over - continue doing her role. My niece will become my daughter's guardian, because a worker can't get paid and be the guardian, which is stupid, but we'll have that argument somewhere else. Her brother, he's not into all that stuff but, "If you want me to sign anything, I will," he says. Then the next step is that if anything happens to Sylvia I have a friend who has now left that job but she has managed an organisation that supports people with the level of disability that Michelle has and she is brilliant at it. My next plan was that she would go and - that would be her next place of call. But you can - you know, plan C is about as far as I want to go.

MS SCOTT: Yes.

MR KALISCH: Yes, but you've got beyond plan A. Yes, that's interesting.

MS STAGG (SACID): Yes. So from SACID's point of view we really support the national disability insurance scheme around long-term support and care. But we also think that - and we think that any scheme should be funded similar to the Medicare scheme, that it needs to be funded from - it needs to be managed from a federal level. If it's done with direct payments - the direct payment model a lot of people say - a lot of people don't want it. But really it's about - the first payment you are offered is you have your assessment done. I really believe in the self-assessment model which they do in the UK which is a resource allocation system where people can say, "I need help with," and there's a points system. Then you get to the bottom line where it says, "Well, you've got so many points and it's worth this much money."

I know it's dehumanising but a lot of us as families believe - we want to know what we're entitled to. Currently we're entitled to nothing. But this system actually enables you to look up, "Well, we're entitled to that much money," and if that much money is available within that system that should be what you get. Then you have your - it comes as a direct payment and then you can choose - the family can choose, "Do I want to do it all myself? Do I want to have someone to help me? Do I want to give it off to another agency, organisation to do it under my directions?" So it's quite simple really. It's not a very hard thought process. We believe that it would reduce administration costs by doing that. Just the fact that I've saved $60,000 a year or thereabouts with Michelle's has indicated that - and it shouldn't really be a cost - - -

MS SCOTT: Just that 60,000, was that the care you were providing, so - all parents and all informal carers save the taxpayer money but I just wonder - or was it the 60,000 was saved because you were managing it versus a system managing it?

MS STAGG (SACID): Yes, this is what the savings of what it would have cost had she remained in a group home with the level of support that she really requires.

MS SCOTT: Yes, got you.

MS STAGG (SACID): Yes.

MS SCOTT: That's important for the record, that's good. I was going to ask some questions about inspectorate programs and community visitors, because I'm interested in that and you've also expressed concern about things that still happen now, it's not just a long time ago. So I was going to go in that direction. But John, before I head off that way is there something that you'd like to ask Dell before I go there?

MR WALSH: No, I was actually going to ask the same sort of - - -

MS SCOTT: All right, okay. So could you talk about your concerns there? I guess, you know, maybe one of the advantages the commission has is our objectivity. On the other hand maybe our disadvantage is how distant we are from the issue. I think if you could tell us how good or bad things are that would actually help. Mind, you are on a public record so you've got to be careful about - - -

MS STAGG (SACID): What you see is what you get.

MS SCOTT: I'm just drawing your attention though, you are on a public record.

MS STAGG (SACID): That's okay. I will start by the fact that in this country adults with disability - and they are more often than not adults with intellectual disability and profound, severe and multiple disability - have no legislative protections around neglect and abuse. Children have, the aged have - not that it really works by the looks of the paper the last few days but there is some level of legislation that people can go back to.

Our adult sons and daughters are not protected by that at all. I think it's because - just because they're adults they're supposed to be able to fend for themselves. Well, people like Michelle and people with intellectual disability often can't defend themselves in situations if they - and they often tell people about things that go wrong and maybe they're not heard correctly or they're told to shut up and don't say anything or repercussions occur. The reason why Michelle - I didn't address things when she was in institutions was (a) I didn't know I could, and (b) I was afraid that what might happen to her if I did make a report. I met people who worked in those institutions who have made reports who have come out to smashed windows, slit tyres, poop in their letterbox, all of these sorts of things by other workers in that house. It's not only the workers that the abuse and neglect is around. It's other people who people live with as well. So that's SACID's major concern, that our sons and daughters who can't speak for themselves, and even those who can, aren't given any legislative protection around that stuff.

MS SCOTT: So one is legislative protection. Okay, got that.

MS STAGG (SACID): Then if you had that then we say we need to have a - Victoria calls it a community visitor scheme.

MS SCOTT: That's right.

MS STAGG (SACID): Whatever it might be. It's a monitoring and auditing scheme where people can go into people's homes - and people with physical disability or people who can speak for themselves will say, "No, we don't want that." Well, that's okay, but for those of our sons and daughters who can't we want to know - well, SACID in particular wants to know that there's always a chance that someone from a community visitor program might pop in any day or night - wonderful things have happened in the middle of the night at some of these group homes - and just come in and they have an opportunity to check their care plans, to make sure that things are being done or not being done, and for people who can actually say to them, "I'm really scared, stuff is happening here," that they are protected, and for the workers who want to say that that they are protected. So I mean that's - we just think that that's just so important.

We also think that anything that emanates out of these visits is then put on public record, that it's been seen to be addressed and that the result is - not necessarily giving personal information or anything like that but, "These are the occurrences. This is how we worked on it and this was the result," and that the people who make the complaint are also referred back to, to say how this worked, because somebody has to be accountable for this stuff. Currently, and I've said it, it's like a secret society. We don't know what's going on in our institutions or in our big group homes. We don't know - you know, we don't know what's happening to our sons and daughters in these places, and it's wrong.

MR WALSH: Patricia, this brings me to the issue of information. There's a lot we don't know. I'm wondering, Dell, do you have any ideas about what should be included in, I guess, data sets that record the needs and services of people with disability? Is it reasonable for a care plan or a life plan type document to be held on the record?

MS STAGG (SACID): Well, it would help if the family carer was to drop dead suddenly. It gives people an idea. There was - a few years ago in this state a mother and the agency that used to be responsible for people with intellectual disability, IDSC, did a paper called Guaranteed Care. It's around. I can find it. It was a plan about what the family - especially of people like our sons and daughters, what they wanted to happen for their son and daughter should mum or dad drop off the twig. It was a really good plan and no-one ever would fund it, of course. As soon as you mention a community visitor scheme, "Oh, who's going to get the money?" Well, who cares if our sons and daughters get bashed? We do - or sexually abused, you know. We do.

So certainly some sort of a forward-looking plan which supports the wishes of the family to make - I mean how it gets monitored, there's another thing, more money. But I think a lot of families if they had something in front of them that gave some ideas of what they might like to think about for their future, because currently most of our families are just managing day to day and the thinking of the future stuff is so terrifying. When they hear me say, "Oh, cut out" - you know, get rid of the big group homes and get - they all go, "You can't do that," because it's so difficult. I think it's so difficult to think about those big things when you're just trying to keep up day to day to day with minimal levels of funding and support.

MS SCOTT: I just want to check that I understand what you're saying. So sometimes parents might not like the community homes but at least there's something they can think about as being there for - - -

MS STAGG (SACID): And we have to put people somewhere, I'm not that naive to think that that's not going to happen. But there are other somewheres that don't include big congregate living or even 16 congregate living. I use the example, for those of us who have got sons and daughters who are going to head out into the big, wide world. It might be 21, 22, 23. Would you take these sons and daughters who don't have a disability, sit them down and say, "Right, when you're 21 we're going to put you in a place with 16 other people 50 kilometres away from here and that's where you're going to stay for the rest of your life." We don't do that to our sons and daughters without disability, and in particular intellectual disability. So what makes it right that we think like that? I think a disability insurance scheme would enable people once they had the capacity to have their supports organised - the way to think of other things. You know, like you can only think like that when you're busy scratching. If you've got a bit more freedom, well, you can think higher and wider, I think.

MS SCOTT: Okay. John?

MR WALSH: No, thank you, Patricia.

MS SCOTT: The Office of the Senior Practitioner is a brief description in your paper. Look, I have to say something to you just right at the start. You're looking to Victoria as - - -

MS STAGG (SACID): Only because I've fallen in love with Jeffrey Chan. He's the senior practitioner in Victoria and I think he does a great job.

MS SCOTT: That's good, and maybe he does a very fine job.

MS STAGG (SACID): Yes.

MS SCOTT: I don't know his work. But we're just from Victoria and of course people in Victoria are saying things aren't all that flash. So talk about the - please talk about the Office of the Senior Practitioner and we might explore a bit more about how things are in South Australia.

MS STAGG (SACID): Well, they have one, we don't. We have - our Office of the Public Advocate has control over restrictive practice arrangements and orders and that sort of thing but there's other practices that occur in these congregate living arrangements that people use it as behaviour management or drug management to keep people still and quiet. In my opinion that's what is also called a restrictive practice, I call it abuse, but, you know, we don't - but there's no - Jeffrey Chan does a wonderful job around, from what I understand, going into these big congregate organisations. Rather than with a big stick, sits down and says, "Let's have a look at ways we can make this work better for you, the worker, and better for the people who live here." We just don't have that. Certainly our department has got policies around restrictive practices. I have seen them. But there is no legislation to back them up. So the Office of the Senior Practitioner as part of the legislation of a Disability Services Act in this state is what I think needs to occur as some - as proper monitoring.

MR KALISCH: It doesn't sound like a very strong sanction. It seems that it's more facilitative and capability building. Is that a fair assumption? Is that the sort of role you're looking for or is it something that would have a bit of a stick as well?

MS STAGG (SACID):   Something that protects people who are at risk of this sort of behaviour. There's nothing in this state that protects anybody. As I said, there are reporting mechanisms and there's policies that I've seen but there's nothing. I guess when you've got legislation around that you've got to have somebody who actually checks to make sure that that's been properly managed and monitored. We just don't have that sort of thing in this state and that really worries me. Our Disability Service Act was last reviewed in 1996 and it was supposed to have been reviewed five-yearly and it never has. We are actually now lobbying for Monsignor Cappo's Social Inclusion Unit for a review of our Disability Services Act to have all of these things legislated within the act.

MS SCOTT: Okay.

MS STAGG (SACID):   Because currently we've got nothing.

MS SCOTT: Can I put an alternative view to you that we've heard, not my view or the commission's view; it's just a view we've heard. One is that while it may well be the case, I'm sure it is the case, that there is abuse and inappropriate behaviour in some community homes, at least there is some oversight; that there is a certain level of professional standards and so on, that if in fact the new arrangements were to see everyone in individualised settings then in fact there's almost no check because - could you react to that? I mean would you - - -

MS STAGG (SACID):   Well, you'd still have your community visitors, wouldn't you?

MS SCOTT: You'd be comfortable for the community visitor to not only have the right to go into a community home but also have the right to visit others in their - - -

MS STAGG (SACID):   Well, if it was my daughter I would be comfortable. I can't speak for other families. But I mean the sensible part in me says that one person living in one house is never - you know, and it's lonely too at times. So that's - idealistically is quite nice but my view would be - our - certainly SACID's, from SACID's point of view we sort of say no more than three.

MS SCOTT: Right, okay.

MS STAGG (SACID): In a group setting.

MS SCOTT: Okay.

MS STAGG (SACID): Because people have to live somewhere. But they also need the opportunity to get in and out if they don't like it.

MS SCOTT: Yes.

MR KALISCH: Yes.

MS STAGG (SACID): That also then causes ructions around the funding around how many - you can't move the funding from one person to somewhere else because then that leaves that house vulnerable for not enough funding. So this is the juxtaposition of the self-directed payments where you make your own decisions or the block funding which then creates a bit of - well, you can't actually do the individually - you know, we had to wait three years before we got our individual funding because Michelle's funding was still attached to the house for those three years because they couldn't untangle it until they got some money from somewhere else and put someone else in her place. The room was empty for the three years because they couldn't untangle anything.

So this is why we say really direct payments out of the allocation and then people can make those choices. Like I might meet somebody who might like to join and live with Michelle. My plan would be that Michelle would live in a house next to me, semi-detached. She could share with another person but I could be there to watch what was going on and they could still do the things that they normally do. But trying to get that through to people - you know, but if we had enough money that - in part of the - part of the national insurance thing would be your allocation would be derived from what it is you need help and support with. That might be something you might be asking for help and support with.

MS SCOTT: Yes, okay. John, are we done?

MR WALSH: No, I'm done, thanks, Patricia.

MS SCOTT: All right, thank you.

MR KALISCH: Thank you.

MS SCOTT: Well, Dell, thank you very much.

MR KALISCH: Thank you very much.

MS STAGG (SACID): Thank you.

MS SCOTT: Well, that means we can actually - Dom, I'm right in thinking we can go to lunch now. Yes? All right, Dom says we can go to lunch. So thank you very much. We are going to now resume at 1.30. Thank you.

(Luncheon adjournment)

MS SCOTT: Good afternoon. Welcome back to our hearings. This afternoon we will give an opportunity to people who have been in our audience who might like to make a brief comment or a brief presentation. So there is an opportunity probably in a couple of hours - probably by half past 2 if you do wish to make any comments you can do so then. But I welcome to the table, Erin McKenzie-Christensen. Have I got that right? Thank you. Erin, you're representing yourself. Have I got that right?

MS McKENZIE-CHRISTENSEN: Yes, and I've got my husband Jeff here as well.

MS SCOTT: Hello, well, welcome to both of you. Would you like to now lead off and make a statement and then we might ask you some questions.

MS McKENZIE-CHRISTENSEN: Okay. Yes, so do you want me to just start with - - -

MR CHRISTENSEN: The dot points are - this is raised in - - -

MS McKENZIE-CHRISTENSEN: Which you've probably got a copy of. All right. We just wrote dot points in answer to all of the questions and some of the questions we thought were more important than others. So the ones with the asterisks are the ones that we just thought were more important. I suppose it's really important to work out who should be eligible and how they can be identified. I know that there has been written about severe to profound disabilities but I sort of went against that and sort of said if somebody needs help, they need help, basically. That might be against what you're doing but that's sort of what we thought.

MR CHRISTENSEN: I think the definition in the Disability Discrimination Act is a very useful one in this case because it doesn't speak as such about disabilities as distinct from medical conditions, which I think is one thing we're definitely aiming at, because it doesn't matter why you can't walk. If you can't walk, you can't walk and you need help. So it's my opinion that eligibility should be based on symptoms rather than any specified disability or medical condition.

MS McKENZIE-CHRISTENSEN: We sort of thought if the person was new to the system, like I am, perhaps they could offer assistance for a period of six months and to allow time to actually get an official diagnosis. If at the end of the six months it has disappeared or whatever then that person won't need any help any more; unless a diagnosis is provided. But it would be really important that people are aware that that would actually happen and that it wouldn't just automatically continue, sort of thing.

MR CHRISTENSEN: I see that six-month period as a compromise between the current situation where you need a specific diagnosis and my proposed situation where it's just purely symptomatic. I'd like it to be purely symptomatic so you can - so if you can't walk, you can't walk, but six months is a compromise.

MS McKENZIE-CHRISTENSEN: The next - do you want me to go on to the next question?

MR CHRISTENSEN: Yes.

MS McKENZIE-CHRISTENSEN: Yes. The next question is about which groups are in most need of additional support and help. I sort of thought that the age group between 18 to 64 it doesn't matter what type of disability you've got, people just seem to miss out because that's sort of like the age where you're supposed to be at work, you're supposed to just be healthy and like, you know, able to do stuff. It just seems that there's like children's services and there's aged care and there's hardly anything in between. Well, that's what I've found, anyway. Do you want to - - -

MR CHRISTENSEN: No, I don't think there's any more to be said on that. Go on to the next one.

MS McKENZIE-CHRISTENSEN: The next one says what could be done about reducing unfairness so that people with similar levels of need get similar levels of support. Well, we basically wrote that the important thing is to establish an enforceable uniform set of national standards with the same eligibility rules and per capita funding. Basically if you complain and you yell and scream and say, "We need help," if you do that you tend to get more help, which is just totally unfair because there are some people who are unable to do that for themselves and therefore they don't get the assistance that they really need. Another idea which there has been a lot of talk about is the idea of self-directed funding, because it means if they had - if the person with the disability or the carers had self-directed funding and they chose one thing over another, well, at least they're the ones that are choosing that rather than somebody saying, "You must have their support," or, "You must have that type of support."

MR CHRISTENSEN: I think a part of that would be a nationwide repository of information so if you're disabled in Queensland they acknowledge you as disabled in South Australia as well. Also that might be of - obviously there are privacy concerns but if you were to get a specialist report at one time and then sometime down the track you wanted to claim something else and that original specialist report was still valid, why go to another specialist? Why use up their time when you've got a report there which is totally valid? I think that's an important aspect of it. It's going to - I mean such an arrangement would be difficult but I think with information technology the way it is it should be able to be done.

MS McKENZIE-CHRISTENSEN: Just tell me when you want to - - -

MS SCOTT: Well, I have got a few questions but I don't want to sort of destroy your thought processes. Would it be okay if I did interrupt?

MR CHRISTENSEN: I think so.

MS McKENZIE-CHRISTENSEN: Yes, that's fine, interrupt.

MS SCOTT: All right, well that's - thank you for that. I had read your material before, so thank you very much. It's very comprehensive and very well set out, so it's great for us. I just want to go to this idea of per capita funding. I mean some of the other proposals we've heard about are about funding on the basis of need or to have a functional test that would say, "Well, this person is" - are you suggesting per capita funding as a means to fund the scheme or are you suggesting per capita funding of the individual person who has a disability?

MS McKENZIE-CHRISTENSEN: I think it should be based on need.

MS SCOTT: All right.

MS McKENZIE-CHRISTENSEN: I mean I don't know about the per capita thing but I think if a person's needs are more severe then they should get more help.

MS SCOTT: Right, okay. I just wanted to clarify that point. About the repository of information, John, who is an actuary in his daytime job, he's very interested in ensuring that whatever emerges as our proposal has a good information base. I guess you're also interested in good information being available. Where would you stand on privacy issues? Would you have people opting or do you think we could make it - suggest to the government that it's a requirement that people have basic information kept about them?

MR CHRISTENSEN: I think you'd have to have basic information. I mean it's purely for capability purposes. The government shouldn't give you any kind of support if they don't have a sound reason to do so.

MS SCOTT: Right.

MR CHRISTENSEN: So I think that it would be a condition of support.

MS McKENZIE-CHRISTENSEN: I've - - -

MS SCOTT: But you were implying - sorry to interrupt. But you were implying later that that information would be available to other - would it be available to services providers or doctors? I mean who is going to have access to this repository?

MR CHRISTENSEN: I would suggest that the people providing the service, be they government organisations; and in anything else, like future specialists or whatever, that access would be limited by the client themselves, so I can tell you who has access to my information.

MS McKENZIE-CHRISTENSEN: I was just going to say, I thought they had information about me now. I mean, it might not be national, but I thought the agency that I'm with has information about me now. They're certainly very interested whenever I see somebody new, and it's not necessarily that I provide all the information that I have to them, because I just don't want to. Surely some kind of basic information, perhaps what your needs are and what your disability is, yes, they can't do without some information.

MS SCOTT: That's true.

MR KALISCH: Just on this information thing, there are probably two things we might distinguish between. One is sort of what might be useful for you, in terms of your dealings with service providers, and I think that's where you come to what information is held by one agency, but, as we understand it, that information is just held by that agency, and if you go and speak to someone else then you need to tell your story again and again.

MS McKENZIE-CHRISTENSEN: Yes, which is really annoying.

MR KALISCH: Yes, a common thing that we have heard. The other aspect is about monitoring of the entire system. I wouldn't mind gauging your views on information that might be held on a broad basis, not necessarily that identifies you as an individual but just keeps a track of how many people receive this type of service or use this type of facility, in an aggregate sense so that there can be some planning and monitoring of the entire system, but not identified to individuals.

MR CHRISTENSEN: I did imagine that there would be some kind of statistical analysis of it, for planning and other purposes. The kind of system I'm perhaps envisaging is possibly on the scale of the Tax Office system, with which I am familiar, and you can draw statistics from that without identifying people.

MR KALISCH: Erin, I'm interested in your experience as a new consumer of disability services. I'd like you to contrast that with your experience as a consumer; how you purchased other products and services in the broader community, and now your experience with the disability sector.

MS McKENZIE-CHRISTENSEN: I actually have another thing. Before I became a person with a disability I was actually a support worker, so that's different again. I certainly didn't know it was this difficult, I can tell you that much. I just went in and helped people; I didn't realise what they had to do to get the help that they received. Now I do. The difficulty that I have, as a new consumer to this system, is that I have been labelled with having a medical condition, hence all this stuff about medical conditions. To be honest, I don't understand their definitions; I have no idea, I'm not a doctor. I'm still in the process of getting a diagnosis. They're working with mitochondrial disease at the moment, but they are still doing tests.

My experience has basically been everybody saying, "It's temporary, you'll get better," and in the meantime I'm getting worse, I'm needing more support. My experience has been long waiting times. The agency that I'm with, Domiciliary Care, they used to be for aged care only, that's my understanding, and then they joined to the Department of Families and Community. I recently applied to Disability SA and was rejected, because apparently I've got a medical condition. I really don't understand the difference. I have been fighting with an advocate to get more support, and so far that hasn't happened. I was given a wheelchair when I first came out hospital that weighs 25 kilos that I cannot move, and it has gotten to the point where I have had to borrow this wheelchair from my neuro-physiotherapist.

I am in the process of waiting for a physiotherapist form Dom Care to come out and work out whether they can give me anything else; because apparently, according to their computer system, it weighs 12 kilos, which is lighter than this one. This one is 17, and I can barely use this one myself. So I need a wheelchair that I can use, it's just quite simple. Because I don't have a confirmed diagnosis, they don't think it's necessary, because they think I'm going to get better, or whatever. I don't really understand their thinking. This particular agency has extremely set rules about what they can give, it's a maximum of three showers a week, and, because I live with my husband, who is my carer, they give nothing else at all. I get two showers a week at the moment, and that's it.

MR KALISCH: Is there anything positive about the engagement with people in the sector that you could suggest should be a feature of any new or improved service?

MS McKENZIE-CHRISTENSEN: I'm sorry, I didn't hear.

MR KALISCH: Are there any real positive engagements you have had or positive experiences that you could point to that should be a part of any new system?

MR CHRISTENSEN: I think that we do get the services eventually, and that is a positive. There are a lot of things which she has applied for and got, which I didn't think she would.

MS McKENZIE-CHRISTENSEN: Yes.

MS SCOTT: What would be an example of that, Jeff?

MR CHRISTENSEN: The Wymo for the car, that was positive.

MS McKENZIE-CHRISTENSEN: But it took six months, and it took me yelling and screaming and talking to the team manager; like, the person above my case manager. Apparently, the original case manager that I had didn't realise that, because the equipment scheme became one equipment scheme, people in Dom Care and people in Disability SA can get the same equipment now. I'm not sure that that really happens, but that's what I have been told. I get told different things by different people. Once they established that, they realised I was actually entitled to get this Wymo.

I went through an occupational therapy driver assessment to establish that I can drive, and, if I'm not too tired and it's not too far, then I do, and I can do it completely independently, and it helps Jeff, because he doesn't have to stick the wheelchair in the car. So that was a really positive thing when they eventually did that. It took probably longer than six months; I think I rang up the OT place in March and I was granted the licence or they knew I would get the licence in about July and then I had the practical thing in about October, and it wasn't a question of whether I was driving, it was just like experience, because I hadn't driven for 18 months, it wasn't to pass a test or something, and then after that they eventually gave it to me.

MS SCOTT: Has the disability services people told you how long you will have to wait in order to meet their criteria as a person living with a disability?

MS McKENZIE-CHRISTENSEN: No. Everything with Disability SA has gone through an advocate with DACSA. DACSA has been fantastic. Disability Advocacy and Complaints Service of South Australia, they have been really helpful, they're very good, and not just with services, they have been helpful with other complaints. So that's definitely a positive. Keep DACSA. Yes, they are really good.

They spoke to the intake officer, and this advocate has been trying to explain to me for the last four, six weeks, or however long it has been, about the fact that I have got a medical condition and it has to be a confirmed medical condition that turns it into a disability that means that it's completely permanent, or something; which is not really a length of time, it's more to do with getting a diagnosis, because I've had trouble, this, what I have got, isn't so easily diagnosed. Like I said, I'm still in the process of having tests. It has been going on for two years.

MR CHRISTENSEN: I think a major thing we have observed with the disability thing is that the stuff is out there but there doesn't seem to be any person that knows all about it. I'm only using the tax example, because I work there, but if you go to a tax agent you expect them to know everything about tax, you don't expect to have to look up the Income Tax Assessment Act every few days. Erin has been able to get things because she has been able to ask for them, but only because she has researched them all herself, and I think that's a shortcoming of the system.

MS McKENZIE-CHRISTENSEN: I got an emergency alarm, to call the ambulance. That was given to me by RDNS, because I'm using their services at the moment, and, because I'm an RDNS client, I happened to mention really needing this button and they happened to tell me. It happened by chance; nobody told me that as an RDNS client I could get a Doctor Safety Line, it happened by accident. It's just a fantastic thing to get funded, but nobody told me about it, nobody knew anything about it, not even the Commonwealth Carelink Centre.

I rang them up about emergency buzzers and they sent me out pamphlets, and when I rang them up for further information they said, We sent you out pamphlets," and I went, "I know, but I want more information." Yes, it was just a chance conversation when I happened to apply for a waiver - that's another thing, I didn't know that I could get a waiver for Dom Care's fees or for RDNS's fees - because I was paying $20 a month, and RDNS was $25 a month. I looked on the bill and it said, "You can apply for a waiver." So when I rang up for the waiver I happened to mention the buzzer, and that person was the person who knew about this buzzer; so it happened by accident.

MS SCOTT: In terms of complexity, Jeff, how would you rate the complexity of the tax system - given that you operate in that field professionally - versus the complexity of the disability services model that we have got in South Australia?

MR CHRISTENSEN: It's a different thing. Obviously the tax system is very complex, and I expect this will be too, because with any system of this kind you have on the one side fairness and you have on the other side complexity and you can't increase one without reducing the other. But the tax system, while it is complex, there are people who know about it, there is a single point where you can write in and say, "This is my question. Give me an answer." While you probably can do that with disability, you won't get a full answer, because nobody knows the full system, as far as I have been able to see.

MS McKENZIE-CHRISTENSEN: My GP rang up and spoke to this same intake officer to find out why I had been not allowed into Disability SA and he said to me when I went to my next appointment, "Well, she told me that you might not get any more help anyway," so if I moved agencies then I might not get any more help; and I'm like, "Well, why am I bothering?" Nobody could tell me what I would receive if I changed over, and I just expected that they would have different rules, at least because whatever I have it's progressing, it's getting worse. You would think as it got worse you would get more help, but I don't know whether that happens either.

MS SCOTT: John, have you got some questions.

MR WALSH: Erin and Jeff, you may not know the answer to this question, but it sounds to me like, Erin, your condition might be a health condition, that you're sort of caught between the health system and the disability system and no-one is prepared to take responsibility. Is that how you feel at the moment?

MS McKENZIE-CHRISTENSEN: That it's falling between the cracks? Yes, I would say so. Yes, that it has being missed out pretty much, yes. But if it gets confirmed that I have mitochondrial disease, that's a progressive disease that's causing me to not be able to walk and causing all these other symptoms, then surely that would make it a disability. That's my understanding of the difference between the medical condition and the disability. The advocate did try to explain it to me, I promise, but I was sort of left really confused and she didn't know how else to explain it. She said if the medical condition led to me losing the use of my legs - well, that has pretty much already happened - then that would be considered a disability, not a medical condition any more. So I'm a bit confused about that, but that's sort of how she explained it to me.

MR WALSH: Did you have any ideas of how this might have been made better? I mean, your first diagnosis was presumably in the health system by a doctor.

MS McKENZIE-CHRISTENSEN: It could have been helped by the doctor, yes, that's definitely true. I won't explain, but that has been one hold-up I think, getting the right specialist to be able to diagnose this, because it's not very well-known, and misdiagnosis is not very useful.

MR CHRISTENSEN: I think the thing we're aiming at is the basis, for our benefit, should have been not that she has got mitochondrial disease or she has got dystonia or she has got the plague, or whatever, it's that she can't walk. Hence it's a symptomatic basis rather than a specific disease or a condition basis.

MR WALSH: What you're advocating is some sort of screening process that a disability is more quickly recognised - - -

MS McKENZIE-CHRISTENSEN: That would be brilliant.

MR CHRISTENSEN: Yes.

MS SCOTT: John, can I turn the tables and ask you a question? In the New Zealand scheme, do you know what would happen if someone was in Erin's circumstances?

MR WALSH: I think that somebody in Erin's circumstances would fall within the disability system. If you're asking, Patricia, would this condition fall within the ACC - - -

MS SCOTT: Yes.

MR WALSH: No, I don't think so. The ACC covers - - -

MS SCOTT: Of course, because of the accident arrangements, yes.

MR WALSH: - - - treatment injuries. So it's only conditions that come about as a result of something caused by a treatment, and it doesn't sound to me as though that's the case here.

MS SCOTT: In the New Zealand Accident Compensation Scheme how long do they allow for the period of uncertainty about prognosis and functional limitations?

MR WALSH: I think it's virtually immediate, in terms of eligibility, and then the level of benefit that's provided depends on the functional need, which is I think what Erin and Jeff are asking for. Where disputes arise in New Zealand is whether a condition is the result of an injury or a medical condition. So there's a boundary issue around the cause of the disability. I think to answer your question, Patricia, the issue in New Zealand is was the disability caused by an injury or something other than an injury? That deliberation I think can take some time.

MS SCOTT: But in the meantime, if a person falls the right side of the uncertainty factor, the person is given assistance?

MR WALSH: I believe so, yes.

MS SCOTT: David?

MR KALISCH: As I understand it, Erin, your expectation is that your condition will worsen over time.

MS McKENZIE-CHRISTENSEN: Because of what has happened in the last two years, that would be my guess. I'm not a doctor, but if you get worse and worse, you don't then turn around and say, Well, I think I'm going to get better." Why would you?

MR KALISCH: So in that environment I suppose you would be expecting a system or a scheme to regularly assess your need, and then respond accordingly.

MS McKENZIE-CHRISTENSEN: Yes, and actually do something about it. Except instead I get assessments, and then they say, "We can't do anything else," because Dom Care are funded to provide a specific amount and once you get to that specific amount, that's it. They have a lot of comments to me and my case managers where they say things like, "Well, you're not over 65, so this doesn't apply, and this doesn't apply," it's like what Jeff said before, that what I've got I've actually found myself. Even volunteer assistance, they couldn't even find me a volunteer, I found myself a volunteer. It might only be once a fortnight, but at least it's something. My case manager couldn't even find a volunteer.

MR WALSH: You may not, again, know the answer to this question, but I think Dom Care is funded by the Home and Community Care program rather than the National Disability Agreement program.

MS McKENZIE-CHRISTENSEN: Yes, it's more federal based rather than state based.

MR KALISCH: One issue that has been raised with us, people have been looking at the option of self-directed packages and care, where people are assessed according to their need and provided with essentially an allocation of funding and then have the ability to purchase services or sort of contract it out to service providers. Is that a model that would meet your needs better?

MS McKENZIE-CHRISTENSEN: I think I like that idea, just as long as there's scope for an increase if the thing actually progresses, because I'm on the Physical Disability Council email list and I have heard from people interstate where their needs have changed and there's no scope in the self-directed funding to do anything about that. I think that's still important to actually still be assessed regularly, even if it is self-directed. But, yes, I think that's helpful.

The other thing that we wrote is there are sort of two perspectives. There's the this national scheme at the moment, if it goes national instead of state based; and there's Disability SA, with 100 different agencies that have contracted out to Disability SA. One is that you've got the 100 agencies all with admin staff, all paying them all and then all the workers. But then if you did only have just one place, there wouldn't really be any competition. So how do you negotiate that? I have got no idea. But that was my question. But that's interesting. We would save a lot of money if there wasn't 100 agencies, because you wouldn't be paying all the admin staff, but if it only had one place and you couldn't choose where you wanted to go, it might be a less productive.

MS SCOTT: It's a good issue that you raise, and you raise it in an area in your paper which leads me to my next question. You talked about, "The third most important aspect is mandatory and improved training for care workers, and so on. In your introduction you mention the fact that you had been a support worker, and now you are actually seeking support services. Could you talk a little bit about that? Can

I tell you, Erin, that we have had people say very different things to us, and we have got to weigh up all these very different proposals. Some people say that it's really important that people are certificate 3s and certificate 4s and that people have training and formal qualifications, and the other is that people should be able to choose their own attendant care, their own support workers, because it's not actually the certificate that counts, it's the - - -

MS McKENZIE-CHRISTENSEN: Experience, yes.

MS SCOTT: Well, experience or aptitude or attitude, or whatever. Could you talk about your view, given that you've been on both sides of the service line?

MS McKENZIE-CHRISTENSEN: When I was a support worker I didn't actually have any training, because that wasn't a requirement at that point. I had first aid and I had manual handling training and I had other training that the agency gave me, but I didn't have the certificate 3. Now I'm about this far away from having certificate 3. This is a bit off topic, but I actually would like to teach music to people with disabilities. That 's the short version. So I'm trying to get this certificate so that I'm actually qualified to sort of do that. I don't know if I really need the certificate.

I started it in 2007 when I was a worker, and then in 2008 I had to stop because I was too sick to continue working. From my perspective, I always felt that I didn't have enough training and I didn't really know what I was doing. I mean, I never told anybody that, but it was really learnt on the job and I think that experience counts. It would be great to be able to choose your own people, but you have to find the right people. From doing the certificate, it's very basic information, like it's not that high a qualification. What I sort of meant was if someone is going to come in and shower me, I want somebody who knows what they're doing. I mean, it's embarrassing enough as it is, but when you have to explain to somebody what to do, it's kind of annoying.

You can't learn everything from a book. So there's sort of two perspectives. You can only learn so much from a book. You can only learn so much from a certificate. I know from other people that I've spoken to that they want to make sure that - in this case it was somebody's child - they was being looked after by somebody who really knew what they were doing, because they were leaving their child with a disability in the hands of somebody else. Some of the things that they said happened were just appalling. A lot of it is commonsense, but sometimes people don't have that. So I don't know, does that answer the question?

MS SCOTT: Yes, it does. Thank you.

MR CHRISTENSEN: I think there's scope for people who don't have qualifications possibly to work with people whose needs are relatively light or who have had those needs for a long time and they're stable and they feel capable of in effect doing on-the-job training for somebody. If the client was willing to accept that, as Erin's first client was, then I think that would be a good way to get people into doing care work. If you have to get a certificate 3 just to get into care work, then you might as well get a certificate 4 and get paid a hell of a lot more.

MS McKENZIE-CHRISTENSEN: The other thing is that there's not enough workers. I think I wrote that. I was getting agency staff for six months because Dom Care didn't have enough workers of their own, and they were coming at all different times of the day and not warning me when they were coming. I was missing the doorbell, because I don't hear it - because I was asleep probably, at 8.30, or whatever time they came. One time it was 8.30 and the next it was 11.00, and I didn't have any choice. So I sort of said, "I want you to come at this time," and then they gave me a regular worker. But I had to actually complain to get that.

MS SCOTT: John, have we just about finished our questions?

MR WALSH: Yes, thanks, Patricia.

MS SCOTT: David?

MR KALISCH: Yes.

MS SCOTT: Thank you very much, Jeff. Thank you very much, Erin. Thank you for coming along, and for a very systematic answering of the questions.

MR CHRISTENSEN: Thank you.

MS McKENZIE-CHRISTENSEN: We're doing a written submission as well.

MR KALISCH: Yes. Thank you.

MS SCOTT: Yes, that's good.

MS McKENZIE-CHRISTENSEN: I haven't actually emailed it yet. It'll come.

MR KALISCH: No, you've still got a little bit of time. You've still got until the mid-August.

MS McKENZIE-CHRISTENSEN: Do I? I didn't realise that.

MR KALISCH: Yes. No, we have extended the time. Well, we worked without the microphone. So that was good. Thanks, Erin.

MS SCOTT: Good afternoon, Helen. Could you just identify yourself, for the transcript. Then would you like to make an opening statement?

MS KEENE: Certainly. My name is Helen Keene. I am a playwright, anthropologist and actor. I am also carer for my son, who has a mild mental health issue. He is a genius and totally wacky. I saw your tiny little advertisement in the paper and I came because I wanted to talk about group therapy. The best group therapy in Adelaide is the Dulwich Centre, which costs $200 a shot, which I can't afford. So I have wanted to come and say to you, "Why aren't you running group therapy, because it's so marvellous?" That was one of my major points for coming; if the system could provide that. So then I thought, "Oh, what else will I say?" So I wasn't sort of quite sure. So I spoke to my son. I said, "I'm going to this Commonwealth ding and what would you have me say?" So this is what he said. One of the things that we have got him into is the disability theatre, in Adelaide it's called No Strings Attached Theatre of Disability, and indeed it saved his life. He said what he's learnt there is about celebration, community and faith. So in the theatre you learn to celebrate yourself, yay, and other people and achievements and other people's achievements and feel good. So celebration is very important because when you go to the therapist, you know, you can just, "Oh, my God, let's celebrate who we are."

So "community" is the other word he used, and that's because the disability theatre gave him a sense of community. Theatre is about working together collaboratively, you can't have theatre without that collaboration. Even if you're doing a monologue on stage you've got all that crew, you've got to be working together. So community was very important. Faith, he said it was about faith in himself, faith in others, faith in the community. It even enabled him to embrace what the Christians call God. So I hope that you will hear that and know that in a way group therapy is a bit like drama. There's something to be said for it.

So I asked him about his therapy. He said, "Mum, therapy is boring." It is true. He's come home from seeing therapists and said - you know, the therapist has told him what to do; okay. It's one on one and it's not interactive. So, you know, "I'm glad you said that," because my first impulse was to come here about group therapy and say, "Why isn't the Australian government running group therapy sessions that are fun where you get" - and this is what he said, "You learn to have a go. Have a go. You learn to trust yourself." When you're working with people, especially in disability and in theatre, you have to trust yourself and trust them. So you learn about trust and it's very important.

What else? I'm just sorry I haven't got my glasses on. Here we have - yes, put your best foot forward. I love that. I love that. They're all out of his mouth. He has learnt that partly through No Strings Attached Theatre of Disability. I would also like to say then I would like the government to fund more disability theatre. In fact, there is some way that we could overlap therapy and theatre together. Somehow that would - especially for people like him who had - he's not quite schizophrenic, not quite autistic, not quite - he's just wacky. Even the doctor can't quite diagnose him; calls it a thought disorder. But he's genius and incredibly clever and talented.

MS SCOTT: Is he able to live independently?

MS KEENE: He does live independently but I'm his carer, and he - - -

MS SCOTT: Could you talk about that a bit, Helen, because - - -

MS KEENE: Okay. Oh yes, okay, that's very good. Very good.

MS SCOTT: I just want to put it in a bit of a picture for you.

MS KEENE: Thank you.

MS SCOTT: If you don't mind. I mean the last person talking to us said that in South Australia here, you know, they have to negotiate the number of showers that she's able to get attendant care for.

MS KEENE: You hear that.

MS SCOTT: And you come along and talked about theatre, and I can imagine it's very beneficial to some people. But, you know, showers, theatre. Do you get what I mean?

MS KEENE: I do.

MS SCOTT: I need some sense of where it fits in the continuum of need, I guess.

MS KEENE: Okay. So I am my son's carer, okay, designated and I have to thank Centrelink for listening to me and being - they were very careful with me and listened. Wonderful, and I thank them very much. However, looking after my son for their little allowance I'm probably getting about $4.30 an hour. So I don't have to shower him but I do have to make sure his kitchen and bedroom and bathroom are orderly, because he's got - you know, he's sort of - and that's very similar for a lot of people with mental health issues, that they just don't see it, you know, airy-fairyness.

MS SCOTT: In terms of financial management, would he be able to look after his own financial affairs?

MS KEENE: Absolutely and totally not.

MS SCOTT: Right, okay.

MS KEENE: Administrative skills - nowhere.

MS SCOTT: Is your son able to work in paid employment?

MS KEENE: Briefly. He can't do it for long. It's tricky and we keep taking him to institution - teaching, learning things and he does a bit here and a bit there and a bit here and a bit there. But he's learned - as I said, he's learned an enormous amount from the theatre. It's taught him to be collaborative and tolerant and to have a go. To have a go.

MR KALISCH: I was going to ask you around that about sort of what you see as perhaps the potential for some of these sort of group activities to enable people to have the confidence, the courage, the incentive to actually then participate in paid employment, potentially.

MS KEENE: That's a very good point. When he was first diagnosed and - he went under the care of the Salvation Army in a program called Towards Independence. So he had a tiny little flat where there was a whole lot of other flats and there was an attendant psychologist-carer-helper person on all the time. He was fantastic there. They had group stuff happening and they groomed them for working and moving into the community. In some ways that set-up that the Salvation Army have called Towards Independence is probably what people like Ab need all the time, not just for six months. It's fantastic that we've got the Housing Trust and they've given him a dear little house in Burnside, for goodness sake. I mean it's just amazing. But that's it, full stop. Without me he'd probably be dead, as a matter of fact.

MS SCOTT: Just thinking about that. I mean what arrangements could be or have been or you think could be made to ensure that your son has someone to oversight his care into the future? I mean - - -

MS KEENE: When I'm dead?

MS SCOTT: Yes.

MS KEENE: Very good. I've been thinking about it. It looks like it'll have to be his sister. I mean I don't know. I don't know. It worries me and, you know, we had this conversation just yesterday. I might be dead in 10 years. What's going to happen then? But we don't know what to do. It's tricky, just tricky. With a lot of younger disabled folk what's going to happen?

MS SCOTT: Is he a vulnerable person? I mean is he - I mean what's your greatest concern if you were - or your daughter - - -

MS KEENE: My greatest concern - you get - do alcohol and that green stuff they smoke to the point of death and do something stupid. I mean I just know that group therapy is just - that's what I came for, that group therapy can be incredibly helpful.

MR WALSH: Helen, it's John from - - -

MS KEENE: Yes, I can hear you, John.

MR WALSH: You can hear me okay? I'm just interested in independence. That was when your son was first diagnosed. Was he - how old was he at that stage?

MS KEENE: That's a good question. 17, 18.

MR WALSH: Sort of leaving school age. Did he go to school okay?

MS KEENE: He was starting not to, sort of trying to get there but not getting there and - it's really tricky. Yes, he wasn't going too well.

MR WALSH: Do you think maybe if there was sort of a screening program as part of the school system that - might have been diagnosed and maybe helped earlier?

MS KEENE: Maybe. I mean there are such a thing as school counsellors. Is that correct?

MS SCOTT: Yes.

MS KEENE: There are. I don't know about their abilities and training, whether they can detect that stuff.

MS SCOTT: Well, we have national screening for little people for hearing and we have all sorts of other screenings. I mean it's not impossible to imagine that if you thought there were particular vulnerabilities that you might have screening for that. It wouldn't mean it would have to occur but you could have an arrangement for that.

MS KEENE: Yes. I guess you'd have to have training. School counsellor would have to be trained to detect.

MR WALSH: The Salvation Army program, you said that lasted six months. Is that because the program only went for six months?

MS KEENE: That's correct. They did an absolutely marvellous job and he was fantastic, but then out in the - just out by yourself. So he's in a lovely little flat in Burnside but he's surrounded by other folk and some of them - heavy drinkers and smoke that green stuff and he hangs out with them and it's tricky. If there was some group therapy - but yes, I don't know. I don't know. That's what I came to talk to you about.

MS SCOTT: Yes.

MR WALSH: How often do you think group therapy would be required?

MS KEENE: Well, weekly would be fabulous but monthly is probably all the Commonwealth can afford.

MS SCOTT: Helen, you mentioned in the points that you provided us before that sometimes your son can be - dealing with your son can be very demanding and even daunting. Could you talk a little bit about that in terms - - -

MS KEENE: About my position?

MS SCOTT: Yes.

MS KEENE: Yes, okay. Well, that's right. It's tricky, you know. You want your children, especially ones that are very clever, talented, creative, musical - you want them to be fabulous, and he's ditzy. So there's a bit of, "Was I good enough, mum?" So there's a bit of that going on. The thing is I have to be there. You know, when things happen I have to be there. So it's a bit tricky for me to run a little business that I would like to be doing and volunteering at the theatre, which I - you know. So it's time consuming and it's boring, right? Whereas it would be fantastic to take him off to group therapy and for him to have a fabulous time and tell me about that. Right?

MS SCOTT: Yes, I got it.

MS KEENE: Yes.

MS SCOTT: John - - -

MS KEENE: I must say though that the most wonderful thing that we got from the shrink was some drug called Abilify, which is a third-generation psychiatric whatever; marvellous. So it's great, the drug therapy is good, but let's get - I don't know.

MS SCOTT: No, we've got - - -

MS KEENE: I've made my point. Have I made my point?

MS SCOTT: Yes.

MS KEENE: Have I made my point, team, right? Do you need me any more.

MS SCOTT: No, I think so - I think we're going to let you go.

MS KEENE: What do you think, John?

MR WALSH: You've done a great job.

MS KEENE: Thank you, sweetheart. Well, thank you all very much for listening and I'll leave you to the next person.

MR KALISCH: Thanks very much, Helen.

MS SCOTT: Thank you very much. Thank you.

MS KEENE: My pleasure. I'm hoping to get a cheque for group therapy next week.

MS SCOTT: Well, I think we are now okay to - if there's anyone in the audience that would like to come forward and make a few comments. Now, someone asked me, "Do you have to then make a submission?" We think the answer is no, so I'm now making that a rule. The answer is no.

So if you would like to come forward and make a few comments. Maybe you've heard something today that you would like to respond to or you'd like to put on the record. This is a genuine attempt by us to hear from you. We're very conscious that people have set aside a whole day to be here, so thank you for doing that. Is there anyone that would like to take the opportunity? Yes, okay, so we've got three, four - lots of people, okay. Right, okay.

So Dom, well, I might get you as traffic cop. I think it's about five or six. Yes, let's get going. We'll have you - I'm sorry, I've forgotten your name. Number two? All right, okay, so - and then Julie, you can be number three, okay? Then we'll take the others straight after that. We won't forget you. Everyone will get a chance to have a say. So just for the record you've got to say - - -

MR NIRTA: My name.

MS SCOTT: Your name.

MR NIRTA: Yes, Steve Nirta.

MS SCOTT: Hi, Steve.

MR NIRTA: And I'm just speaking on my own behalf.

MS SCOTT: Good.

MR NIRTA: I do belong - well, I am with the Physical Disability Council of South Australia but I'd like to be here on my own representing myself, thank you.

MS SCOTT: Sure.

MR NIRTA: I'd just like to thank everybody for coming today and for those people who gave a talk I think they had some very, very valid things to say. It actually - that's what prompted me to come up and introduce myself anyway, because some of the topics were - crossed over into areas that I've had to deal with in my own life, particularly the - a parent.

MR NIRTA: Yes, what … had to say and her mother, very interesting points. I could relate to what they had to say because I have, as I say, two children myself. They're now grown up and left home but there were a lot of areas that - was a crossover there. Very disappointing that there's not enough support for the kids because one thing that is not really - well, it wasn't touched on today is that these kids that have got parents or siblings with a disability, they also do tend to have to put up with a lot of prejudices within their own friends and in the school life as well. There really is not enough support for them. I'm very upset about the fact that they've actually - that the government has withdrawn funding for the projects that they were doing, particularly the social interaction that they had with each other as support groups and also the lacking of support in the education. I am fortunate in that I have a wife who was very supportive as well, whereas … only had her mother to back her up and she would have found it really tough. My hat off to you. That's on that issue itself. I've taken a few little notes anyway.

MS SCOTT: Okay.

MR NIRTA: So I'll refer to those, if I can read my own writing without my glasses. With regards to the self-managed funding, that's an area that obviously would need to be looked at very, very seriously. I'm all for self-managed funding but also I realise that it can't be for everybody, because not everybody is going to want to manage their own funding, I mean just the administration side of things, or they'd be able to - a lot of people. Gee, really tough one. The NDIS is a great concept. I hope it does come through. We do need something like that in place because there's a lot of people who are falling through the cracks. I'm sorry, I'm losing the track here.

MS SCOTT: No, that's fine, you're doing well.

MR NIRTA: No, I'm not. Sorry, I'll get off that one. I just want to go on about the carers. I was really happy to hear from Erin in the fact that she was a carer herself and now on the receiving end and the insights that she has would be invaluable. I feel that this is an area where somebody like Erin could find employment as a trainer or an educator for people who are getting into the carer industry. I didn't come very prepared for this. I think I'll have to stop there.

MS SCOTT: All right. Well, thanks very much, Steve. Thank you for coming forward. Just before you go, any questions? No.

MS SCOTT: Okay, Mel, thanks. Thank you for coming forward. Mel, just for the record, what is your full name?

MS LECKIE: Melissa Leckie. I'm here just as an independent, just interested to see who is here, how many people, what sort of ideas people have. Whilst I intended to make a submission, I certainly haven't had the time to sit down at a computer and plan it out. But I have heard some really interesting things today. It has brought up a lot of my own points and my history. The first one is whether it's physical, mental health, intellectual or a combination of disabilities.

Everyone needs care and support in different needs; whether that's physical help and whether that's access, like an accessible bathroom or kitchen; whether one needs help, like Erin, with having a shower - everyone deserves more than two showers a week, I don't think anyone would say that that's sufficient; whether its people with some mental health issues, they might just need a friend or a buddy or someone that just needs to look after and watch over them, to make sure that they don't hurt themselves. Every situation is different.

I'm in the wheelchair because of a suicide attempt, thanks to school bullying, which led me to attempt suicide, and so now I'm a paraplegic, belly-button down I've got no movement or feeling. I spent over 12 months as an inpatient in the Hampstead Rehab Centre because government funding would not help with a bathroom so I could go home to my mum. The one bathroom that we did have was probably as big as that table and it just wasn't going to be wheelchair-friendly, so we had to get one added on the back.

One area of government then spent over $300,000 keeping me in the Hampstead Centre and would not give us 15,000 tops to help renovate a bathroom so I could go home. I could go to Melbourne and stay in a backpackers with a mate, but I couldn't go home and sleep in my own bed. I was 17 at the time, so I was between Crippled Children's at the time and Disability SA, or whatever it was back then, and I was just getting thrown around and handballed on. Accountability. Who is responsible? Everyone just seems to get handballed. I know I'm going very off-track, but I've got like 320,000 points I can make.

MS SCOTT: No, that's fine. You're doing okay.

MS LECKIE: The lady before that was talking about the disability drama, or whatever, that's all good and well, and it has made me think of Project CONNECT. I am an athlete, I'm a Paralympian that hand-cycles, I ride a bike with my hands, and Project CONNECT is a federal initiative of funding that has gone around to try and make able sporting organisations inclusive. I have been trying to get into sport since I got in the wheelchair, and everyone just goes, Oh, no, wheelchair. Go to Wheelchair Sports," and Wheelchair Sports go, "We don't have any money, we're only a recreation thing. Go to your local athletics club," and "Go back to the athletics club;" and they go, "Oh, no, we don't have any wheelchair athletes." Again it's like just handballing. All of this money, God knows where it has gone.

Even in the state funding there was half a million, funding for disabled sport, of recreation up to elite level. I'm an individual, I'm not a charity. I'm a member of Cycling SA; and I'm a member of Wheelchair Sports, just because I have to be. But even contacting them, I wasn't able to apply for funding to help get another bike, get to competitions. But they won't apply for it for any help in the cycling either. Everyone is always like, "Well, I don't know anything. I won't take responsibility. Go and talk to your local" blah blah blah.

Mental health issues, that is a big one, especially as far as funding and what is necessary. Obviously I know the physical side of things. If someone can't get into a bathroom, one would think that's a fairly high priority issue. When you've got mental health as well, who is to say whose needs are higher or what needs they have. Falling between the cracks, yes, well, we have certainly all done that. I applied for individual funding and got rejected, for whatever reason.

MS SCOTT: Is that back to the sport now or is that - - -

MS LECKIE: No, that's for the current disability stuff. I live on my own in a unit that my mum has had to take out a second mortgage for, and this is going to the carer thing. My mum works 40 hours a week to pay for the roof over her and my head. She also cares for me for literally 40 hours a week. She is around, she calls me every morning , every night; and even when I was in Hampstead she was there every morning, every night, but because I wasn't living with her her carer allowance got cut off. I'm very fortunate that I do have my own place.

The tenants moved out February last year, and we found out December the year before, so it was like, "Right I need to move out. Again I need the bathroom done." I go to Disability SA; oh, no, not going to happen. So mum took out another couple of - several thousand, and we said, "Fine, all right, we'll do the bathroom. Put us on the waiting list for the kitchen." Now, we have finally come through for the kitchen to be renovated, because it has just got all the shelves and cupboards up here and one of those old stoves with all the knobs at the back, and the hotplate.

So through Dom Care I believe, they're doing kitchen renovations. We have got the builders come tomorrow morning just to measure up everything. I have no idea if there's a max on the funding, if it's, like, "Here's $5000 for this," or, you know, "You can have up to here," or "This needs to be done." But a stove and a cooktop and the things that I can't currently use in my kitchen are not part of the funding, that's like doing bathroom renovations and saying, "Yes, but you can't have a toilet." There is so much missing or specific definitions of, "We will only alter what you have in your current kitchen."

With my fridge, there's a space next to it and I currently just have like a wire rack that I put my stuff on, and mum said, Well, we need some drawers," because if I can get under everything - they're not going to have any drawers there, and I certainly can't have anything up here. But we're going to have to pay for that ourselves because it's not part of the kitchen that's being renovated, it's not part of what is already there, it's just an empty space. So that's now our responsibility. I'm so lucky I've got my mum. But she's petrified what happens if she has a stroke, and it is literally myself and my mum.

MS SCOTT: Do you get any attendant care?

MS LECKIE: No.

MS SCOTT: Are you eligible for attendant care?

MS LECKIE: Possibly, but that's the thing, I don't necessarily need any help toileting or having a shower and stuff. I need help doing the dishes, cooking, cleaning, taking the garbage bin out, and all of the stuff which is apparently not daily essential needs to have carer allowance. If my mum goes away for a couple of weeks, as she might for work, we might get someone in sort of every now and then. My mum rings me every morning to make sure I haven't fallen off the shower chair and hit my head, and whatever. If I don't answer my phone she comes around and goes, "Oh, my God, where are you?" and blah blah blah.

It's the same with the caring for the parents. We're doing it with family. We don't have any other family or friends to call on. What are we going to do when that's not there? The self-funding, the individual funding, is a great idea. No-one knows what I need more than me. I have everything I think as far as disability and doctors and all of that should be online, accessible. If we all had a UR and a pin number or something so that anyone could access it, because I have got to so many doctors and I've got to remember, "Well, I went here for this, and I went here for this and this, and this one is in the public sector, this one's in the private sector," and it's all so complicated.

For the last couple of years I've spent however much just going to the GP solely for script updates and referrals. I don't go there because I'm sick, I go there because, "Oh, well, this one has run out." It's like, if we 're on the same medication and we're going to be taking the same medication for the rest of our lives, because of incontinence or whatever, why can't we have a script that lasts for at least 12 months. Stuff on the PBS, don't even get me started on that.

MS SCOTT: Next inquiry.

MS LECKIE: Yes. Any other questions? University and disability access plans, that's an interesting one. Because I'm a university student, I come under their disability access plan and elite athlete status. Uni SA claims to be disability and elite-athlete friendly, and it says that, as part of this, okay, I can have alternate arrangements for test exams; like, I might get extra time, or, as far as disabilities go, what you can and can't do, you can have alternate assessment arrangements.

Yet no-one has been able to put that in place because, with the exception of extra time, no-one knows how to - okay, say, this is the essay we have to write, but if I can't sit at a computer or I can't write that, you know, "Can't I do it orally, or something?" No, that's not an option. I'm very lucky with my abilities. I know there's a lot more people that would have a lot more problems, especially the vision-impaired, or all the rest. Yes, there are programs they can use, but it takes so much more time and effort that it really - - -

MS SCOTT: So the point there is that they have got something which sounds good but in practice it's - - -

MS LECKIE: Again, it's all on paper, but it doesn't happen. That's a huge thing with all the bureaucracy, all the red tape, all of the people that work for Disability SA, who then go to this place to get this, and this place to get this, and this place to get this. I mean, why do we have wheelchair sports for all the states, and then we have got the cerebal palsy sports things, or we have got the blind sporting things, and we have got something else. Like, why don't we all just sort of stick together and get one big federal thing, and then filter it down through that.

Yes, OTs and nurses are horrible. No, honestly, I was prescribed my first wheelchair and the OT specifically said to me, "You're in a wheelchair now. You will get fat." The wheelchair was giant and chunky. Compared to ones in Adelaide, it actually looked okay. Compared to chairs in the rest of the country and the rest of the world, it looked like an old hospital wheelchair - which, you know, being 18 at the time, is not something that I want. I fought for seven years to get $3000 to put towards this chair, which is titanium, and it has got carbon sides and the front wheels flash. I had to put in the extra.

MS SCOTT: What was the extra, Mel?

MS LECKIE: It cost $5500 to get from the US. Like, I prescribed it. I know how wide I am, I know what I want. Some I kept the same, one of them being the front and rear height, and now that my feet are actually taking the weight I'm way too bendy. So now that I've got the chair, yes, now I know there's a few little adjustments I could make. But I can fit in non-disabled toilets. I'm incontinent, I have a catheter, I drink beer; it makes life easy. Because the disabled toilets at the uni bar at Magill are like, you know, miles away, I started using the men's urinals because I couldn't fit into the non-disabled toilets in my other wheelchair. I then got asked not to by security because I might offend some people.

MS SCOTT: David, you're not going to believe this, but I had to convince Mel to come to the microphone. Last points? I'm just conscious we have got a few more people.

MS LECKIE: Yes, I know. One just of interest I think. It's really ironic that the Special Olympics was successfully held in Adelaide when no other elite sporting national competition will be held here, because we don't have facilities enough or suitable for elite sport. Euthanasia is a huge and very controversial issue. But it is one where a lot of people are taking a lot of funds, as such, in hospital beds, whether it's elderly people dying or children born with disabilities. Obviously it's up to the individual or their carer, if it were an option.

My accident, I hit my head and I was borderline vegetable at Julia Farr, and I'm very lucky and very glad that I'm not, but if I was that incapacitated and I needed someone to feed me, someone to do everything for me, there's no point in me living - and obviously that would be my mum's decision, technically, but it should be an option, and I know a lot of people support that, especially in the disability sector. The age thing. Pick an age. Is it under 16? Is it under 18? Is it under 21? Is it under 25? Is it over 65? Like, pick one and stick to it, as well. Thank you.

MS SCOTT: Thank you very much. John, any questions?

MR WALSH: No. Thanks, Melissa. I think it's many examples of where a small amount of money would have made a big difference.

MS LECKIE: Yes, little things can go a long way, even just for those that are client and parent looking after each other, if they both had a pension or whatever, and then that could be extra income to help provide for the medical needs, whether it's buying gloves or wound dressings. Even just all the medications I'm on, it's not cheap.

MS SCOTT: No. Okay, well, you've given us some good examples. Thank you very much for coming forward.

MS SCOTT: Julie, I think you're next. Who was also wishing - yes, Margie, you want to go number four; and number five, Jenny, yes. Stefan, were you going to - you're happy to be number six? So Julie, Margie, number six is Stefan. All right, Julie, would you like to state your name into the microphone so we can get it on the record, please?

MS SUTHERLAND: I am Julie Sutherland.

MS SCOTT: Okay, thank you. Would you like to make some points?

MS SUTHERLAND: Yes. I'm one of the convenors of the Australasian Network of Students with Disabilities. We are a multinational organisation which was formed at a Pathways in Higher Education conference which is held every two years. We are very strong supporters of having a long-term disability care and support scheme. Mel made some very good points about care and support and I'd just like to say that students with disabilities are increasingly coming into higher education places like universities and TAFE colleges.

One of the biggest barriers for more severely disabled people that I speak to who want to get into higher education is the ability to have access to attendant care at institutions. Then at the institutional level as well, who funds that, when it's the university system, because they're obviously federally funded. The other thing we'd like to see is having a cost of disability allowance which would - we'd like to see it means-test free to cover things like the costs of special equipment, for the computer or taxi transport or whatever a person needs that doesn't have any strings attached.

MS SCOTT: Good, all right, thank you. Any questions, John?

MR WALSH: No, thanks. Thanks, Patricia.

MS SCOTT: David, any questions for Julie?

MR KALISCH: No. No, thanks, Julie.

MS SCOTT: Thank you, Julie, that's great.

MS SCOTT: Okay, so after Julie was going to be Margie. Thank you.

MS CHARLESWORTH: Hello.

MS SCOTT: Thank you for coming up.

MS CHARLESWORTH: I'm Margie Charlesworth. I'm the vice-president of Women With Disabilities Australia.

MS SCOTT: Yes.

MS CHARLESWORTH: This is Elisia. Elisia has come to echo me because I know there will be people who might not understand what I'm saying.

MS FARRUKH: Okay. This is Margie Charlesworth and she's the vice-president of Women With Disabilities Australia. Margie has asked me, and my name is Elisia Farrukh, to be here just to echo anything Margie says so everyone understands.

MS SCOTT: Yes, that's good.

MS FARRUKH: Thank you.

MS SCOTT: Could we get you to move the microphone just a little bit closer to you. That'd be great.

MS CHARLESWORTH: Do you need an echo or do you want to just ask if you don't understand?

MS SCOTT: I understand most of what you're saying, I think. David, how are you going?

MR KALISCH: I'm going pretty well but it is actually probably helpful for our staff as well that go to get the transcript, that it might be easier for that.

MS CHARLESWORTH: Okay, yes, fine.

MR KALISCH: Thank you very much.

MS SCOTT: Okay, is that all right? Are you okay with that, John, too, just for the transcript, just to keep - John, are you okay if we keep on going?

MR WALSH: Yes. Yes, thanks, Patricia.

MS CHARLESWORTH: Well, I do have a couple of issues that I'm (indistinct) in support of. The first was violence against people with disabilities. Dell Stagg talked about violence in group homes.

MS FARRUKH: The first thing Margie wants to provide support behind is - or to talk about, the issue about violence against people with disabilities. Dell Stagg earlier on spoke about violence in group homes.

MS CHARLESWORTH: But there's actually a lot of violence towards women with disabilities by their carers or their support workers and there's nowhere for them to seek help.

MS FARRUKH: Okay. So what Margie is saying is there's also actually a lot of violence towards women with disabilities by their support workers or carers. There's nowhere for women to seek support if that occurs.

MS CHARLESWORTH: I think that's a very important issue that I would agree with Dell when she said there needs to be somewhere for not just women but for all people to have support.

MS FARRUKH: What Margie is saying is it's a very important issue and she would agree with what Dell Stagg was saying earlier, that there needs to be somewhere for people, all people with disabilities, to have support if they're experiencing violence against themselves.

MS CHARLESWORTH: Yes. The second thing I wish to talk about - and my colleague Steve Nirta reminded me of - and that is that the disability support pension and the carer's pension is means-tested. I don't think that is fair. It actually does not provide enough incentive for people with severe and profound disability who want to work, like myself, but we daren't - we can't afford to lose the benefits of the DSP.

MS FARRUKH: So what Margie is saying - hang on, if I can read my writing. Basically Margie had a chat to Steve Nirta earlier who reminded Margie that the disability support pension and carer's pension is means-tested. Margie highlighted that she doesn't think it's fair and - sorry, doesn't think that it is fair and it doesn't provide enough incentive for people with severe and profound disability who want to work, like Margie, but they can't work because they can't afford to lose that pension and the benefits that it offers.

MS LECKIE: Unless you're blind.

MS CHARLESWORTH: Yes.

MR KALISCH: Yes, that's the exemption.

MS SCOTT: Yes, I was going to say.

MS CHARLESWORTH: Yes, there's needs to be a fair and equal payment for all people with disabilities; and yes, that's me.

MR KALISCH: Okay.

MS FARRUKH: So the last thing Margie highlighted there should be fair and equal payment for all people with a disability. Is that in regards to the pension or just work-related?

MS CHARLESWORTH: No, in regards to the pension.

MS FARRUKH: In regards to the pension.

MS SCOTT: Yes.

MS FARRUKH: Okay.

MR KALISCH: Yes, okay.

MS SCOTT: And then you're making the reference to the blind pension.

MS FARRUKH: Yes, that's right, in reference to what Mel was saying earlier.

MS SCOTT: Mel, okay. Margie, thank you.

MR KALISCH: Righto, thank you.

MS FARRUKH: Thank you.

MS SCOTT: Okay, John, move on? Have we lost John? John, could you just say something? I'm just not too sure we've got you still.

MR WALSH: Yes, can you hear me?

MS SCOTT: Yes, good, thank you. That's great. Look, Stefan, we might move on to you if that's all right, because Jenny seems to have just stepped out. I'm sorry, what's your first name?

MS LOWE: Joan.

MS SCOTT: Joan, you'd like to go after - - -

MS HAY: Just a very quick one.

MS SCOTT: Yes, that's fine. That's okay. There's a bit of a traffic jam, Stefan. Okay, Dominique, if Jenny comes back in - I think it is Jenny that was sitting over there, we'll just do her after Stefan. Joan is coming after Stefan as well. Okay, so welcome.

MR SLUCKI: Thank you. So for the record, Stefan Slucki, and for the sake of the transcribers so if I read the transcript my name is spelt right it's Stefan with an "f" not a "ph". I lack pH balance. And Slucki is S-l-u-c-k-i. I'm speaking as a - I'm making private comment today but I am a teacher of Braille and also introduction to computers and also have the privilege of serving Blind Citizens Australia among other things.

I was motivated - I was promising to come along today and be quiet but I was motivated by our first speaker, Robbi, who referred to the term of reference, the eight sub-point or bullet point about access to employment with the qualifier phrase "wherever possible". I do realise that such documents and such phrases can be read in a positive or negative context and he chose to interpret it as being potentially in a limiting context. But from my experience I actually think it could also be read in a positive context and could be very affirming. From the experience that I have had in teaching people from the blind and low vision community, I think it is a realistic expectation. After all, this is the Productivity Commission. It is a fact that we have to face that there are some people whose disability will mean that it is going to be impossible for them to be employed. We've already had reference to one person whose disability they've been diagnosed with has meant that they cannot work.

Now, I know that there is discussion about those kind of diagnoses which can be over-limiting of people in their lives and I am all for encouraging employment as wide and as broadly as can be done. However, I'm not in favour of dragooning and forcing people into meaningless repetitive, menial and demeaning kinds of work. So there is a balance. The first thing I want to say is that I think that phrase in the bullet point can be interpreted positively wherever possible and I would certainly want to warmly encourage that to be taken in the positive sense wherever possible.

Speaking from the microcosm of the disability sector that deals with blind and low vision people I would just like to very briefly speak about education, because it seems that from where I have been and from my experience as an educator of blind and vision impaired adults, mainly, that the best way to encourage people from our sector to be employed is to promote their literacy and numeracy and the best way to do that is by encouraging Braille early. It's a great disappointment to me that only 10 per cent of the blind community is literate in Braille in Australia. That, I won't go into. That would be another inquiry, Madam Chair. But it's absolutely incomprehensible why Braille is not made compulsory for children that are blind and low vision in schools and why that happens. But anyway, that's another story.

Okay, so that's the first point that is a positive and I hope that in the future report it will be given more flesh on that dot point. Second thing is - following on from that is about the taxation potentially of pensions. I pick up the point from what Margie was saying and also what others - and what sort of been just bothering me a little bit in terms of I am also in favour of the proposed NDIS. But what is concerning me is the matter of the disability support pension and particularly blind, and I declare - as counsellors would say, "I declare my interest," as a recipient of the pension blind, which is - at the moment is not means tested. As a receiver of or recipient income in addition to it, of course, I have a stake in it personally but the principle is there.

Many people who have disabilities have substantial outlays of cost. As an example, I don't know what people in the room's watches cost them. That watch cost me $185. A lot of people can buy watches these days for $20, $30. No subsidy, right. For a person who is on the pension only they've still got to buy that watch for $185. No subsidy.

MS SCOTT: Yes.

MR SLUCKI: I don't have any medications, thankfully, associated with my disability that are not covered by PBS whereas a lot of people do. So there are issues of cost that come into it for people. I would greatly argue that for a lot of people that people who have an incentive to work, these payments should not be means tested below a certain threshold. I would argue that if people get employment that they not be means tested below what is determined by the government as the poverty line. Now, that's not an official BCA policy, that's my own personal view, because otherwise there is a disincentive for people to seek work, as Margie just said, your previous speaker just said. So there are very practical down to earth issues.

The unemployment rate amongst the blind and vision impaired is about 60 to 70 per cent, depending on which statistics you follow, which is an alarmingly high rate. I would like to see that changed. So literacy is one issue but there is also an inherent concern that if people seek employment they will lose - well, amongst the blind at the moment they won't but in other sectors there is this concern and fear that if they get employment of a casual or a temporary kind they'll lose entitlements. I think in the US there are moves at the moment to seek to encourage people into casual employment, part-time employment, but in such a way that they will lose minimal benefits, if any. So I would like to just make those points today.

MS SCOTT: Thank you very much. Any questions, John or David?

MR WALSH: No. Thank you, Stefan.

MR KALISCH: No. Thanks, Stefan.

MS SCOTT: Joan, I think you're next. Joan, would it be easier up this end?

MS HAY: My name is Joan Hay. I'm a bit nervous speaking. I'm an old polio person, from 18 months. As Stefan said, the ability to work is very important, and I was very fortunate in Canberra to work for many years in the public service and had a boss who employed me for my ability rather than my disability. I have got a wonderful carer husband, who married me for my ability, took me on. I'd like to mention, as Stefan said, the extra costs for my husband; boots, calipers. You used to be able to get a bit of tax relief, things like that. Nothing like that.

The other point I'd like to make is that you hear of all these things. We came back to Adelaide and someone said, "You've got to find out for yourself. No-one lets you know that you can get." My husband was able to get a non means tested carer's allowance, which just helps out for all the extras. Every time I go to get a new pair of boots I've got to provide a number for the man who makes my boots, but I have to go to a GP, because that's what's needed to get money back from the private medical funds. There's so much bureaucracy, and I'd like to see some of it cut out. You never get rid of polio. Why do I have to keep, with the Carer Allowance, having to go back to the doctor? I'm not going to get over this. Why can't it just be accepted?

MS SCOTT: That's good. It's very clear, Joan. Thank you. Just before you go, I'm not very familiar with some of the tax measures that exist. I wish we had Jeff here, who knew about tax. I thought if your expenditure went over $1500 out of pocket then you could then get a tax deduction. Are you eligible for any tax concessions at all for the cost of your boots? You said you used to get tax - - -

MS HAY: No, this wheelchair we had to buy, could get nothing back from Medibank Private. But people at the time they could get golfing equipment, because that's sport, that's to help them combat obesity, everything like that, but I could not get a refund, and you still can't.

MS SCOTT: I have got that. John, any questions of Joan?

MR WALSH: I think just clarifying that one, I think there is - it has reduced significantly - a rebate of something like 20 per cent, expenditure on medical items above a certain amount.

MS HAY: Well, with my shoes, for instance, I'm allowed now to build up a bonus, and that takes a bit of the cost off that, through the health fund we're in. But just generally, it's very expensive with medications that are not on the PBS, things like that. It's an expensive burden on my husband, and I praise him for accepting it.

MS SCOTT: Yes. Very good. Thanks, Joan.

MS SCOTT: Maurice, please state your name for the record, please.

MR CORCORAN: Maurice Corcoran, from Adelaide. I just wanted to reinforce a couple of points that were made today, on the public record. I just think it's really critical that we have an opportunity with this to really apply early intervention when people acquire a disability. There is so much emphasis in other countries where someone acquires a disability, either through a traumatic injury or illness, that there is early intervention about them rejoining in the workforce and being retained in the workforce and/or re-shaping or retraining through their rehabilitation at a very early stage.

It is certainly something that happened to me, I had an offer to return to work within two weeks of being hospitalised as a quadriplegic, and it was a major incentive for me to be able to re-shape my rehabilitation and re-focus. I just know, as a social worker, working back in those areas, if people have a hope that they can return to their job or to retrain as part of their rehabilitation, their motivation is so much better and they don't fall into that sick role and or have a mindset that they're going to be on a Disability Support Pension for the rest of their life. I think that's something - the economic benefit and the cost benefit analysis that the Productivity Commission is so expert at doing - that needs to be looked at, that early intervention model, in a whole range of areas.

Along the lines of what was said earlier by Mel today about the difficulties of people being maintained in rehabilitation centres and hospital beds because small modifications can't be made to the home or to a place where they can move back out into the community. The cost of that nationally must be astronomical, in terms of people being retained in beds. We have heard of people being kept in hospitals for 18 months, two years in high-level beds because of the lack of personal support that they're able to get in the community, and the cost differential is quite incredible, and I think we need to do that.

Also I would argue, for the same reason, that this should be about productivity of people with disabilities and it should be about having an opportunity to build in incentives to any NDIS so that there will be incentives for people to retrain, to develop their skills and to get back into the workforce, and there be also incentives for employers, such as traineeships and opportunities to hire and contract people with disabilities. A key incentive I think is the one that has just been mentioned again by Joan, and it has been said a couple of times today, the fact that I can't purchase a wheelchair and claim it back on tax or claim a high proportion of it on tax.

There are huge waiting lists around the country for equipment. If people who are employed were able to claim the costs of their equipment back on tax, as they are with motor vehicles and a whole range of other things, then I just think that's a really important thing. It's a great incentive for people to get into work if they can then think, "I can get all the equipment I need and I can claim it back on my tax." I just think there are some real benefits.

Along the lines of something that was mentioned a while ago by Stefan, who was so articulate about the nondiscretionary costs associated with disability. At the time of the welfare reform inquiry that was commissioned there was a strong push by all the national disability peaks that I was involved in at that time for a non means test disability allowance model, which covered those nondiscretionary costs associated with disability.

John is probably the most informed person about that in Australia, so it's great that he's involved in that. That disability allowance model that covers the costs whether you're in employment or not. I think there's a lot of people who don't take that gamble and move off a Disability Support Pension because of those nondiscretionary costs and concessions that people will retain if they stay on the Disability Support Pension. So I think that's a really important. The individualised funding model I just think allows people to move from primary school to secondary.

Whether they need personal supports, whether they're in primary school, secondary school, TAFE or universities, it shouldn't really matter, they should be able to take their support package with them. An individualised model takes away that barrier that we have that was investigated here in South Australia, where the Social Inclusion Board and the Social Inclusion Unit looked at the transition points for young people with disabilities if they moved from secondary school and to other options afterwards.

The communication that we got back from many parents and young people was that while they were at secondary school they were entitled to transport and they got a whole range of things; when they moved into secondary school, et cetera, they got transport assistance to get there. But as soon as they moved away from that, the issue of personal support within TAFE was a real issue and a lot of people had to give up TAFE courses and give up university because they could not get the personal support they required while they were in those institutions. That's an impediment that just should not be there for people trying to build up their skills and productivity. I'd just like to have those sort of things on the public record. Thank you.

MS SCOTT: Thank you very much, Maurice. Any questions from Maurice, John?

MR WALSH: No. Thanks, Maurice.

MS SCOTT: No. Thanks for doing that.

MS SCOTT: Welcome, Jody. Please state your name and if you're representing a group or not, and then just your points you'd like to put on the record, please.

MS HOLDBACK: Jody Holdback, and I'm from Blind Citizens Australia. Even though Stefan has a better title than I, I get paid. Sometimes it pays to be the under dog. Actually I'd really like to follow up on a point that Ross from SACOSS made earlier about community involvement and awareness, and following on, Patricia, about your comment about the person who wanted to go fishing and having community awareness about disabilities and what supports may or may not be needed and if there's any minor adjustments that may need to occur.

Sometimes there's not even minor adjustments, there's just acceptance into the community and as part of the community to be able to be socially included. In some circumstances that we're aware of that would actually cut a lot of funding requirement down that could be put into other areas where there is actually genuine support needed. I actually work as an advocate for Blind Citizens Australia and I'm all too aware of the amount of discrimination that actually goes on, and I just work with people who are blind or vision-impaired, I don't work with the whole disability sector.

Literally day after day I hear story after story where people have been excluded or discriminated from particularly community events or community involvement because they have a disability and there just isn't that awareness that actually arises from the community that otherwise should. Can I take my Blind Citizens hat off actually now and put my mothering hat on?

MS SCOTT: Sure.

MS HOLDBACK: As some of you may have seen, I have a guide dog, so I'm actually totally blind. I also have a son with an autism spectrum disorder. We have had to fight for him to have an education and fight quite hard. His father and I are separated, which has actually nothing to do with him. But on a financial basis, if we weren't separated and getting individual pensions we wouldn't have been able to actually afford to keep educating and supporting him.

He has Asperger's and it's a very tricky disorder to get funding for, because I guess it's classified as one of the hidden disabilities. He spent basically three years out of school and now is in a program. In order to keep the funding of this program going, his father and I have to go to Brisbane every six to 12 months to get recommendation from Dr Tony Attwood to ensure his funding is ongoing.

The biggest problem is that the funding is provided to get a program going, the children start to develop and start to cope within that program, they stop the funding and then the wheels drop off, so to speak; because while the child was developing -

or even adults this can happen to, while they were developing in the program they were developing with support, and in particular guidelines and boundaries of the program. When they stopped the funding all the support stops as well, then everyone is back to square one. It's not really a productive system to be able to have young children, young adults or older adults in, for them to be able to continue to be productive in today's society or even in their own selves.

MS SCOTT: Jody, could I get you pause just for a second. Can I go back. I have just got a question about the fact that you and your former husband have to go to Brisbane every six to 12 months. Is that because the specialist services you're after are only available in Brisbane? Could you just talk a little bit more about that? It seems a very expensive way of doing things.

MS HOLDBACK: Yes, it is.

MS SCOTT: Adelaide is a big city. Big, compared to some of the towns I've lived in.

MS HOLDBACK: No, we just couldn't get heard here, and in the end we were so desperate we went to Brisbane. So we got obviously a letter of recommendation, a letter of support and a report from Dr Attwood. Because we had that report, in order to keep funding going we actually had to maintain reports from him; even though there's obviously specialists here, and there's Autism SA here, which doesn't have enough resources to do anything. Because we had fought and felt we were so rockbottom that we had to outsource, I guess, so to speak, to Brisbane, we have to maintain that to keep his funding going.

MS SCOTT: David and I have got it now.

MR KALISCH: Yes.

MS SCOTT: It makes sense to us now. It actually echoes something we heard in one of the other hearings. So it's very interesting.

MR KALISCH: A family in Melbourne was talking about the good level of services and support they received in Brisbane.

MS HOLDBACK: Services for autism spectrum disorders in Brisbane is outstanding. Like, we're just aware of particularly that area, because that's where we concentrate, but I can't rave enough about it. They're just so on the ball. They're unbelievable. Thank you.

MS SCOTT: Thank you very much.

MR KALISCH: Thanks, Jody.

MS SCOTT: No questions, John?

MR WALSH: No, thanks.

MS SCOTT:

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and Dom, were you telling me we had another customer? If we stay much longer than this we'll be living in Adelaide. So Nick, I think this will be our - you're our last customer. Okay, Nick.

MR RUSHWORTH (BIA): Thank you. This is very, very impromptu off-the-cuff sort of presentation.

MS SCOTT: So you have to identify yourself and - - -

MR RUSHWORTH (BIA): Sure. My name is Nick Rushworth, I'm the executive officer of Brain Injury Australia, actually based in Sydney. We are referred to as the peak of peaks, so I sit at the apex of a very, very small triangle of organisations that are in turn their peak acquired brain injury advocacy outfits in their jurisdiction. They in turn have their own individual members that comprise organisations, people with an acquired brain injury, family members and carers and so on and so forth. So that's who I am.

MS SCOTT: Okay, thank you.

MR RUSHWORTH (BIA): Look, I've actually just come from giving a presentation across the road at the inaugural National Indigenous Drug and Alcohol Committee Conference. I think that one thing that immediately struck me about that in the context of the issues paper, for example, is that one of the underlying assumptions of the issues paper is that everyone knows their disability, can name their disability and might even know what their needs are. The last the Australian Bureau of Statistics surveyed the Australian population in regards to age and disability was in 2003. They arrived at a figure of 432,700 individuals with experience of acquired brain injury. That did not include the 14,000-strong sample that the ABS relied on to provide their estimates; didn't include people who lived in regional and remote Australia, for example, didn't include the homeless, didn't include people who live in prisons.

If you look at any decent local or international survey of those populations - for example in prison, between 40 and 80 per cent of prisoners have direct experience of a head injury with loss of consciousness. Any decent local or international survey of homeless populations will tell you that between 10 and 30 per cent of those populations have direct experience of either traumatic brain injury from a motor vehicle accident, an assault or a fall or from alcohol and other drug abuse. It is also extremely important in the context of the commission's work that there are people in - that the rates of ABI in indigenous communities, even though the data isn't particularly good, will be roughly three times that of non-indigenous communities. When you add onto motor vehicle accidents, assaults, the rates of which in indigenous communities are very high to begin with anyway - you add to that alcohol, petrol, cannabis - the disability rates with ABI in those communities is extremely high.

It's also important to note there are enormous obstacles in the way of my constituents to open disclosure of their disability. It applies to disability generally but I think there are particular enforcements away from open disclosure of ABI particularly because of the severity, multiplicity and complexity of those disabilities involving things, for example, like challenging behaviours: verbal, physical aggression, disinhibition and so on and so forth. I think it's extremely important to say that there are people who would benefit from whatever scheme, whatever policies result from the commission's inquiry process who are completely outside the current service and support system who may in fact not know they have a disability let alone what their needs are.

I think that should almost be a starting position for any inquiry process - are the people who are currently not serviced because they don't know they have a disability and don't know what their needs are. I'm certainly hoping that whatever scheme results from this inquiry process that there be some kind of education and awareness-raising component so that people are educated in disability and in what their needs might be arising from their disability. That's the first thing that I would like to say.

MS SCOTT: Can I just check?

MR RUSHWORTH (BIA): Yes, sure, sorry.

MS SCOTT: I think you've had two points there, Nick.

MR RUSHWORTH (BIA): Sure.

MS SCOTT: One was some people don't know they have a disability, so they under-report. The other one was the ABS is likely to be under reporting because the sample they use didn't include three groups - I think I've got three groups - - -

MR RUSHWORTH (BIA): Yes.

MS SCOTT: - - - who have particularly high incidents of acquired or traumatic brain injury.

MR RUSHWORTH (BIA): Yes. I should say as a kind of rejoinder to that that COAG gave $16 million additional funding to the ABS for the next iteration of their survey of ageing, disability and carers.

MS SCOTT: Yes.

MR RUSHWORTH (BIA): So that I'm assuming - - -

MR KALISCH: 2009 survey.

MR RUSHWORTH (BIA): - - - a better sample size.

MS SCOTT: Yes.

MR RUSHWORTH (BIA): And some inclusion of those groups that I just mentioned, I think it's extremely important: homeless, prisons and indigenous populations, particularly in regional and remote Australia.

MS SCOTT: Okay.

MR RUSHWORTH (BIA): The other couple of points that I would like to make very, very quickly. Brain Injury Australia wrote a policy paper for the Australian government last year on the leading cause of traumatic brain injury throughout the developed world. It is not motor vehicle accidents, it is not assaults, it's falls. These aren't drunken falls off a balcony at 2.00 in the morning on a Saturday after 45 rum and Cokes too many. These are older Australians who fall over and land on their head.

At the moment, certainly in New South Wales, at the brain injury unit where I went as a client, if you are aged one day over the age of 65 you don't get access to that program. You don't get access to that unit. I am extremely concerned about how the commission is going to describe "natural processes of ageing" because the leading cause of TBI is falls. If you are 85 years of age and over and you fall over on your head, all the local and international research indicates you die. If you're someone who is working part-time or full-time, 66 years of age, 70 years of age, 74 years of age - if you're stupid enough to believe you can have a six-pack of beer over lunch and then climb the ladder to clear gutters, fall over and land on your head, chances are in Australia you will end up in standard geriatric post-stroke rehabilitation; whereas your work capacity might be retained up until your 80th birthday. So your need for brain injury specific rehabilitation will adhere up until those kinds of age ranges.

So I would love to find out more in the process of the inquiry's work about how they're going to define natural ageing processes. Whether, for example, stroke will be included in that. One in five strokes occurs in a person aged less than 55. Stroke is highly preventable, whether it's part of the natural process of ageing or not is highly debatable both on a research and an academic basis. That's one of my other concerns. I'm just going to go through my list here.

The other thing which I think is probably a starting issue, and I know that John Walsh has done some fantastic actuarial work in producing the true costs of particularly traumatic brain injury for the purposes of developing a lifetime care and support scheme in New South Wales. The last policy paper that Brain Injury Australia wrote for the Australian government was on the leading cause of death and disability in children who have been abused, what's referred to as inflicted traumatic brain injury, one subset of which is what's referred to as shaken baby syndrome. The lifetime costs of a child - and ordinarily these children are less than one year of age - the lifetime costs of disability for that child will be $5 million or thereabouts.

While I have great confidence in the kind of actuarial work that PricewaterhouseCoopers has done in the past I think that my constituents and my member organisations need to be reassured that in a generic scheme that is cross-disability that the true and real costs of acquired brain injury are going to be estimated correctly into the accounting for any proposed scheme of a social insurance kind or any other kind.

MS SCOTT: Not for now but maybe for your submission, Nick, I wouldn't mind knowing why you think that your client base would fare particularly badly. I guess what you're saying this is a very high number the average person in the street might not have estimated.

MR RUSHWORTH (BIA): Yes.

MS SCOTT: But I mean John is now onto other people and PWC's work is known more generally. I mean I guess what I wouldn't mind you addressing in your submission as to why those calculations wouldn't be more widely available or discerned by other people.

MR RUSHWORTH (BIA): Yes, I think that part of it is to do with the constituent fear that - I certainly hear this from time to time in the context of New South Wales, even though lifetime care and support is relatively young, that when you look at the way the costs are distributed when it ends up at the client's and the services provider's front door often while there might have been expectation originally of a Rolls-Royce service what they end up with is a Mini-Minor approach to the way that funding is actually spread through the system. So I think that - you know, it's important to say that while the traumatic brain injury population is a small one, it is, on a per capita basis, incredibly costly for obvious reasons.

MS SCOTT: Yes.

MR RUSHWORTH (BIA): I think all I'm trying to say in very crude terms is that in a cross-disability scheme that the true costs of particularly traumatic brain injury are incorporated into funding models.

MS SCOTT: Okay. I'm not an actuary and John is going to have to correct me after this session but I would imagine you look up big tables which - - -

MR RUSHWORTH (BIA): Yes.

MS SCOTT: You know, the idea would be that either there's some sort of functional assessment or some sort of needs assessment. I mean we've asked the public to come back to us and give us advice about the type of assessment it is. But if it turns out that someone has substantial loss of functioning or has high level of impairment one would imagine that you would calculate the cost. I'm just trying to work out why your client base in particular - you know, not people who suffer polio or someone who has other conditions - you know, why your client in particular. So not for now - - -

MR RUSHWORTH (BIA): Yes, sure.

MS SCOTT: - - - but if you could explain why you think they would be particularly worse off I'd be keen to know.

MR RUSHWORTH (BIA): I also should say - there are two points I would say in response to that. The first is that I would cite the results of the longest long-term follow-up study ever conducted in Australia of the outcomes of brain injury, the brain injury outcome study conducted by Robyn Tate from the University of Sydney Rehabilitation Studies Unit, I'm sure John is aware of that work, where the use of services and the need, unmet need, for services continues for many, many years post-injury. I think that there was something like three-quarters of the sample or the cohort that went through the hospital system in the 1970s were still accessing services or expressing an unmet need for services; very, very long, up to 30 years post-injury.

The second thing that I think is important to say, and I absolutely understand that any government needs to have some kind of gate-keeping process of access to any kind of scheme that might result from the commission's work. What makes brain injury different in some respects is there may be some people who fall outside the moderate to severe end of the spectrum but may in fact be towards the milder end of the traumatic injury or ABI spectrum who still have ongoing issues that don't necessarily resolve. So the vast majority of traumatic brain injuries in this country, as throughout the western world, would be in the mild category. Most of the symptoms to do with information processing, memory, cognition would ordinarily resolve within six months. However, there's a minority of people with mild traumatic brain injury that will have ongoing issues many, many years post-injury.

So I think it's very - I think one of my constituents' concerns is going to be what kind of assessment tools are going to be used by whatever scheme comes into place and who will be excluded on that basis. If it is something as crude as moderate to severe - in whatever terms are used - I think there will be some people who have got ongoing needs and ongoing daily needs for supports and services who might be left out of that.

MS SCOTT: Okay, well, thanks. It's a good point, Nick. We would welcome your group's input into what you consider would be the most appropriate eligibility arrangements.

MR RUSHWORTH (BIA): Yes.

MS SCOTT: And the most appropriate assessment methodology, tools and so on.

MR RUSHWORTH (BIA): Sure.

MS SCOTT: Just one or two other quick points?

MR RUSHWORTH (BIA): Sure, yes.

MS SCOTT: Anything else you want to say?

MR RUSHWORTH (BIA): No, but if you've got any - - -

MS SCOTT: No, no, that's fine.

MR RUSHWORTH (BIA): No, okay. I'm just trying to think. Again I think having been here today for the purposes of presenting at a conference where the whole notion of disability in connection with alcohol and drug abuse is not even really thought about that - in talking about disability in that kind of forum, I wonder whether government fears the floodgates would open if there was a genuine attempt to educate the entire Australian populace about disability, about need. There will be a whole range of people who are outside the service system who will qualify.

MR KALISCH: That's an issue for the government.

MS SCOTT: That's right. We're not government.

MR KALISCH: Thankfully not for us.

MR RUSHWORTH (BIA): On a social justice, on an equity basis I think that - - -

MS SCOTT: Well look - - -

MR RUSHWORTH (BIA): Yes, I'm sorry.

MS SCOTT: Just toy with me another little minute. I mean a very large proportion of Australians actually do identify as having disability, as you know from the census.

MR RUSHWORTH (BIA): Sure.

MS SCOTT: As the issue paper says of course some of us can get by with a hearing aid and a set of good glasses or medication or therapy every now and again. Others have more ongoing needs or unmet needs and I guess - but you make an interesting point. Look, we might bring it to a close there, I think.

MR RUSHWORTH (BIA): Sure.

MS SCOTT: Unless John, you've got any questions for Nick?

MR WALSH: G'day Nick. How are you?

MR RUSHWORTH (BIA): Good, John.

MS SCOTT: Well, it sounds like no. All right. Well, thanks, Nick.

MR RUSHWORTH (BIA): Pleasure.

MS SCOTT: Well, thank you very much everyone for coming along and attending. I'm not too sure who got the ball rolling for such good audience participation but Adelaide takes the prize in audience participation, so we're very grateful for that. Well actually, in some ways the unstructured comments will be very useful because they're sort of quite revealing, aren't they, about things that have worked and don't work and so on. So thank you very much for displaying the confidence and courage to come forward.

I now adjourn - hearings, we'll be continuing them now in July. Transcripts will be available on our web site. Our draft report will be available in February, we hope, next year. We will go through another process of seeking comments on our draft proposals and our draft recommendations. So please don't lose interest in the inquiry - if you want to forget about it for awhile but come back, be interested in around February because that's when we'll have proposals that we would be seeking particular comments on. So thank you very much and have a good evening.

MS ....: Can I just ask one thing? If there's a change of government will the inquiry still keep going on?

MS SCOTT: Yes.

MR ....: When will the transcript be available online?

MS SCOTT: I can't tell you exactly when. I think it's about a week, isn't it, Dom? Ask Mr Sparkle. When will you have the work done? Say again?

MR ....: One week.

MS SCOTT: One week. Okay, all right, thank you very much.

AT 3.51 PM THE INQUIRY WAS ADJOURNED ACCORDINGLY